Alex's Story
The 20th Year

Thursday, April 2nd, 2015

It is impossible to connect with the people I need at Berkeley Mental Health (BMH) who are supposed to be helping me with Alex while he's being held at Villa Fairmont Mental Health Rehabilitation Center (Villa). At least Alameda County claims that BMH is the one designated to help Alex. I called the BMH Compliance Officer, Yvette Katuala, again. Yvette's phone that I got from calling BMH at 510-981-5290 is 510-981-5280, so I left a brief message that nothing has happened with Marcela Sabin since I met with her on March 9th. No meeting. No return call. Nothing.

I guess Marcella did finally call because I picked up her message today that was left yesterday, April 1st. Calling her back today, she said she'd left the message on Monday March 30th. In any case, it took 2 weeks longer than she said it would take, for her to get back to me. From my few years in outside sales, I knew she'd never get the account if she followed through like that, yet she gets away with this kind of performance in the social work arena because they don't know who the customer is. Apparently, they don't have to know.

I wanted to connect with Yvette to let her know that I didn't appreciate what Marcella was doing—nothing—and left a message at the number at the adult clinic. I said, "I had an appointment with Marcella Sabin on March 9th and I met with you even earlier than that. Today is April 2nd and still nothing. I returned her call today after hearing her message.

She sounded very negative, when we finally spoke, about any future meeting at Villa. She's very busy with such things as meetings and teaching, she said. Alex doesn't want a meeting, she said. I inquired how she obtained that information, because I told Alex about a meeting, too, and he didn't respond negatively to me. She said that "staff" told her. So, she's getting information from the wrong people, and giving up too easily. She's supposed to be setting up a meeting with the doctor, the social worker, me, Brenden, Alex and herself. And that meeting was not even her idea. She didn't have any ideas so she asked me what she could do. If she doesn't know what to do in regard to helping Alex, and isn't interested in doing anything to help, and is so easily dissuaded from what she is intending to do; if she doesn't understand that Villa wants to hold on to the status quo and doesn't want to have to have any meeting because they don't care about any infection, then she doesn't understand the urgency of her job to set up a meeting regardless of what they want. She said she might not be able to see Alex because he doesn't know her and might not want to talk to her. When I suggested that I could be there with Alex and her to introduce her to him, she brought up the "confidentiality" aspect so I told her Alex had already signed all the papers enabling me to know, but she still didn't think it would happen. She's very meek and difficult to understand because English is not her first language. This is what help BMH is giving me? I need to get my son out of Villa before the infection returns, not after. Villa isn't doing their job of enabling the doctor to talk to Alex—yet Dr. Beatty was the one who went to school for learning how to talk and listen to people—to communicate. He's a psychiatrist, so he should have some extra insight into how to make Alex understand the situation. But, they don't want to let him perform his job of helping Alex to see that he will hurt himself if he doesn't get the tooth extracted, because they don't care if he hurts himself and continues to wait until the infection wakes up and does the damage it is predicted to do. Berkeley Mental Health is the one that the county points to that is supposed to help out. Why didn't they know that in December when I told them the situation? Apparently, they knew they were the responsible party, but they knew that I might not know, so they didn't feel accountable and didn't think I would find out. Now that the county let them know that they are the party responsible for resolving the problem, BMH is putting it into the hands of an advocate who can't do the job. The job needs someone more aggressive, less meek, more concerned about clients, less blasé. Am I really stuck with Marcella? If that's the case, I won't waste any more energy hoping to get help from BMH. It's not my job to train them. If my son is hurt because BMH didn't do anything, since I'd already alerted Peggy on December 8th of last year, BMH will be accountable when I take them

to court. Katuala only connected with me because the county alerted her to the fact that it was her job to be involved and serve the client, not because I complained to Peggy in early December. The Director, Steve, already knew about the situation, too, according to his own admission at the Berkeley Mental Health Commission meeting last month, yet no connection with me was made and nothing was done. That was 4 months ago. I was never in the loop, if there was any concern at all, about a BMH client in danger, Katuala needs to be involved, if Marcella is too busy to do what she says she will do. She said she'd get back to me the week of March 16th and she called me instead on March 30th, she said, although I didn't get the message until April 1st. If this is the kind of help they're planning to give me, they needn't bother. And when Marcella and I finally did talk today, there was no plan, only excuses about why she couldn't/wouldn't/shouldn't. That's not good enough. But, I can't make them do their jobs. I have visions of walking into BMH and asking to speak with their director and encouraging him to take the lead, but I'm not going to do that. Steve already had the chance in December to show what he would do and he didn't do anything either. I'm just going to stick with those who sound more authentic, like SAMHSA. They definitely are authentic. There's no way he could have written that synopsis without reading the journal. And Senator Feinstein sounded concerned. And David at Cal NAMI is for real. So far, there are three to work with. I'm not sure on whose tape I left a message at the state level, after Senator Feinstein gave me their phone number, but I never heard back and was told there isn't anything at the state level in mental illness.

I spoke to Alex's public defender, Molly McClure, when she called me back. She said the dentist has to come in to court. They let her know she could come in as early as 8:30am, so she doesn't waste her day, but she has to testify in person that the oral surgery is necessary and urgent. Although Dr. Nicholas said Alex could make his own medical decisions in September, Dr. Beatty changed that in February, McClure said, but Alex still can make his own surgical decisions. This is what Molly McClure said based on another case that went to court. She told me to call Shanna Connor. So, I did. Connor said she's not handling day to day work on his case anymore, but we talked for several minutes so she could inform the new council. There's a difference between non-medical and medical, she said. Alex still has the right to make non-medical decisions and surgery is considered non-medical. Connor said they haven't subpoenaed the dentist yet. I don't understand. I thought Dr. Sharma was already subpoenaed and was somehow able to get out of it or detain it with her own legal council. They actually haven't even given a subpoena to the dentist? That's crazy! Who's crazy here? I concluded the conversation with Connor saying that she's going to talk to the person in the county council office who is presently dealing with Alex's issue. I don't have luck with people with that last name...Connor. The Conservator Nicholas Renzi told me that they were going to subpoena the dentist and they never did. I wonder why he led me on to think that they already did when they didn't.

Apparently, they were able to bring Alex's case to the court without my knowledge in mid-February, when they decided that he could/should be conserved for another 6 months. Why wasn't I invited? Why wouldn't county council have let me know, if not Molly McClure? Why did they decide to keep him for another 6 months when they are not even taking an active part in helping him get to the

dentist? Why do they want him in their facility? Money? They'll never see it. They intentionally didn't let him come home so I couldn't have the time I would need to work on the issue while he's at the hospital. He cuts me off when I visit, and walks the other way or goes into his room and closes the door if I try to talk about the dentist. And I'm only allowed to be there for an hour or less. Only once did he say he would go, when I brought it up a couple weeks ago, but just to be seen by the dentist, not for surgery.

Friday, April 3, 2015
Zyprexa 15mg; Fish oil

Today I received a reply from SAMHSA. I have to scan it. It was very helpful. And I need to follow up. But, I was so wound up over all the conversations I had yesterday with Alex's attorney Molly McClure, County Council Shanna Connor, the BMH Compliance Officer Yvette Katuala and their Advocate Marcella Sabin, that I became upset and couldn't focus on writing to or calling the Ombudsman (1800-896-4042) at the Office of the Mental Health Ombudsman for the California Department of Health Care Services. So, I just emailed her this afternoon:

> Joan Miro <joan@joan-of-art-centerpieces.com>
> Attachments3:35 PM (7 hours ago)
>
> to MHOmbudsman
> To: Office of the Mental Health Ombudsman for the California Department of Health Care Services.
> From: Joan Miro, Mother of patient at Villa Fairmont Mental Health Rehabilitation Center, San Leandro, CA
> Date: April 3, 2015
> Re: Concern over negligence at the above facility in taking care of my son's health
>
> I am going to quote from the letter I received today from the Director, Office of Consumer Affairs, Keris Jan Myrick, M.B.A., M.S., of SAMSHA, Center for Mental Health Services. After receiving my admittedly lengthy correspondence, Myrick summed it up better than I can:
>
> > "Your letter states that you are deeply concerned about the safety and wellbeing of your son, a resident of the Villa Fairmont Mental Health (Rehabilitation) Center. You explain that your son is refusing treatment for an abscessed tooth and you fear this may cause him permanent harm if neglected. You state that the measures taken by the staff in the facility have been inadequate. You are seeking immediate intervention so that you can safely get him to the dentist. Additionally, you question his 'right' to make his own medical decisions because you feel he does not have the capacity to do so in his own best interests due to his schizophrenia."

To elaborate a bit more, my son's mental illness disables him from being aware of the dire consequences that more than one dentist has predicted in regard to not following through with urgent surgery on the abscessed tooth. Basically my son has informed me that "no one can predict the future" so he can choose to ignore the dentist's referral to oral surgery. He thinks he, himself, is a doctor, even though he became psychotic a few months before graduation and never even graduated from high school. The consequences of not having the tooth removed will cause him permanent harm, once the infection gets into the blood and travels where it will if the facility continues to neglect seeking immediate intervention.

All of the staff and administration at Villa continue to say it is no longer urgent since the antibiotics administered between September 17th and September 26th made the infection dormant. They are waiting for the infection to come out of the dormant state and then they will take him to an oral surgeon after the infection becomes painful. But, that's not what the dentist said to do. She first wrote to take care of it "ASAP," but when I saw that they did not respond appropriately to ASAP, I went to her again for her to rewrite the referral and she wrote "urgent" on the paper. That still did not move them to action, so I went back to the dentist and she dictated the following letter:

> To whom it may concern:
>
> My patient, Alex Anderson, is putting himself in a dangerous position, walking around with an abscessed tooth without understanding the urgency of taking care of it. As I already explained to his mother, Joan Miro, the abscess did not go away when the antibiotics were administered in September of last year. A dental infection is unlike a medical infection. The infection simply remains dormant after the administration of antibiotics, and following an unspecified, unpredictable amount of time, that is, a few weeks to a few months, the infection 'wakes up' and does damage to any organ that the blood carries it to.
>
> That's why he is in a dangerous position.
>
> Indu Sharma, DDS

As the mother, I am not willing to take that chance with his life. He is already suffering enough with the schizophrenia. He cannot work, make friends, or go anywhere so it is a very isolated life. I don't want him blind, too. He appreciates being able to see and to walk and eat. I am seeking immediate intervention before he is hurt further. Not only has Villa, the facility in which he has resided since last September 10th, said they will not deal with the issue until the infection returns, they have decided to put him on another 6 month hold at their facility (the first 6 months ended last February) so that I cannot take him home to deal with the issue, and get him to the dentist on my own.

Villa has ignored the responsibility of his physical health in all this time, and has instead, charged me with the responsibility to encourage him to go and to get him to the dentist while they keep him locked inside their facility, making it more difficult for me to motivate him to go. Additionally, I am informed today by my son's public defender, Molly McClure, that although his present psychiatrist, Dr. Beatty, at Villa has recently re-stated that my son can no longer make his own medical or psychiatric decisions, according to a previous court case, a patient still has the right to make non-medical or surgical decisions. This information is from County Council Shanna Connor. I feel that he does not have the capacity to make any kind of health decisions in his own best interests due to his serious degree of schizophrenia.

To add to the problem, the dentist who saw him last October, Dr. Sharma, who referred him to oral surgery ASAP, has refused to come to court since requested by the County Council Connor, in January to do so, but for some reason, the court hasn't yet subpoenaed her, council said yesterday. My son knows that I insist he go to the dentist before he comes home to live, or at least on the way home, and he is smart enough to choose to stay at Villa instead, where they don't care if he goes to the dentist or not. To add to this, the advocate from Patient's Rights, Gwen, told me when I called her a couple of weeks ago: "I don't care what the dentist said! He doesn't want to go!" Apparently, the Villa administration agrees with her. None of them care what the dentist said. However, I do care if he goes blind or gets some other organ infected when the infection begins to travel somewhere by chance. He's suffering enough and I don't want him hurt further.

Thank you for any intervention or ideas you can offer.
Sincerely,

Joan Miro
510-418-8568
joan@joan-of-art-centerpieces.com
attachment: journal
2 Attachments

I am just going to continue communicating with the people I've already written to, like David at NAMI California who said he wanted to talk to me on the phone this month, and Senator Feinstein who sent me information that I have to get back to her about, and SAMHSA who gave me a contact that seems to be a working e-mail address. Of course, I'll only know if they communicate with me.

Alex seemed as good as he could be when I saw him last night. It was late, time for medicine, and I watched him take the generic 15 mg Zyprexa as well as the rubbery looking fish oil tablets. I showed him the photos and videos of the places I've been going to, in order for him to see what he's missing by hiding out at the hospital. It's something to talk about because I'm losing ideas of things to talk about with him. He really liked the pictures of the museum in San Francisco I showed him a few weeks ago. It was a small animal museum and he loved the owl. He's such an animal lover. I'm sure he'd love going there, but I can't seem to get him into the van to go anywhere.

Saturday, April 4th, 2015

I told Alex last night that I wouldn't return until Sunday, and that's turned out to be true. I took the moment to go to San Francisco again, just to do the laundry and hear a band at the café on Ocean Beach. Alex liked the video of one of the bands I showed him on my phone. I'm thinking that it was odd that Dr. Beatty changed the note that the conservator had about whether Alex could make his own medical decisions. Renzi told me that the first psychiatrist on Sept 15th wrote that Alex *could* make his own medical decisions. Last month Beatty

changed that to Alex *could not* make his own medical or psychiatric decisions. As it turns out, that didn't do much because apparently, according to County Council Shannon Connor, that doesn't affect Alex's ability to make his own non-medical or surgical decisions. So, Alex still doesn't have to have surgery on his tooth if he doesn't want it. But, my question is: How come Beatty all of a sudden had this change of heart? Because he knew Alex a little longer than Dr. Nicholas knew Alex, he was able to see that Alex couldn't make his own medical decisions? Which brings me to the fact that psychiatrists see patients for 15 to 20 minutes per week, according to the information that a few of the patients told me. So, how long did Nicholas know Alex on September 15th when he wrote that Alex could make his own medical decisions? Alex had only arrived there on September 10th. Or did someone, like the accrediting agency who emailed me, put pressure on Jones to put pressure on Beatty to make that change happen. I don't understand; everything is such a secret.

Thursday, April 9th, 2015

Apparently BMH is not overseen by any particular organization. Marcella Sabin, their Patient Advocate, said, "the Department of Mental Health was taken away 2 years ago. They don't have one (particular) office for mental health. It's combined with substance abuse" (and some other departments).

Marcella called me back this morning after I tried to get BMH moving yesterday on the new development. I asked her who the oversight organization is for BMH. She didn't know, she said. She thinks it may be the county or the state. She's good at not knowing. That was before she said that there is no state organization. She's really good at double talking. I think she allows her English as a second language to be used as an excuse for not understanding, because I know she understands, but doesn't want it known that she understands. I left a few different requests for help on a few different lines: The Consumer and Family Assistance Office, 510-830-3805 and MHOmbudsman@dhcs.ca.gov at the phone # of 1800-896-4042 Monday through Friday 8am to 5pm—given to me by SAMHSA. The state ombudsman called me right back just before I found out that Alex can be released. I had thought that it would have been the state ombudsman office that made Alex's discharge happen, but no, it couldn't have been, because they never received my email last Friday, April 3rd. I didn't know until NAMI's David told me that my email still wasn't working.

The new information as of Thursday, April 9th at 4:30 pm, is that Villa's social worker, Gene, called on Tuesday and when I returned his call Wednesday, yesterday, he said that they were going to discharge Alex. On Tuesday, when he'd left a message, he said it wasn't urgent. How wrong that was! If he doesn't think it's urgent to me, he's on another planet! But, Alex's health never was urgent to Villa, so I understand where he's coming from. It's not urgent to BMH either, because they are going to take their good old time getting back to Villa with the one thing Gene asked for, in order to discharge him before the weekend: an appointment time for Alex to see his doctor. There

was no way I could convince BMH to give Alex an appointment since Alex's doctor, Jeffrey Johns, Ph.D. was on vacation this week, and apparently only makes his own appointments. I left a message with Yvette Katuala, their compliance officer; I spoke to Marcella Sabin, their patient advocate; I left a message with the case manager; then went to visit BMH and spoke to the nurse, Peggy Higgins, and she sent the team supervisor, Marianne Davis, out to speak to me. That was yesterday, 4/8/15. I just left BMH after all those conversations and gave up on their doing anything because everyone concluded that there was nothing to be done until Johns returns on Monday. It took a lot of energy out of me and I couldn't wake up this morning, Thursday, April 9th, until 11am when the phone rang with a call from Marcella Sabin getting back to me about all she couldn't do and why. I really let her have it, telling her someone had better get back to Gene at Villa very soon with what he needed so he could make the arrangement for Alex to be discharged "before he changes his mind." By 4pm, Gene called as I was arriving for a stroll around Lake Merritt to unwind. I danced instead. He said the case manager was able to give him the appointment he needed. I guess somehow the word spread that it was urgent. And it was my favorite 60's song that was just sold for over a million dollars. I turned it really loud and danced on the pavement with my usual partner, my van's door.

I received these two calls at the same time on Thursday, April 9, 2015. One is the state ombudsman agency I already emailed last Friday, April 3rd. The person I spoke to, a different Steve—not to be confused with Steven Gronic Mc Clurg, the Mental Health Manager at BMH—who had called me back after I left a message earlier today saying he didn't know about last Friday's email, but he was trying to be very helpful when I lost him, putting him on hold as I tried to pick up another call from David at NAMI CA. It looks like they never got my email either, because joan@joan-of-art-centerpieces has not yet been working. It works when I send myself an e-mail, just not when others do it.
916-650-6610
916 -564-5446

Thursday, April 9th, 2015

I wrote to a Steve at the California Dept. of Health Care Services
Mental Health Services Division:

> mhombudsman@dhcs.ca.gov
> att: Steve…licensing and certification 916-323-1864 (this is the SAMHSA recommendation that I received in the reply from SAMHSA and Steve said that SAMHSA is their funding agency) 1800-896-4042.

916-650-6610
916-564-5446

One of these 2 numbers above is NAMI CA; David called me back to let me know that he couldn't email me because the joan-of-art-centerpieces.com was returned, i.e., didn't go through, so he called instead and I couldn't pick up his call because I was talking to the state ombudsman, Steve.

Consumer Assistance returned my call and Patrick said Wilma Gaines (510-289-7103) will be in tomorrow. I think she's the one who was giving the presentation at the Alameda County Mental Health Board meeting last month after which I asked her boss if he could recommend someone to help me, but he never got back to me. But, Patrick, a co-worker of Wilma's called me on 4/9/15 because Wilma wasn't in.

Monday, July 20, 2015

I've been calling around just to find there is no "system" in the mental health system. I need a lawyer in order to gain the title of conservator from the Alameda County jurisprudence system in order to get my son to the oral surgeon. A week ago Alex woke up from a deep sleep around 3am because he couldn't catch his breath. He ran into the living room and after around 20 more seconds, he started breathing again. In the meantime I had called 911 but by the time the paramedics were standing in the living room, he was fine. I told them he needed to go to the emergency room, but he told them he didn't want to go. One of them stayed to tell me that I ought to become his conservator because that's the only way they would be able to take him against his will. So, I called around and talked to a Stephanie Marsili in Alameda County:

> Conservator paperwork
> Sent By:
> Stephanie Marsili, SSA On:Jul 07/13/15 5:37 PM To: JoanOfArt44@comcast.net
>
> Hi Joan,
> Just got your message; sorry the email did not go through.
> Please call Ms. Johnson at 577.3585- she is the social worker who handles the applications for conservatorship- she will be able to mail the paperwork to you, and answer any questions.
> -Stephanie
>
> FW: Probate Conservatorship
> Sent By:

Yaxchilan Johnson, SSA On:Jul 07/14/15 1:56 PM
To: JoanOfArt44@comcast.net
Alameda County ...Conservator.doc (34 KB) Download | Remove
Alternatives to...ervatorship.doc (34.5 KB) Download | Remove
Download all attachments as zip file
Remove all attachments

"Yaxchilan Johnson, ...
+ Add to Address Book
Message

1) Please see the links below regarding question about conservatorship Private Conservatorship:

http://www.courts.ca.gov/selfhelp-conservatorship.htm
http://www.courts.ca.gov/1302.htm

Note: You may be required to seek legal assistance if "proposed conservatee" resources (i.e). Bank accounts, pension, or Real estate).

Yaxchilan Johnson, M.A., SWIII
Probate Intake and Benefits Coordinator
Alameda County Public Guardian-Conservator's Office
P.O. Box 2071
Oakland, Ca 94604
Direct line: 510-577-3585
Fax: 510-577-5619
Email: ygriggs@acgov.org

There was so much information on line about conservatorship, (over 100 pages) definitely a legal matter, that I put some of it at the end of the journal so I can study and reorganize it.

Thursday, July 30th, 2015

Finding a Dentist for Alex at the University of California Dental School

Hit me over the head, please. I need a jolt of some kind, because I think I heard a young dentist say we would *talk with the psychologist at UCSF Dental School* at my next appointment in the Adult Faculty Clinic, to see the best way to approach getting Alex to be seen there. The young man's name is Justin Becerra, DDS, in Advanced Education in General Dentistry in the Department of Preventive and Restorative Dental Sciences at the School of Dentistry at UCSF in San Francisco. We talked about my teeth for a while, (Did I tell you, keyboard friend, that Dr. Arnold diagnosed me with 5 abscessed teeth? That's 2 more than Alex has.) until I brought up my son's situation during the conversation, which was the real reason I decided to try UCSF. And after 3 separate visits to UCSF—the Emergency Room, the Student Clinic, the Faculty Clinic—I met Dr. Becerra, DDS. He listened. He responded in a concerned manner. He immediately suggested a plan, after telling me that he's already seen a few other patients with schizophrenia, and seemed to understand how to respond to their being controlled by voices. So, now I only have to get Alex into my van and over the bridge to 4th and Parnassus. That's another story. In the meantime I'll send a letter and a journal to Dr. Linda Centore, PhD, the psychologist who also works at the dental school. The other Linda, behind the desk inside the faculty clinic waiting room, was unusually sweet, exceedingly efficient, and extremely customer service oriented. She had called Dr. Arnold's office at her own suggestion on Tuesday, so my x-rays were already on the screen, when I sat down on Justin's chair. He told me to call him 'Justin,' but each time I addressed him, 'Dr. Becerra' seemed to want to come out. It's probably because I learned that they spend 4 years in dental school after the 4 years of undergraduate school, and then they specialize for a couple more years. So, that sounds like 10 years of study to me, definitely worthy of acknowledgement of "Doctor" for all of his time, persistence, energy and focus. He refused to charge me for today's appointment—since he didn't actually work on my teeth—not the normal procedure in the dental world. I was so elated and relieved that I decided to celebrate with lunch on the beach since it was only a few more miles west. There is hope yet.

Meanwhile, the Neighbors

Now that Alex is addicted to smoking, and he can't smoke inside the building, he has to go into the backyard. There's a private area, now filled with unused outdoor grills, discarded furniture, crates, etc., that would make a lovely outdoor sitting area, if the landlord would remove the junk and the 5 clothes lines that no one uses, behind the 8-plex. Sandy, the owner, said Alex could smoke there rather than under my window in the front, where I would be able to see him, because our apartment faces the street and all the neighboring homes, where he would be more visible. I already told Sandy—when he came over with prospective tenants last month—that Alex is now a smoker since his hospitalization. Sandy first thought Alex had taken up sleeping outside, after seeing him in a reclined position against the fence. It must have surprised and/or annoyed him to see Alex lying against the fence next to the apartment that he was showing, so he, with a concerned expression, came over to me sitting in my van to say, "Alex is sleeping in the back!" That was before Alex put his desk chair back there, so it may have looked like he was sleeping, but in fact, he was smoking while reclined against the fence. So, I let Sandy know

about Alex's new smoking status. He had to give it some thought and came back the next day to let me know that the backyard would actually be better than the front. At the time, I thought so too, because it's private and Alex wouldn't have to be on stage, as it were, visible to the street with its passerby's and home owners. But, even hidden from sight is not the whole picture; I've had to educate Alex in regard to noise level. Smoking sounds like a quiet activity, but not necessarily, in the hands of someone who hears voices and occasionally responds, and occasionally breaks out in manic laughter because BMH took him off the Depacote a couple years ago, a medicine for mood swings. And certainly not in the hands of someone who refuses to believe that the dentist thinks 3 of his teeth are infected, and that the combination of infection and/or smoking is making the lungs need to cough and spit.

I've been successful in getting Alex to understand the illegality of any kind of noise between 10pm and 6am, but not in understanding that the neighbors don't want to hear him even after 6am. He gets up early, between 5 and 7am, as though he's going to work—and actually he tells me he is working—and goes into the backyard to smoke. I've already explained to him, ad infinitum, that he will lose points (dollars) if he goes outside before 7am during the week and 8am on weekends, but he left this morning at 6:50am just, I think, to show that he knows he can. But, not all of the neighbors want to hear his coughing and sputtering at even 7am. I used to sleep 'till 9am while he was hospitalized, but now I'm up whenever he gets up. Neighbors aren't interested in adjusting. I prefer sleeping later too. This morning I was monitoring his noise level keeping my door ajar, and I could hear a female voice yelling. "Who is that making so much noise?" Alex didn't answer. Her voice came from the other side of the fence he was leaning against. She continued, since she wasn't getting any answers from him. "Who are you? Why do you have to wake me up?" On and on she went explaining her predicament: "Every morning I have to get up just because you're making all these noises. Why are you outside doing all that coughing? I don't get up this early and I don't want to get up this early. I need to sleep. Who are you?" By that time, since he wasn't going to get involved, I hurried back there to answer her. "Hi, I'm his mother. And I've kept him inside as long as I can."
"Who are you?"
"I'm Joan. And you?"
"Judy."
"Nice to meet you," I called over the 10 foot solid wood fence. "We've lived here almost 10 years, but he's only been smoking since he was in the hospital a few months ago. That's where he learned to smoke." I should have said what Alex told me, that "the doctor told me to smoke," probably because it keeps the patients calmer—just another example of Villa's Hospital Philosophy: 'good for the employees; not so good for the patients.'
"What do you mean 'He learned to smoke in the hospital?'"
"I mean an employee would say, "Smoke break; everybody out!" a few times a day and all the smokers would get a chance to be together to smoke and chat on the lawn. The non-smokers didn't get to go outside for a special *non-smokers break*. After a while, maybe he wanted to be sociable, too."

"Well, I appreciate you answering. Maybe you can tell your landlord that this is not such a good arrangement."
"I will let him know, and I appreciate your saying something, so my son could hear it from someone other than myself. I've been telling him all along. Even if it's not illegal, it's still disturbing."

The very next day, as a kind of explanation point, there was a huge yellowish pile of dog doo starting 2 ½ feet up the fence and dripping down to the grass. I'm not sure if her husband simply brought their dog over to emphasize the point of his wife's complaint, or if all of a sudden after 10 years of residing here, a stray dog on its own walked around the back of the apartment complex by chance, to poop. Somehow the former explanation sounds more realistic to me, especially since the poop was a couple of feet from Alex's chair. I gave it grave thought as I donned rubber gloves to remove the feces and made sure Alex knew to avoid the back yard before 9am. How to get that engraved into his mind would have to be by someone with more authority that he thinks I have. After all, I'm only Alex's caretaker, according to Alex. So, I called the Berkeley Police Department. After a longer than necessary explanation, she agreed to have an officer call me. Within the half hour a call came through which I put on speaker phone so Alex could hear. The tone of the officer's voice was believable and Alex was more willing to remain in the apartment until 7am. I made arrangements with Alex to go outside somewhere else until 9am so he didn't disturb the same neighbors every day. And for the most part, he is going to the park down the street to do his smoking/coughing routine there. I picture him in the middle of the dog park reclined on the grass from 7 to 9am, although I haven't gotten dressed to actually go with him, so I'm hoping that no one shoots him from their window surrounding the park. All of the mornings since this incident last week in the beginning of August, Alex has returned unharmed and happy that he has a bigger spot to move around in. I usually go back to sleep, but not today, as I've taken the time to jot it all down before all but the bad feelings are erased from memory.

Saturday, August 29, 2015

Alex didn't take his medicine last night. Alex didn't come home last night...Friday, August 28. It's already 7am on Saturday. He left at 9pm Friday night. I think he was mad at me for accusing him of something he didn't do, because that's when he left. He'd gone outside in the back to smoke at 8:30pm. He should have stayed in at that time, because that's when he usually comes back from smoking. So, he was already off kilter. He was already upset to have gone out. I'd come home late for dinner because I stopped at Kaiser, since I had to pass right by after doing laundry in Alameda, and I wanted to pick up the medicine that the Stanford ER doc, Dr. Anderson, prescribed for my headaches the day before. It took the pharmacy longer than usual to fill the prescription because Dr. Anderson had faxed the prescription to an address listed in the computer, the old "main pharmacy", which was now an empty building. Kaiser had either never bothered changing the phone numbers on their website to those for the new hospital building on Broadway, or the Stanford ER had the old numbers that were never updated. In either case, I knew the old building was now desolate, and I wouldn't be able to get in to retrieve the fax, so I called the

number on Stanford's discharge paper I had filed in my van, and the woman who answered in the ER said they faxed it to the West McArthur main hospital pharmacy when I was there on Thursday, so they couldn't fax it again. But, she was willing to call the Kaiser pharmacist's number that I gave her, and spoke to the manager or maybe he called her with the number to Stanford's ER that I gave him. Less than an hour later the manager said my prescription was ready and "you can get in line (again) and pick it up." So, between the laundry and another hour stopping at Safeway, I didn't get home until a little after 7pm. That's late. He was probably wondering what happened to me. I'd told him when I left for the laundry at 1:30pm, that I'd likely be home by 6pm. I probably shouldn't have food shopped in Alameda, but I was done with the laundry by 4pm and needed milk. I guess I pushed the limit by stopping at the Kaiser pharmacy, but I wanted my headache to go away, so I did, since it was right on the way home.

I didn't blurt out a warm "hello" when I walked in. Instead, I played it *cold*, as opposed to simply *cool*, after I saw that he didn't sign the paper I'd left for that purpose. So, I just brought the groceries into the kitchen quietly. I already had a top round steak marinating all day and when he asked me to get a pizza; I said "no" intentionally adding, "I'm not doing anything special for someone who wouldn't even sign the paper I left on the table for him to sign." It was the *Authorized Representative Form and Authorization for Release of Protected Health Information* from Alameda Alliance for Health, the organization who handles the county's Medi-Cal. It took his OK on the speaker phone earlier in the week for them to send it to me, but when I received it on Thursday, he said he couldn't sign it. He said he could "witness" the signing and directed me to write his name. I told him then, that that wouldn't be good enough. It was *he* they wanted a signature from; as a witness, he "would have to sign in order to show that you witnessed something," I tried to explain. He didn't buy it; he walked out. By Friday, I decided I needed to be tough. I can only guess that he took that as the end of our relationship: no pizza, my continuing to insist that he sign, my being unfriendly. But there was more. I realize now that I did the undo-able. I accused him of something he didn't do. While I was preparing the steak and veges, I heard a loud voice yelling, "F___ you!" and ran outside and around to the back where he was smoking. I really thought he might be talking to his imagined people. It was just getting dark. Although I said it nicely, it didn't matter. "Alex was that you yelling?" As I stood there under the window of apartment 8, I could hear loud voices. But, the accusation was already on the table. And he doesn't take well to being accused of anything especially when he didn't do it. He started out calmly, but accelerated into, "You'd better get another Joan! I'm leaving! And don't follow me!" So, that's how I killed my kid. It was a slow strangling by a loveless insistence on his signature so he could get the doctor he can walk to, the unfounded indictment of his saying "F___ you!", and the unnecessary denial of pretzel pizza from Little Caesar's.

I checked my e-mail and noticed that my brother had recently written to me. He's been very kind since last August when Alex connected with him by calling my eldest brother, Jay, to get his number. Before that, we hadn't spoken for 15 years or more, not long after Alex became ill in 1996. The last action he took was to send me a manuscript that a friend of his was writing, about how the mother is the culprit in the child's demise into schizophrenia, and after that, no more communication. I was pleasantly surprised that he became interested in

communicating only last year just before my laminectomy. He offered to pay for the woman who was supposed to take care of Alex when I would be away recuperating from the surgery. And after talking to Alex on the phone a few times, he was the one last April to convince Alex to see the dentist, Dr. Arnold, who discovered the 3 actively abscessed teeth. He's been sending me $1,000 a month while Alex was in the hospital since the hospital has claims to Alex's social security (that's another story) as about half of Alex's social security had been necessary to pay the rent since I spent all of what was left of my retirement to take Kaiser to arbitration. (That's another story, too.) In fact, Jerry hasn't stopped sending me money.

Jerry Mirrow <jmirrow@aol.com>
Aug 27 (2 days ago)

to me
Hi Joan,

This is the address you prefer? Do you check it daily, or do you like a text to remind you to check?

On another subject, the tenant in the unit next to mine (3Y) is moving out at the end of September. It is a 2 bedroom / 2 bath condo. Before I give it to my agent, I was wondering if you wanted to give it a try. If you like it and decided to stay, I wouldn't charge rent. You would be responsible for the Maintenance and electric (about $500 / mth). Let me know if you want to try it. Kaiser is all over Florida, and I have a good dental team here.

Aloha,

Jerry

Sent from my iPhone

Dear Jerry,

I must have pressed something and deleted everything. Anyway, no, I haven't been using the computer much with these headaches. I finally decided to go to Stanford after getting not much from Kaiser doctors. They're not stupid, I think. They're just not interested in my headaches or someone would have already prescribed the Gabapentin that the Stanford ER doc gave me immediately. He was very compassionate. I swore I had painful varicose veins in my skull, but he said it's bone and muscle. But, it hurts anyway, in a half of a circular pattern on the left side of the top of the head and not on the right. That's how it goes with me. As soon as one thing is done, something else takes its place. The 2nd spine surgery was only a year

ago and I'm already into the headaches. They were so nice at Stanford, starting from when I set foot in the door and a young lady saw I was in need of some direction. They seem to understand about customer service down to the lowest on the totem pole. The triage nurse called the doctor right in because she didn't think I needed emergency treatment. That would have meant waiting 2-3 hours, so the doctor told me to make an appointment in neurology and sent me right in to see an ER doc for a quick consultation anyway. He was very compassionate. No one at Kaiser ever recommended anything for my ongoing headaches, almost 2 years. I just couldn't always feel them because the back and leg pain were overpowering. Now that that is mostly gone, I can feel the rest of my body.

I was saying that Alex just walked out at 9pm tonight, the time that he is supposed to have his medicine, but he didn't take it. He's mad at me and told me "You're breaking my star!" (I think that means he doesn't like my demeanor or maybe I'm getting meaner) "Go get another Joan before I come home." I drove after him and found him a few blocks away but he told me to leave him be and turn around. I thought I should just wait for him to come back. Then, after a couple hours, I called the police at 11:30pm but she said he was "old enough to go out," so I called back at 12:30am and was able to convince her to send me a police officer to put in a "missing person" report. I just told him the situation about Alex not wanting to go to the doctor or the dentist and that's why I had to have him sign a paper to give me permission to talk to the Alameda Alliance for Health (Medi-Cal) people so that when I call they won't hang up on me. I have to get them to dis-enroll him from Kaiser so he can go to another doctor closer to home. He rarely will get into my van. He doesn't go anywhere. It's very difficult talking to these government workers. The wait time is enormous and then they transfer you to a voice mail and you have to keep calling back until you get someone with some sense.

I want to perform a u-tube video about the horrible mental health system. I'm going to put my hair in one style (a foot long natural brown colored braid) on the left hand side of my head, and on the other side, I'm letting it go white and cutting it down to one inch so it can stick up, like spiked. I want to look crazy because I will be interviewing myself, as one of me pretends to be another person, like Alex's psychiatrist, Dr. "Fan" (not her real name) The skit is called, "Who's Crazy Now?!!" For instance, after I explain what the show is about, I turn to look at Dr. Fan so the viewer sees my long hair side of my face saying, "Dr. Fan, please help me find a way to talk to Alex. I'm not sure I told you that he hasn't taken a shower in 2 years! I don't know how to get him to get into the shower! He's filthy! He stinks! How do I handle it?
And she replies as I turn my head: "Oh, Ms. Miro, I know. Don't worry about it. They take too many showers in America."
Then I turn face forward, looking two faced in one, and say, "So? Who's crazy now?! (pause) If you said the psychiatrist, (bell) YOU WIN!!"

I have written over 4,000 pages of conversations and other material pertaining to the mental health "system" with such dumb, nasty, odious, and dumber comments and actions, that no one, except avid readers, will read. So, I just came up with the idea of putting it on u-tube in 5 minute episodes.

Finally, thank you for that offer of an apartment. I can't wait to move! Wow! $500! Are you sure about that? I've been about to embark on a "HUD" project, or what they call, "Affordable Housing" in California. I have 100 pages listing $300 to $600 apartments. I've had the paperwork for several months. Just haven't felt up to it. I'm definitely up to moving. Thanks for thinking of me.

Love,
Joan
G-d, it's after 2:00. I can't believe he's not

Click here to Reply or Forward

Sunday, August 30, 2015

Having left my usual one light on before going out to look for him, I walked anxiously into a dark apartment to be greeted with a cheery, "Hello!" Alex returned on his own Saturday night at 9pm, 24 hours after he left. I had called the police again Saturday morning after I saw him sitting on the curb of the parking lot at the Ashby Flee Market where I had stopped just to see if he were there. I kept a record of what was happening all day by sending texts to Brenden who has become tired of knowing the ordeal, but I did it anyway:

ME

6:30am Saturday…You might want to know that I called the police @midnight (Friday night) to look for Alex. He left at 9pm to "go into town" without having taken his medicine. (He was mad at me.) It's 6:30am now and ***he never came home***. I'm going to start driving around again.

BRENDEN

Hi. My phone was dead last night so I am just seeing all this now. ***Glad that he made it home this morning and that everything was OK.*** I can call you later if you want. I'm actually in LA till Sunday. We just got here last night.

ME

That sounds fun. I spoke to him at the Ashby flee market this morning and he responded properly, saying he'd be home soon. He smiled when he saw me as if we were playing "hide and seek". The main thing is he hasn't taken meds since Thursday at 9pm and it's past the 36 hour half-life of the Zyprexa, so he only has maybe 5 mg in his blood instead of the 15 mg that he takes, so I called Mobile Crises and they're talking possibly a 5150 if they find him. I definitely don't want that. They do need to adjust his meds (or find better meds.) Sorry to bother you. At least he sounded OK and he fits in in Berkeley wearing my pink short shorts and silky short red robe as a jacket over his new blue T-shirt. Did I tell you he said he was at Cal's Opening Event? They had an acapella choir of students to introduce the freshmen to the school. When I told him I saw it on the 11 o'clock news, he said, "Did you see me? There was a dance afterwards and then we went to someone's house," he said, where he spent the night. I can't believe that. I was watching the choir on the news from my bed because I was too anxious to sleep. It was a fairly lengthy piece and then I got up to write about the day until 2am because I have no one to talk to except my computer friend. I finally got to sleep from 2 to 6am. I did all I could do. He's mad at me and said, "Get a new Joan!" because I'm insisting that he sign a Medi-Cal form so they can talk to me, so we can dis-enroll him from Kaiser and get him a new doctor in Berkeley. When I told him that, he said, "Maybe the new building won't be safe." I'm tired. Apparently he can get around the street fairly safely, so I'm going back to sleep. Enjoy yourself in LA.

BRENDEN

That is crazy about him staying at someone else's house for the nite. I guess just wait till tonight for meds and he just misses a day? At least try that before they try 5150.

ME

5:45pm Saturday…I'm just getting up from an all-day nap. He didn't come home so it seems like I'll have to get the police more involved. Someone should have seen him already. I had to catch up on sleep 'cause I can't do on 4 hours. It's the only way I can block this out. He doesn't even have money on him. He seemed to be happy when I saw him this morning. Said, "I'll be home soon." He was at the Cal event last night that I saw on TV news. That must have been nice for him to see such activity. Maybe he realizes that he's missing something so he doesn't really want to come home. I think he wants more of the same. He probably has some realization that he's been missing out. Maybe he can do on less medicine.

ME

6:00pm Saturday…Guess what! When I counted the meds in each of the 4 vials last night, they were accurate with 2 pills in each vial (accurate for a Friday night). Before I saw him at 9am (today) there were still 2 pills. After about 10 minutes of conversation, we parted and I went home (he headed east towards Walgreen's) and I put the med vials, a cup & a bottle of juice into a plastic bag and went out again, thinking I might catch up to him at Walgreen's or Berkeley Bowl. Buying a few things while I looked down the isles for him and talking to the managers or security in each store kept my mind off the situation, and when I came home I became extremely tired while putting the groceries away and fell asleep on the sofa around noon. So, I'm just waking up before 6pm and counted the meds again and there's only one in each vial. That can only mean he snuck in here while I was sleeping and took them. So, that's good. I always put 7 in each vial every Sunday, so tomorrow is the beginning of a new week, but I'm going to have to hide the vials so he doesn't take more tonight. So this is all good. I hope he changed out of my pink pants. No, they're not on his floor. Well, at least that makes it easier to identify him. I put $15 in his money drawer in case he returns. I told him I'm charging $5 for me to have to wipe the pee off the toilet seat. First he said he would pay me $1 to clean it, I said "No! I'm not doing it for $1. You do it!" That was before he disappeared yesterday. So, I'm feeling much better knowing that he came home sometime today and took his meds. That was my main concern. It's still light so I'm going to the gym. I'll think no more about it.

ME

9:00pm Saturday…Alex came home to stay as long as "Joan is the right Joan." I was out looking around Telegraph after the Y, and after another look at Walgreen's, I arrived home at 9pm to his overly happy "Hello!" He doesn't have a clue about what he caused. He tried to explain why he left. I'll have to email you with the notes I scrawled as he explained. Enjoy the rest of your weekend.

What he told me from his bed, the only place in the apartment his voices allow him to sit was:

"I know that Joan is not breaking me…I'll be a perfect gentleman. When she breaks me—I don't know how she breaks me—it's like Kryptonite…when you bring the other Joan around, it's like Kryptonite. I get paralyzed. I start to, like, catch fire. She burns me. It's a painful, magnetic burn. I lose my cool. That's what you lose…When you get a temper, (I get upset.)…Why don't you take an extra $10 out of my account for your troubles."

Brenden's first text tells all that's needed to understand how he's resolved himself to deal with his brother. He must have not read my text, maybe just lightly glanced at it, in order to conclude that Alex had already come home. I told him Alex had just left at 9pm Friday night; I didn't say he came home. But, he'd already showed me he doesn't want to be involved any more.

Tuesday, September 1st, 2015

I doubt that Alex slept at all last night. He was really manic, laughing until the break of dawn. He woke me up almost hourly and I would go into his room each time to tell him he's too noisy, and the neighbors can hear, et al. He didn't drink the honey tea I made once he started coughing although that might have helped. It seems that the laughing leads to the coughing. By 5am he was sitting on the edge of his bed cutting his toe nails, so I got up and made pancakes with fruit which he committed to eat, but instead, came to the table with a handful of "grains," he called them, that he had pulled out of his back pack and didn't eat the pancakes. He's been eating out of his backpack for breakfast for over a week. The pancakes were delicious; I added chocolate milk. It must be the ginger sugar that he eats out of his backpack that's making him manic, or maybe he's really not swallowing the meds. I already told Dr. Johns that he needs the Depacote that one of the psychiatrists at Villa took him off of. No response from Johns so far. The case manager, Alberto, called to say he's coming over after 3pm today so I will bring it up. He got a long report from Jan at the Berkeley Crisis Team who I called on the weekend. I'm thinking Alex needs to move. I can't handle him because he's not listening to me. For, instance, he just went to the back of the building to smoke and we'd already agreed that he shouldn't go there until after 9am. It was only 7am, legal but still annoying to the neighbors in the back, who like to sleep later than legal time. It's the coughing that gives him away. Otherwise, he's just sitting there quietly. But, now we have the manic laughing in addition to the coughing. We did have some success yesterday getting him closer to a new doctor in Berkeley.

Monday, August 31st, 2015

I left the form sent to me by the Alameda Alliance for Health on the dining room table, in order to give him all day to look at it, telling him that the form needed his signature, so that the Alliance would be able to talk to me over the phone, and I could ask them to recommend him a new doctor within walking distance. I'd already called several doctors in Berkeley, who are listed in their telephone book of doctors who participate in Medi-Cal, sent to me by the Alliance. When I told him what I was doing, he seemed apprehensive, at best, about switching out of Kaiser to any new doctor. I heard him say under his breath. "How do I know that the building is safe?" So, the psychologist at UCSF Dental School was right, saying that "safety" is a very important concern to a person with schizophrenia. I guess that's why he won't go into the building at Berkeley Mental Health (BMH). And the doctors at BMH have been willing to either come outside to talk to him by my van parked on their corner, or just walk over to our apartment 2 blocks away. They must be aware of the safety issue, too, and made the decision to meet their patients on each patient's own turf when necessary.

The Conversation with Alameda Alliance for Health

We will email a receipt to your Alliance representative to dis-enroll him from Kaiser and put him on the roster of another medical facility, so Alex can walk to a nearby clinic, but the representative needed to explain, ad infinitum, how important and necessary it is for me to fill out their form and have him sign it. I told him that another representative already told me that they don't even check the signatures to make sure it was that person who signed. So, why do they insist that the patient do the signing if they wouldn't even know whether it was he who signed after all? Both representatives were letting me know that I could sign and no one would be the wiser. They didn't say that exactly, but it was definitely implied. Unfortunately, that goes against my own code, therefore it would lessen my sense that I was adhering to what is right, if I were to sign Alex's name. And that's the reason I had called them again, so the Alliance employee would be able to hear Alex say that I could get and give information and so I could then tell them to switch his coverage. The representative seemed reluctant to process the information I was giving him, insisting that it was only during the time of each call that he would be able to tell me anything. I said, "That's OK, and for this call, I want to tell you that he wants to dis-enroll from Kaiser and join a group called LifeLong Berkeley Primary Care at Adeline near Ashby, so he can walk to the doctor's office." Of course he asked to speak to Alex, who, during the entire time that I was speaking, was laughing hysterically in the background. When it was Alex's turn to get on the phone to talk to the representative, he told him in an unnecessarily loud voice and in no uncertain terms what needed to be done: "You have to tell my Joan anything she needs to know because the Universe is going to end if you don't." Alex went on and on, ad infinitum, explaining about the effect on the Universe. I tried telling him to stop, until I couldn't contain myself and broke out both laughing and crying, which, apparently made the representative speechless, and without further ado he made the change. He was willing to switch Alex out of Kaiser and said I could call LifeLong the very next day to make an appointment. I was so relieved, after making at least a dozen phone calls over a month's time, that it was finally done! The process was so confusing. So, the next day, Tuesday, September 1st, I called the new organization to get him an appointment. That wasn't going to happen until October, she said, so I asked and found out that I needed to call again and ask for a triage nurse, which I did and he called back shortly. As we were speaking, he said an appointment just came up for today at 3:30pm only an hour and a half away. Elated, I ran into the back yard and told Alex he could go today, unaware of the information he was about to disclose. "No," he said, "I'm going to see the place with Alberto." I had called BMH for help a few days before since Alex had stayed out all night and didn't take the medicine. He had come over a few times to speak to Alex and apparently told him that they would walk over to the new building together just to check it out. And that would have been appropriate, since Alex is overly concerned with safety, and doesn't like surprises. The only problem is that Alberto doesn't include me in the conversation, nor did he let me know what had transpired, yet I'm the one who made all the arrangements, not BMH. I'm the one who spends all the time and makes all the effort on Alex's behalf, not BMH. BMH does a lot of talking about what they're going to do, but little doing.

Earlier on in the year when Alex was discharged from Villa, there was talk about what BMH would do, but never action. They had informed me about LifeLong, and said I could call to make an appointment, which I did back in May, but I never heard from LifeLong again because they wrote down my phone number in the wrong order, and ended up making an appointment for Alex for July 15th, leaving the appointment in a dead end slot in their computer since they didn't connect with me at the right phone number. Because when I called on Sept. 1st after having dropped Kaiser, the woman told me Alex already had an appointment on July 15th. I assured her that he did not and walked over there to straighten out the information, because she said she couldn't over the phone make him another appointment, since he didn't show up, and was still attached to Kaiser in July. So, that's all that BMH did in regard to helping to get Alex dis-enrolled so he could go to a medical doctor locally…nothing.

The Position on Mental Illness from The White House

It's been a while since mental illness came to the forefront where it can be talked about in a positive way. Even the White House has entertained the conversations, but that's all there is…talk. There is not yet real help for those seriously mentally ill, that is, no medicines that really work – for schizophrenia at least – little research to understand etiology, little attention paid to what would be the best medicines for their patients by the treating psychiatrists, little understanding or respect about why it's important for practitioners to get necessary information from the people who know their patient best—the parent. The important issues have not been dealt with. Yes, there are medicines that help somewhat, but where is money for the research to understand the cause so researchers can create better ones? Yes, the stigma issue is being addressed. Yes, there is acknowledgement that there is a problem. In fact, that happens again and again as each crazy incident of murders unfold. And several different professional groups have ongoing meetings. Now what? Where is the medicine? What is the cause? Where is the money? What is the plan? Where is the action?

This paper is from the white house conference on mental illness on June 4, 2013

Remarks by the President at National Conference on Mental Health
East Room

10:00 A.M. EDT

THE PRESIDENT: Thank you so much. Welcome to the White House. And thank you, Janelle, for that introduction and sharing your story, and making such a difference through your organization. We're really proud to have you here.
I want to thank Secretary Sebelius, Secretary Arne Duncan, Secretary Ric Shinseki for their leadership and helping to organize this event. And I also want to acknowledge some outstanding members of Congress who are here and who care deeply about this issue.

And finally, I want to thank all of you for participating in this national conference on mental health. We wanted to bring together folks who've suffered from mental illness and families who've supported them. We wanted to bring together advocates and educators, faith leaders, veterans, local officials.

All of you have shown an extraordinary commitment to what is a critical goal, and that is to make sure that people aren't suffering in silence and that we have the capacity to pull together all the resources and support and love that's out there to go after an extraordinary challenge in our society.

The main goal of this conference is not to start a conversation -- so many of you have spent decades waging long and lonely battles to be heard. Instead, it's about elevating that conversation to a national level and bringing mental illness out of the shadows.
We want to let people living with mental health challenges know that they are not alone, and we've got to be making sure that we're committed to support those fellow Americans, because struggling with a mental illness or caring for someone who does can be isolating. And I think everybody here who's experienced the issue in one way or another understands that. It begins to feel as if not only are you alone, but that you shouldn't burden others with the challenge and the darkness, day in, day out -- what some call a cloud that you just can't seem to escape -- begins to close in.

The truth is, in any given year, one in five adults experience a mental illness -- one in five. Forty-five million Americans suffer from things like depression or anxiety, schizophrenia or PTSD. Young people are affected at a similar rate. So we all know somebody -- a family member, a friend, a neighbor -- who has struggled or will struggle with mental health issues at some point in their lives. Michelle and I have both known people who have battled severe depression over the years, people we love. And oftentimes, those who seek treatment go on to lead happy, healthy, productive lives.

So we know that recovery is possible, we know help is available, and yet, as a society, we often think about mental health differently than other forms of health. You see commercials on TV about a whole array of physical health issues, some of them very personal. (Laughter.) And yet, we whisper about mental health issues and avoid asking too many questions.

The brain is a body part too; we just know less about it. And there should be no shame in discussing or seeking help for treatable illnesses that affect too many people that we love. We've got to get rid of that embarrassment; we've got to get rid of that stigma. Too many Americans who struggle with mental health illnesses are still suffering in silence rather than seeking help, and we need to see it that men and women who would never hesitate to go see a doctor if they had a broken arm or came down with the flu, that they have that same attitude when it comes to their mental health.
We see it in veterans who come home from the battlefield with the invisible wounds of war, but who feel somehow that seeking treatment is a sign of weakness when in fact it's a sign of strength. We see it in parents who would do anything for their kids, but who often fight their mental health battle alone -– afraid that reaching out would somehow reflect badly on them.

We see it in the tragedies that we have the power to prevent. And I want to be absolutely clear: The overwhelming majority of people who suffer from mental illnesses are not violent. They will never pose a threat to themselves or others. And there are a whole lot of violent people with no diagnosable mental health issues. But we also know that most suicides each year involve someone with a mental health or substance abuse disorder. And in some cases, when a condition goes untreated, it can lead to tragedy on a larger scale.

We can do something about stories like these. In many cases, treatment is available and effective. We can help people who suffer from a mental illness continue to be great colleagues, great friends, the people we love. We can take out some pain and give them a new sense of hope. But it requires all of us to act. And there are a few ways we can do our part.

First, we've got to do a better job recognizing mental health issues in our children, and making it easier for Americans of all ages to seek help. Today, less than 40 percent of people with mental illness receive treatment -- less than 40 percent. Even though three-quarters of mental illnesses emerge by the end of -- by the age of 24, only about half of children with mental health problems receive treatment. Now think about it: We wouldn't accept it if only 40 percent of Americans with cancers got treatment. We wouldn't accept it if only half of young people with diabetes got help. Why should we accept it when it comes to mental health? It doesn't make any sense.

The good news is, there are plenty of groups that are stepping up to change that. So a former colleague of mine, Gordon Smith, a former Republican Senator, lost his son to suicide 10 years ago. And I remember him speaking so eloquently about it. Gordon is now the head of the National Association of Broadcasters, and today, the National Association of Broadcasters is announcing a new campaign designed to change attitudes about mental illness through TV ads and social media, because Gordon doesn't want other parents to go through the agonizing loss that he's endured. So we thank you, Gordon, for that great work. (Applause.)

You've got secondary school principals who are holding assemblies on mental health. You've got organizations like the YMCA who are volunteering to train staff to recognize the signs of depression and other mental illnesses in our young people. You got leaders from different faith communities who are getting their congregations involved. And dozens of other organizations have today made similar commitments, so we're very thankful to all of you.

There are other people who are leading by example. My great friend, Patrick Kennedy, when he was running for reelection back in 2006, he could have avoided talking about his struggles with bipolar disorder and addiction. Let's face it, he's a Kennedy. (Laughter.) He was -- his seat was pretty safe. Everybody loved him. And yet, Patrick used his experience as a way to connect and to lift up these issues, not hide from them.

And one day, a woman came up to Patrick at a senior center and told him she was afraid to tell her friends she was taking medication for a mental illness because she was worried they might treat her differently. She told Patrick, "You're the only one who knows aside from my son." And so Patrick started realizing how much power there could be for people to speak out on these issues. And Patrick carried these stories back with him to Washington, where he worked with a bipartisan group of lawmakers, including his dad, to make sure the mental health services you get through your insurance plan at work are covered the same way that physical health services are -- a huge victory. (Applause.)
So because of Patrick's efforts and the colleagues who worked with him, it's easier for millions of people to join him on the road to recovery, which brings me to a second point. It's not enough to help more Americans seek treatment -– we also have to make sure that the treatment is there when they're ready to seek it.

For years now, our mental health system has struggled to serve people who depend on it. That's why, under the Affordable Care Act, we're expanding mental health and substance abuse benefits for more than 60 million Americans. (Applause.) New health insurance plans are required to cover things

like depression screenings for adults and behavioral assessments for children. And beginning next year, insurance companies will no longer be able to deny anybody coverage because of a pre-existing mental health condition. (Applause.)

We're also investing in science and basic research to make it easier to diagnose and treat disease early. And earlier this year, I announced an ambitious initiative to develop tools for mapping the human brain, which could help scientists and researchers unlock the answers to conditions that affect mental health.

We're also doing more to support our troops and our veterans who are suffering from things like traumatic brain disorder -- or traumatic brain injury or PTSD, Post-Traumatic Stress Disorder. Today, we lose 22 veterans a day to suicide -- 22. We've got to do a better job than that of preventing these all too often silent tragedies. That's why we've poured an enormous amount of resources into high-quality care and better treatment for our troops.

And today, under Ric Shinseki's leadership, the VA is going even further. They're partnering with 24 communities in nine states to help reduce wait times for veterans seeking mental health care. And they're -- they've met their goal of hiring 1,600 new mental health providers, which means this summer they're going to hold more than 150 summits like this one in communities all across the country so that every one of our service members and veterans understand -- just like you take care of yourself and each other on the battlefield, you've got to do the same thing off the battlefield. That's part of being strong.

For many people who suffer from a mental illness, recovery can be challenging. But what helps more than anything, what gives so many of our friends and loved ones strength, is the knowledge that you are not alone. You're not alone. You're surrounded by people who care about you and who will support you on the journey to get well. We're here for you.

And that's what this conference is about. That's why these issues are so important. So if there's anybody out there who's listening, if you're struggling, seek help.
AUDIENCE MEMBER: Thank you, Mr. President.

THE PRESIDENT: You're welcome. (Applause.) If you know somebody who is struggling, help them reach out. Remember the family members who shoulder their own burdens and need our support as well. And more than anything, let people who are suffering in silence know that recovery is possible. They're not alone. There's hope. There's possibility. And that's what all of you represent with the extraordinary advocacy and work that you've already done.

So thank you all for being here. Let's do everything we can to help our fellow Americans heal and thrive. And now I'd like to turn it over to Secretary Sebelius who will be leading our opening panel.
Thank you very much, everybody. (Applause.)

END
10:15 A.M. EDT

Close Transcript

Friday, August 28th, 2015
Zyprexa 15mg; Citalopram HBR 20mg; Metoprolol 50mg; Amlodipine 5mg.

There was no one to unburden myself to since my other son, Brenden, was already mad at me earlier in the week, accusing me of no less than causing Alex to be ill. Before I told him he should leave, I reminded him that he should also accuse me of causing himself to be the way he is—Brenden, that is. And he's just embarked on his quest to study for a masters' degree so he'll have some more credentials (he should already have gotten) in order to establish a new on-line college. And what about his daughter? Alanah *accused* me, before she ran off to Harvard on a full paid scholarship, of being her "inspiration." Can I put that on my resume? Or do I have to limit it to, "As a mother, I have the ability to cause schizophrenia in young children?" Writing is so therapeutic. The nice Berkeley Police Officer, Officer Smith, is supposed to call me. It's already 8:30am and I called the desk at 6am. Where is my Alex????????????

Sunday, September 6th, 2015
Zyprexa 15mg (taken at 2pm); Citalopram HBR 20mg; Metoprolol 50mg; Amlodipine 5mg.

Alex ran away again. This time he was fuming and hurt looking because I locked him out. Why did I do that? The last of the 3 times since 8:30pm that I'd walked onto the back patio, I told him I'd put the chain lock on at 9pm, "so you better come in before 9 for your medicine." And each time I warned him that he's supposed to be in before dark, he would say, "I'll be in in a few minutes." By now, it gets dark at 8pm. But I don't enforce it because he is 37 and he's just sitting in the back patio of the apartment building surrounded by 2 huge fences between our lot and the back and side neighbors, and the third side is the windowless building itself. The only real potential danger is that there is only one exit/entrance and there have been groups of wandering animals on the property. At 9pm he was still outside, and I did put the chain on the door, as I told him I would. I wanted to have the conversation I needed to have, so he wouldn't just come in and lock himself in his room. I guess it back fired. I had the three items I wanted to discuss right on the table next to the door and when he opened it with his key, he still couldn't get in. It was only 9:02. Should I have just let him in? only 2 minutes after the hour? Then, I thought, he'll continue to come in when he wants to and take the medicine at other than the prescribed time, if I do. Just a few days before, he came in at 10:30pm. No, I needed to get his attention. I don't want him darting to his room and closing the door. That's his refuge. He blocks everything out in there. And he needs to know that he can't just stick the medicine that's supposed to go in his mouth, into a napkin like

what I found on his shelf that contained both Zyprexa and Metropolol. No, I needed to make him look at the medicine he hid. I needed him to account for it. So, I didn't take the latch off. First, I addressed the issues: "What's this medicine that I found on your shelf today?"
"Oh, I keep an extra there in case I need to take more."
"No, no, Alex. You can only take these one time in 24 hours. At 9 pm. Nice try."
"What about this note I left you about the bathroom sink being stuffed up. It says 'please don't use the sink.' But you used it anyway. And now the water level is higher. What happens if it goes over? A mess! That's what happens. And I can't get hold of Miguel until after the holiday. You can read. Why did you turn the water on? Just use the tub or the kitchen faucet."
"Joan I need to come in! I live here, too!"
"If you have a complaint about me, you can always call the police. Just a minute; I'll get your phone."
But, by the time I came back from his room, he'd already vanished. I should have unlocked the door and run out after him, I guess. But I was too annoyed; I had one more item on my agenda to discuss: the sweatshirt that I found on his closet floor that smelled like urine. No, I'm not going to deal with his peeing in the closet again. I already had to have the carpets shampooed earlier this year while he was still hospitalized. And the smell doesn't really disappear. It permeates the apartment. He's not taking the meds correctly, since he ran the first time, a week ago. So, I figured he'd be back in a few minutes and I left the chain on. He wasn't back. He left. It was going to be another one of those nights from hell. He was punishing me. He knew how to do it. I drove around until 11pm, getting out of my van to walk in and around People's Park, driving around Telegraph Avenue and all the other side streets from Bancroft to Ashby, and College to California. Didn't see him. Too tired. He was gone in only a thin shirt and pants. Went home to contemplate the next step in this continuing horror story. Since I know he knows his way around Berkeley, I wasn't as upset as usual. I didn't want to bother the police right away, so I waited until 3:30am to call them, after I popped up from a few hours of sleep. Did I do the wrong thing? When he cheeks the medicine, this is what happens. Officer Kaplan arrived at 5am. I had been typing on the computer since I got up. We recognized each other from earlier times. He seemed stern, but concerned. We agreed that we should wait to do the Missing Persons' Report since he might show up in the morning like he did before. And Alex did show up at 11am. It was a 14 hour ordeal. I called the non-emergency number to tell them he was home and the officer came over again and said he'd just finished his Missing Persons' Report when the desk gave him the news that Alex came home. I told him that it was his concern and willingness to make the effort that brought Alex home. Alex has a sixth sense when it comes to who cares about him.

Thursday, September 10th, 2015
Zyprexa 15mg (taken at 2pm); Citalopram HBR 20mg; Metoprolol 50mg; Amlodipine 5mg.

I already informed Alex at his last all-night run, that if he stayed out all night again, I would have to find him another place to live. Well, sadly, I guess I have to. My reasoning, from a pitching background, is "Three strikes and you're out." When I returned home at 10pm tonight, he wasn't at home…again. I texted Brenden, against my better judgement, at 1am:

ME

I just came back from looking around Peoples' Park again for Alex. I'm going to have to get him another place to live. I don't think he's taking the meds. I guess this is going to be another all-nighter. I can't take this anymore. I came back later than usual from my NAMI meeting, at 10pm, and no Alex. So, I waited a little and then drove around. The police had recently evacuated People's Park, so they can only sleep on the parameter, Christopher, a homeless, but not carless, man told me. I don't know where he is, but he knows his way around, so I'm going to sleep. I think he faked taking the meds at 2pm. I've been moving the time up (for taking meds) an hour each day, since the last run away 2 days ago, when he took the meds at 11am. So, now he hasn't taken them since 12:30pm on Tuesday. I gave him his $20 this morning because he was willing to take off his filthy shoes (and leave them by the front door) and let me scrub his feet. He's filthy from sleeping on the ground (and not showering or changing his clothes). He really doesn't want to go to the new doctor (either). Alberto, the BMH case manager, took him to the new building (where LifeLong, his new provider, is located) to check it out and Alex told me (after he returned) that "It's a crack house so I'm not going there."

BRENDEN

Yes, he'll be fine. He is always super safe and scared of everything so he knows to come home if he has concerns. He does need a new place. Him as a roommate is not worth all the stress. You can help him better when you can get a full nite's sleep. I'm heading to bed now. I have a long day tmrw. Good nite.

He returned at 10am this morning saying he left because "I wanted to be with people. It was dark and I don't like being alone at night." I already told him several times that he could be going to the Creative Living Center where there are plenty of potential friends not a mile away. He hasn't been there since the non-profit moved to just south of Ashby, within walking distance. And he had only been at the old place near campus on two occasions, each time immediately following his discharge from Herrick Hospital several years before when he was still willing to get into the van. When he asked for his money for today, I reminded him that he doesn't get it when he runs away. Apparently he doesn't want to go to the new medical facility, just like he didn't want to go to Kaiser, not because of the location, but because he doesn't think he's sick so he therefore, doesn't need to go to a doctor. The only other options I have are to bring a doctor to the apartment, which I did once before. At that time, the doctor prescribed a cough medicine which is probably what he would need now. He was nice enough to do something he hadn't done before, make a house visit, but overcharged a bit at $300/15minute home visit. I did find another one in the Alameda Alliance for Health provider phone book who charges $175 (cash only)/house call. And he called me back right away, so it appears they're on top of things. It's not really about money; it's just that I don't have any. So, I can go that route before I give up on Alex altogether. We still do have an appointment at LifeLong on September 21st, but I'm feeling shaky about it now that Alex said it's a *crack house*. I know what that means… "I'm not going!" It jogged my memory because he said the very same thing about his first

psychiatrist's office, the one who co-authored this book. So, schizophrenia is, admittedly, not a very good judge of character. I'm at a loss. The last option is to go the conservator route. But, why do they make it such a complicated process? Can I do it before he goes blind? or worse?

Maybe I should go to court in San Leandro tomorrow. They have court for these kinds of cases on Tuesdays and Fridays. I remember reading in all those pages that when the LPS conservatorship ends upon discharge, a Probate conservatorship can be assigned to another person. Where did I see that? They provide too much information from both Santa Clara and Alameda Counties; somehow it should be combined. It needs to be studied and organized so it can be used statewide. I'll add it to the back of the book after I read through the over 100 pages of information and pick out what pertains to becoming a probate conservator of the person. In the meantime…

Sunday, September 13, 2015
Zyprexa 15mg (taken at 2pm); Citalopram HBR 20mg; Metoprolol 50mg; Amlodipine 5mg.

The last few days were days from hell. Is it just coincidence that it started on 9/11? I don't even remember anything. I'll have to refer to the texts I sent to Brenden all day which describe what happened in the moment.

Thursday 9/10/15

ME

He returned at 10:30am, just as I was about to inform the police; I just waited 'till he usually returned before calling. It's a lot of work for the police. I had already told him if he did it again he couldn't stay with me. I'd like to find a better, cleaner place than Fulton Place. Anyway, he's safe for now. Have a good day. And thanks for your comments.

ME

I need you and A.D. to take him to the local doctor on the 21st, if he lives that long. He has an appointment on Adeline near Ashby with a doctor re: his coughing. He was just sleeping and got up quickly…couldn't breathe. I called and the fire trucks both arrived in just a few minutes but he started breathing and walked quickly toward the park (when he heard me on the phone. I ran after him, but they arrived and stopped at the building). They wouldn't chase after him. I'm going to run over to the new clinic and see if they will give him a closer appointment.

Friday 9/11/15

BRENDEN

What's up?

ME

He won't go to a doctor even if it's close, and his lungs are getting much worse. I had to call 911 twice yesterday becz he couldn't get a breath and was running around the apartment trying to get some air, but after what seemed like most of a minute he started breathing again. When the ambulances came, he wouldn't go, so they wouldn't take him. I'm sleeping lightly listening to his breathing. He has to see a doctor. He promised he would if he could walk but it doesn't look like he's owning up to the promise.

BRENDEN

Then you have to be willing to have him live somewhere (else) if he doesn't follow basic rules and follow through with what he agrees to. Maybe he does need to go back to the hospital. And even if he goes to the doctor that doesn't mean he's going to listen to them and take any prescriptions. Is he still smoking all day? Did you stop giving him money each day? Are you still videotaping his episodes with your phone? He may just need albuterol for his breathing. I can bring some by so he can try it and see if it helps. It really sounds like it's too much to have him as a roommate. I can help look for a place for him and a place for you if you need a cheaper place.

ME

I have 100 pages listing 800 places of cheap housing. I'm just running around after him or telling him to stay out of my closets or cooking what he doesn't then eat because he has to go out and smoke first or eat out of his backpack where he keeps bags of cereals & snacks. He's mad that I take the $20 away when he does something bad like stay out all night. He has to do something good to make up for that, like eat breakfast, brush his teeth, take a shower every day, or at least every other day, wear clean clothes, et. al. I'm still trying to train him so he can live independently, but he fights it all the way because of what the voices tell him he must or must not do. Like right now he's in the back yard with only socks on. I took his shoes to wash them, thinking I would do laundry yesterday, but that's the day he had the labored breathing so I was busy twice with the firemen. I could hardly breathe myself from the stress. So, with him around, I can't plan anything becz everything depends on his wiles. Yes, I do want to apply for HUD or other affordable housing. I just don't have time or energy…I think I need to go back to sleep. He got up after 5am so I made all sorts of breakfast but he didn't eat (any of) it. OK, see you when I see you. Thanks for your help. It's the thought that counts.

BRENDEN

He also fights it because it's annoying when someone is always telling you what to do and what not to do. All the time. Multiple times a day. I get annoyed if Monica tries to tell me what to do. So I understand it. You get emotionally beat down after a while. Then you just tune the other person out.

ME

Since you understand him so well, why don't *you* get him to the doctor? I was able to make an appointment (for him) to see an urgent care doc at the new place for 1:15 so I came back to pick him up and he won't go. He says he's not sick. But he can hardly breathe! You can hear the shallowness. The fireman took his vitals and said he was OK. That's a lie. Why don't you talk to him on the phone? I'm not giving him money 'till he goes to the doctor. So he's mad. I'd rather he be mad than dead.

BRENDEN

You can bring a horse to water, but you can't make him drink. But how do you make him thirsty? We need to figure out how to make Alex thirsty. He won't be forced. I can call him in a little bit to talk to him. But, he is also big on words. He won't go to the "doctor," but, he may go to the "healer.":0]

ME

Very clever!
Did you reach him? I just wonder what I'm going to find at home (when I return).

ME

He was alive but arrogant (and angry), grabbing the soda I brought inside for my dinner. I'd already made salmon with broccoli and applesauce before I left and he ate it. Instead of asking, he just grabbed and drank it from the can. I'd brought a gator aid inside for him. I keep the drinks in the van until he's mostly through with what he has. When I told him he should have asked or poured it into a glass, he arrogantly kept drinking it then said, "You know, Joan, I'm bigger than you, so don't try to take what I want." It was something like that, kind of a threat. Brenden, you need to let him in on who I am to him. It would be believable coming from you. Just let him know that I'm your mother and he'll figure out the rest. I'm not about to put up with that kind of talk, much less having him manhandle me. I feel very threatened and don't feel safe now. You better talk to him this weekend.

Alex walked out to smoke again, but this time without shoes or socks to greet the first cool morning we've had in a week's time. No breakfast. Thin clothing. It just gets worse and worse. I decided then, that I had to do something else.

I texted Brenden again.

Saturday 9/12/15

ME

I just called the police for a wellness check. They're here in the back talking to him now and one already came back to me to say he's answering all the questions OK. Got any ideas about how they might see it differently?

Brenden never saw the text. He's busy. I just told Officer Flores that Alex knows the day and year because the firemen asked him the same questions just yesterday. (Apparently) he was close enough. But, if you keep asking him questions for a few minutes longer, you'll soon find out that he's very much out of this world and in his own. Ask him who I am for instance. I guess Flores told the other officer because Officer T stepped back from Alex and called to me, "Who is Cest?" I don't know what else transpired, but Alex let the cat out of the bag and I guess they realized he was not OK.

ME

They decided to take him to John George for a 5150 (they told me) after he told them his mother's name was "Cest." And the fact that he'd run away 3 times already this month and didn't take the meds consistently, I guess made them think they could officially conclude with the 5150; so that's it. He's going to John George, not my first pick, but at least he should be able to get medical attention there, too.

I'm having to choose between 2 bad options…his not going willingly to see a medical doctor with possibly disastrous results, and his possibly getting a psychiatrist who will overdose him but probably not kill him in so doing. There is a new head at John George, if he's already been hired. I do know that they are now espousing the philosophy that they are trying to improve (using less restraints). I gave my journal a couple months ago to the administrator's secretary (right after the national NAMI convention) and I'm going to make an appointment with her. So that's what's happened.

BRENDEN

I'm going to the real estate class at Berkeley library 3rd floor. Starts at 10:15am. I signed you up if you wanna go. But, it only counts if you stay all 4 hours. It's to help get a no-money-down loan. I'll be up there. I can stop by afterwards to talk with Alex.

ME

He's at Herrick! I did want to go (to the real estate class), but I sat instead in the waiting room at the ER from 10am to 2:00pm, rather than spending time inside with Alex in case that made him mad, but I did go inside (briefly) to see him a couple of times. He wasn't too thrilled to see me. I think those people there (the nurses and psych techs) are very nice. I just have to make sure he doesn't get assigned to Dr. Connor.

By the time I left, at Alex's request, to bring back some food, he was gone. That was upsetting. Why did the guard tell me to go inside to bring him the food if he wasn't there? Isn't there a way that they can look up if patients are still there or not? The nurse behind the desk wouldn't let me go out the ambulance exit so I had to go all the way back through the lobby and down the ramp and all the way around even though I can't walk fast. I became frantic, afraid I'd miss him and hadn't been told where he was going other than John George. The ER doctor had never talked to me, although the triage nurse came out at the beginning to find out what I had to say, and told me he'd tell the doctor. But, why the whispering down the lane? There were a few ambulances parked outside, and when I asked if an Alex was in the back, the first ambulance driver I passed said he couldn't tell me, but he looked like he had him, so I gave the bag from Whole Foods to the driver, peeked into the back of the ambulance to make sure it was Alex, and hoped he would be able to eat it once they arrived at Herrick.

The First Week at Herrick

It was a letter-writing week and I was bent on informing every nurse and charge nurse about Alex's need to get some medication for his cough/chest cold/infected lungs, whatever was going on, especially since the ER doc didn't give him anything except a chest x-ray. So, I started writing to the doctor even though I know they abuse HIPAA and get around consulting with the parent. Day 1, Saturday, 9/12/15, after sitting all morning in the ER, I typed more recent information to put into the journal and rushed it to the printer to update the book, and

left it at the 4-East desk for whomever the doctor would be. Fortunately, there were some attentive nurses on the floor and I spoke to 2 of them, Phyllis, the charge nurse, and a man whose name I've forgotten. They were both very receptive and willing to listen. On Day 2, Sunday 9/13/15, I spent most of the day writing a letter regarding his medications this year which I printed and left at the 4 E desk the next day for the doctor:

9/14/2015

To Whom It May Concern at Herrick:

Alex has been taking Zyprexa for most of the past 18 1/2 years. It is OK in that it's better at 10 or 15mg than when he takes none of it. It doesn't help him to be normal and make good judgments, however, and it hurts him at doses higher than 15mg. Page 98 of *Alex's Story, the 18th Year*, describes the doses of Zyprexa: "At no Zyprexa, he's completely off balance, but at 10mg, he's the best he can be (on Zyprexa only) whereas at 20mg, he doesn't realize who is who, and at 30mg, he is very easily angered and at 40mg he's almost comatose and can't even get up to go to meals."

He was best on a combination of 100 Clozapine, 10 Abilify and 17.5 Zyprexa (2007- but he wouldn't get the required blood tests then). He did willingly get the blood tests from Nov. 2009 until 2012 when he was admitted to John George Hospital and it was stopped for 3 days, then started at too high a dose (150mg) instead of the required 25mg. And he didn't want it after he felt the reaction to that misuse of the medicine.

So, we've been back to just Zyprexa. 20mg of Zyprexa was not good for him. Dr. Fitzpatrick wanted it at 20 and said that Villa could adjust it downward, but they didn't, until 4 months and 4 doctors later…January of this year. It would be great if there were a small dose of something else that worked together with only the 10mg dose of Zyprexa. I don't know what that would be. I know it shouldn't be Clozapine, Abilify, Haldol, Cogentin, Resperdol, Navane. (I'm writing this off the top of my head and don't remember all of them that were harmful.) But, I do know that high doses of anything are harmful.

Clozaril is out of the picture now because he really doesn't want blood tests and I don't blame him. He's better at low doses of 2 or 3 antipsychotics. He gets the best out of the Zyprexa at 10mg. It doesn't harm him. He doesn't have as many, "I can't do that" thoughts. You'd have to read the journals to see what it does.
He also is better with an anti-mania med, like Depacote. Just ask my neighbors. He was discharged with it last September (2014) from Herrick, but one of the doctors at Villa decided he must be depressed. And I have the hysterics on tape from just last week when he went off the Zyprexa and ran away all night on 3 different (but not sequential) nights. He's just gotten back to taking the meds on time (8-9pm), because when he ran for those 3 nights since 8/28/15, he would return sometime between 9am or 11am and take the meds from the night before, so I administered the medicine each of the subsequent days 1 hour later so he would finally end up taking them at 8 or 9pm because they make him tired so he'd rather take them in the evening, he said.

I don't know why Dr. Beatty at Villa decided to give him an anti-depressant earlier this year. It seems to have made him more manic. He's rarely depressed. He always looks at the positive. For instance, when I told him, "It must have been horrible to be locked in a padded room for days at John

George," he replied, "No, it was OK. It was a good place to meditate and collect my thoughts without hearing the noise outside." I won't say he hasn't said he was sad sometimes, especially since he doesn't see his family anymore, do anything anymore. That is sad. So, that's about it. My main concern in calling the police was because he still won't go to the dentist or the doctor, even though he said he would, if I dis-enrolled him from Kaiser so he could walk to a doctor or a dentist in Berkeley. So, I dis-enrolled him, but, he (still) wouldn't go. I made 3 appointments so far at LifeLong on Adeline just south of Ashby Bart and he walked there with the case manager from Berkeley MH just to see the building, and told me he can't go there because "they do crack cocaine" over there. He has an urgent care appointment there on 9/21/15, and a regular appointment on October 1st, but he refused to go to the 2 other urgent care appointments over there last week since I dis-enrolled him from Kaiser.

My main issue is to make sure he keeps breathing until someone comes up with a medicine that actually works, that gives him a chance to live normally in *this* world. Who knows if it will happen tomorrow or in a decade or ever? And that's why I finally called the police for a well-person check. He is having a great deal of difficulty between the coughing and the infections that have been active inside 3 or more of his teeth that are predicted to have already invaded the bloodstream to go wherever they may go. The last dentist he saw in April, Dr. Arnold, said that when the infection is on the bottom tooth, it usually goes to the lungs. And he's been coughing a lot for the past several months. *His* main issue is that he's not in this world. He really thinks he's in the sky flying a space ship and "saving all the children."
Sincerely,

Joan Miro
Mother

Noticing the journal, that I'd left for the doctor at the counter on day 1, still on the counter on day 3, Monday, 9/14/15, I asked Dianne for it back, and gave her a newer one where the photographs weren't blacked out. I didn't blame the doctor for ignoring it because it was so huge having been printed only on one side. I imagined that the doctor would prefer a smaller version. Afterwards, I thought, maybe the doctor would prefer not reading that one either, because it was still 175 pages, so I spent 5 hours on day 4 reading through all the pages and excerpting paragraphs about medicine and what symptoms they each produced, so she would only have to read a 5 ½ page synopsis. I brought that into the administration office since the doctor seemed to not be getting the other information I'd left at 4 E. I felt comfortable that Veronica would be able to get it into the doctor's hands and perhaps the psychiatrist would then be more motivated to read something that emanated from her boss' office. So, I skipped checking up on whether Dr. Compton received any of the other written matter, because I'd already left a message to her with Nurse Sydney when he was Alex's nurse that had my phone number on it and a request for her to call me. I waited. No call by Day 5. So, I wrote a memo. I couldn't give up because I saw in the computer on day 2 that she had already raised the Zyprexa to 20mg on day 2. How high was she intending to go, I didn't know. I left administration alone the day after I gave Veronica the synopsis. I waited. I had faith in Veronica. But I also connected with Brenden with a new plan.

ME

9/15/15 Brenden, can you go there at lunch? The doctor already raised the Zyprexa too high—20mg. I need him out of there. They did start giving him meds for his cold or cough but she won't talk to me, hasn't yet picked up the book I left on day one, hasn't read the letter about meds. Today I gave a 5 ½ page synopsis of the history of his meds to the administration office manager, Veronica, (who actually remembered

my name), and said she'd make sure Dr. Compton got it. Maybe the other 4th floor office didn't give the papers to her (the doctor). The letter and synopsis explain everything so she doesn't have to read the book, but she already raised the dose without talking, reading, asking or communicating in any way. I need him out of there, and I need your assistance before she raises the dose even more. She can't do whatever she wants and ignore what I know.

Thursday, September 17th, 2015
Zyprexa 20mg; Metoprolol 50mg; Amlodipine 10mg; Omega-3 Ethyl Esters 1gm cap (fish oil).

Brenden and I went to Herrick's Administration Office together. Veronica came right out to talk to us. I let her know how many times I tried to communicate with the doctor and to ask her to call me. Brenden asked more pertinent questions about their protocol, and I did my anxiety dance, although he kept telling me to calm down. Veronica said she'd take care of it. At Veronica's request, I gave my phone number to her for the doctor to call me although I told her I'd already given it to Nurse Sydney. At home the next day, I had just finished outlining more thoughts on paper:

MEMO

Re: Alex Anderson
Date: 9/18/15
From: Joan Miro, Mother
To: Herrick Administration

A. **HIPAA and the misunderstanding of it by employees.**
1. The parent can still give information to the doctor, even if the doctor doesn't give any to the parent.
2. There are other ways for the patient to give consent to authorize the doctor to speak with the parent even if the patient won't sign his name to your form. Alex won't sign his name to anything just because he's ill and he thinks that's the way he can stay in control. Alameda Alliance for Health, for example, enables their Medi-Cal recipients to either sign their form giving authorization, or to speak on the phone in the presence of the person he's giving consent to, so that person to whom he's giving authorization can tell the Alliance what she wants them to know.

This is what it says in the HIPAA addendum (p. 106 in Journal):
The first part of the addendum follows: (bold marks are mine)

> **HIPAA privacy in emergency situations: Imminent Danger Health care providers may share patient information with anyone as necessary to prevent or lessen a serious and imminent threat to the health and safety of a person** or the public – consistent with applicable law (such as state statutes, regulations, or case law) and the provider's standards of ethical conduct. See 45 CFR 164.512(j).

Director
Office for Civil Rights
Washington, D.C. 20201
January 15, 2013
Message to Our Nation's Health Care Providers:

In light of recent tragic and horrific events in our nation, including the mass shootings in Newtown, CT, and Aurora, CO, I wanted to take this opportunity to ensure that you are aware that the Health Insurance Portability and Accountability Act (**HIPAA**) Privacy Rule **does not prevent your ability to disclose necessary information about a patient to** law enforcement**, family members of the patient, or other persons, when you believe the patient presents a serious danger to himself** or other people.

B. **What I have done so far**, (day 6) in trying to inform the doctor about my son's health all the while keeping within the HIPAA guidelines:

I have given my 173 page 2014-15 Journal to the 4th floor desk on day 1, a 2-page letter about his immediate situation on day 2, and a 5 1/2-page synopsis of the journal with the 3rd floor administration office on day 3. In addition to those typed items, a note from one of the nurses (Sydney) included my phone number and asked the doctor to call me at 510-418-8568 on day 3, and conversations with several of the nurses to both make them aware of his condition and my wish to speak to the doctor took place each day during my visits. Some of the nurses I spoke to were Phyllis, Beth and Sydney. I can't remember all their names. Phyllis was able to make the medical doctor aware to look at Alex's cold symptoms by the very next day, day 2, because I was surprised that the ER doctor hadn't at least given him medicine for his cough. But, after calling from home and asking for the doctor, I was transferred instead to the social worker, Katherine, with whom I did speak and who called back the next day to say that she left a note with the doctor about my concerns. But, I wanted to speak to the doctor, too, and called back later the same day and the same man who answered the phone in the morning told me I couldn't reach the doctor because she didn't have a phone.

The 3+ written papers that I gave to different people to be forwarded to Alex's doctor, I have no knowledge that the doctor received, because the doctor didn't call me or leave a note for me that anyone has given to me. I was distressed to find the journal, that I had left for the doctor on day 1 still on the receptionist's counter when I went there yesterday, on day 4. Diane asked me what I wanted to do with it so I gave her a smaller copy, printed both sides, in which the photos weren't blacked out, so it was more pleasant to look at.

C. My concerns:

That Dr. Compton will go up even higher than the 5mg she has already raised the Zyprexa to (from 15 to 20mg) without reading anything about the doses that I've documented for the past 19 years. Herrick has 3 of my journals since 2010, so some information is available. I know that 15mg is Ok but 10mg does about the same with 5mg less. 10mg is all the Zyprexa that Alex really needs; 10mg gives him all of the benefits that Zyprexa has to offer, without over sedating him, making him agitated, frustrated or catatonic. I wanted to ask Dr. Compton if she knows any other medicine, other than the ones that haven't helped: (Haldol, Navane, Seroquel, Respirdol, Prolyxin, [Closaril is history, not because it didn't work, but because he won't do the blood tests anymore]). Dr. Fitzpatrick left the Zyprexa at 20mg (last September, 2014) against my better judgement. This was what he said on my phone tape last September (journal p. 28):

> "Hey Joan, this is Dr. Fitzpatrick getting back to you….I did get your messages as well as the, ah, kind of, the write up. I remember Alex just from back a couple of years ago. So, you know, what I have done is kind of split the difference in terms of the meds, maintaining the Depacote at 1,000. I inched up the Zyprexa, the Zydis, to 20, none in the morning, just 20 at night. He's actually doing well with it. Denies any problems. And he's slowing down. He's getting there. A little bit more linear in his thinking. A little bit more organized. A little bit less agitated. So, we're moving in the right direction. I have no intention of doubling it or increasing it. I understand that excess causes acathesia or side effects. Ya know. Yea. My sense is we're on a good trajectory. Now, in terms of the overall plans, that's more the relevant question, I understand you're recovering from surgery to kind of have the conversation of when he is stabilizing, what next? Whether you'll able to take him home? Whether, I guess, the possibility of a short term board and care? Villa? There's obviously the normal host of options. We can kind of work to coordinate that through Craig as well. Anyway, I hope you are doing well in recovering and I'm hopeful that things are moving in the right direction. All right? Take care. Bye."

Yet information in more than one journal documents that the 20mg dose was too high for Alex: he can't go anywhere, do anything, is very lethargic, and starts to get antagonistic at the drop of a hat). Dr. Duvale, MD, PhD, at Villa finally lowered it to 15mg the day before she left…Tuesday, January 6, 2015, probably because she knew Dr. Montandon, MD, PhD, which I imagine increased my credibility, and asked if she could keep the journal. Alex had the unfortunate experience in 2008 of another psychiatrist at John George, Dr. Tomasini, MD, more than doubling it to 40mg after Alex's November admission, and since that abuse took place, I've been very concerned about anyone else not knowing that Eli Lilly only did research on up to 20mg. He was practically catatonic at 40, too angry and agitated at 30 and couldn't do much on 20mg. He didn't even know I was his mother at 20mg. 10mg was the best dose that Zyprexa can offer Alex. I used to think it was 17.5mg, but that was in combination with a little Abilify and Closiril. I guess things change with time. I wanted to ask Dr. Compton to try him on a little of another medicine, if there is one, since Zyprexa doesn't do too much on its own. Let's say that 10mg was the least harmful dose (he does do a little more quiet contemplation on 10mg, that is, he's very preoccupied) and 15 was OK, too, on its own. Dr. Beck at Gladman always settled on 15mg. But, I'm thinking that since he was best on smaller doses of Abilify (10mg), Zyprexa (17.5) and Clozapine (100mg), maybe he would be good on one or two others,(in small doses), in combination with only the smaller amount of Zyprexa. I don't know if there are any other, newer ones, other than the ones that were harmful (Haldol, Navane, Seroquel, Respirdol, Prolyxin, [Closaril is history, not because it didn't work, but because he won't get the blood tests anymore]).

D. The urgency of taking Alex to an oral surgeon because he is a danger to himself if he doesn't get the infections out before they damage his organs or kill him.

I would like to request that Herrick get him into an ambulance or some other official transportation to go to UCSF where I've already connected with a dentist, Dr. Justin Becerra, DDS, and a psychologist, Dr. Linda Centore, PhD, in the:

Advanced Education in General Dentistry
Department of Preventive and Restorative Dental Sciences
UCSF School of Dentistry
707 Parnassus Avenue
San Francisco, CA 94143-0760
Tel: 415-476-9656

who have already been enlightened about Alex and are willing to work on his abscessed teeth. (Journal p. 158) He won't go with me. He doesn't get into my van or take any public transportation. There has to be someone in uniform. Someone official. I'm just Joan, his caretaker/friend, according to Alex at 15 or 20mg. At 10mg I'm recognized as his mother, and sometimes at 15, too.

Now, that would be the ultimate in customer service. Why do I ask Herrick? Because Alex spent his first month of illness at Herrick under the care of Dr. Zim almost 20 years ago this coming March. Herrick is like home to Alex; he even requested that I set him up with Alta Bates when he dis-enrolls from Kaiser (but the Alameda Alliance for Health didn't have Alta Bates in its directory, so I couldn't). He is familiar with and likes Alta Bates/Herrick and is more comfortable and feels safe there. When he's home, he will sometimes walk over there just to buy lunch downstairs. Alex has probably been a resident of Herrick for more than a dozen times over the past 2 decades.

I'm not accusing Herrick of hurting Alex. It's not Herrick's fault or their psychiatrists' fault that they couldn't provide medicines that really work because no medicine has brought Alex back into the real world so he can have better judgement and stop depending on his voices to tell him what to do. It's bigger than Herrick.

The fault lies with all of us. The fault regarding lack of interest in brain diseases lies with the United States of America and the rest of the world. And we all know who that is…The People. Especially the people who have mentally ill relatives who haven't yet stood up and demanded more extensive research for medicines and research to find the cause of schizophrenia and the cure for schizophrenia. As Paul Yoder, the Legislative Advocate from CAL-ACAP stated at a meeting last year of mental health advocate organizations…politically speaking, he said, "Low voter turnout in this last election could have massive consequences...Mental Health is not a priority." At the same meeting past Senator Steinberg said, "Everyone should be taking on a mental health issue." In other words, it shouldn't matter that he is stepping down because each senator and representative should have at least one issue to drive forward in Congress that pertains to mental health advocacy. We're still in the Dark Ages as far as what causes the disease. Millions of years after Adam and Eve and we still don't know? How is that possible?

Without that knowledge of cause, there is no real direction for undertaking research into what to put into the medicine, and without the correct ingredients, Alex won't have the good judgment to go to an oral surgeon on his own volition. But, HIPAA says in its message to our health care providers, that "**when you believe the patient presents a serious danger to himself,**" and 3 dentists have already said that (plus there is Dr. Sharma's signed letter at the end of this journal, attesting to the fact that he is 'in a dangerous situation') so one can conclude that the health care provider can within the law talk to the parent.

Can we move that acknowledgement a step forward to say that since the health care provider is allowed to talk to the family, can they also move forward to save the patient based on what information the family provides? The logic here points to the fact that if the patient is in a dangerous situation, but he can't understand or believe that fact, that he is in that situation due to the schizophrenia that the providers can't cure, because there is no medicine that works well enough to give him better judgement or eliminate the hallucinations, maybe the health care providers can therefore authorize to take him against his will to the dentist, because he's in a dangerous situation and can't fathom that it's dangerous. By not being willing to remove the infection, he is a danger to himself.

Add to this that the Patients' Rights people, who are helping him to know his *rights,* aren't asking the right questions. They are just asking him *if he wants to go to the dentist*. They are not asking him *if he wants to die or go blind or infect his lungs so he eventually can't breathe*. If they asked him *those* questions, he would then tell them 'no, I don't want to die,' because he wants to see and breathe and live. He has said as much to me and I have documented it. But, since the medicine isn't working to enable him to have good judgement, he does not believe that the abscesses could do those things…infect his vital organs. He hallucinates that he's a doctor, instead, and listens to the voices that tell him nonsensical ideas. But, we know he's not a doctor because he doesn't have a high school diploma, and we know that it's the schizophrenia, that we can't cure, that is speaking…so I'm requesting, based on this evidence, that Herrick take him *against his will* to the oral surgeon, that is, if we insist on posing the question, "Do you want to go to the dentist?" and he insists on saying 'no' to that. But, if we change the question to, "Do you want to die?" then we are not even taking him to the dentist against his will. *We are taking him because that is what he wants…to live, to be sighted, to breathe.* I put into writing that we won't sue Herrick for so doing.

My goal here is simply to keep him alive until this country puts a greater value on people who are mentally ill, by appropriating enough money for research into etiology and medicine to discover the cause and the medicine that works, and until this country comes to the realization that the mentally ill among us may be worthwhile if only for the fact that they are the ones who can make the normal, more fortunate people see greater value in life and not take it for granted. We don't know who they might have become…maybe a genius who could move this world forward, maybe a philosopher who could teach the world how to get along, maybe a productive worker, happy to be employed and go home to the family. Because, throughout the past almost 20 years, my Alex still wants to live even in this altered, ostracizing, unattractive, isolating condition. I think I would have called it a day more than a decade ago. In conclusion, I'd like for Herrick Administration to save him from himself and please take him to the oral surgeon at UCSF or any other facility that you may use.

Friday, September 18th, 2015
Zyprexa 15mg; Metoprolol 50mg; Amlodipine 10mg; Omega-3 Ethyl Esters 1gm cap (fish oil).

3:30pm
The phone rang. Yea! Dr. Compton called just as I was finishing the above memo so there was no need to send it because she was willing to discuss the meds with me. She said she had read my letters and noticed I asked her to give him something new along with a lower dose of Zyprexa. So, she's going to start Latuda along with the Zyprexa. I had heard about Latuda some months before through Brenden, who told me his friend was one of their sales representatives, and said it had very few side effects. (According to Nurse Beth's research, Dr. Compton did lower the Zyprexa to 15mg on Friday September 18th, and then started him on 80mg of Latuda as of Monday, September 21st.)

Thank you, Veronica! You are always so helpful, compassionate and in tune with the family. I was so lucky to have had the Berkeley Police take him to Herrick where there are more doctors who don't mind communicating with the parent and where most of the nurses are very customer-focused and make themselves accessible to the family. The behavior and attitude of staff always comes down from the top.

On the other hand, why is it always necessary to go this route just to communicate with the doctor *before* they decide what to give the patient?

A Turn of Events

Monday, September 21st, 2015
Zyprexa 15mg; Metoprolol 50mg; Amlodipine 10mg; Omega-3 Ethyl Esters 1gm cap (fish oil); Latuda 80mg.

Oddly, but in keeping with the nature of the Mental Health System, Alex's discharge order was written the very same day as the first dose of the new medicine was administered, Monday, September 21st, 2015. How do I know this? I received a phone message on that same Monday, from Case Manager Alberto Flores, at BMH, stating that Herrick's social worker, Katherine, had called him so he wanted to call me "to talk about Alex's discharge." I ignored it, thinking he had heard wrongly, because I knew the 80mg of Latuda had just been started a few hours before he called that same Monday, so any discharge would be unlikely, because the doctor would want to watch her patient's reaction to it for at least a week to see how it was working and then decide whether to adjust it or discontinue it. I have to apologize for my inability to understand the doctor's logic. Apparently, since she lowered the 20mg of Zyprexa to 15mg on Friday the 18th, after talking to me, she thought he was well enough to go home (surprise!) even without the Latuda so she didn't need to follow up and monitor the Latuda. I can't really know what her thinking process was, because I'm not she, but, to me, the icon of vindictiveness, it had the ring of vindictiveness. That is, she was made to call me by administration, against her will, so since she felt she had to institute what I asked for, consequently Alex could be thrown the hell out of there, now that she did it. And the day after she wrote the discharge order, Tuesday, I was told at evening visiting hour, that I could pick him up the next morning. In fact, Alex broadcast it himself, through the windowed door, as I didn't enter the unit because I still didn't feel well enough to share my germs. So, there you have it: Another instance of the cost of doing business with physicians with blimp-sized egos who don't legally have to talk to the stupid parent, even though the parent's suggestion of lowering the Zyprexa apparently worked.

It took me a few hours to figure out what really happened. And Tuesday evening, not too long after I first heard of the discharge, as my pondering took form, I made a few phone calls as I tried to prepare myself for the abrupt discharge on Wednesday. But, one can't really prepare oneself for what ends up being like a fight-at-the-bar, where the weaker guy is virtually thrown out, because as I wrote (in point D of the rather large memo), I had been hoping for Herrick to step up to the plate and take Alex to the dentist. I had come up with the idea before I knew of the discharge. 'Though I had only given the memo to Veronica on Wednesday morning, the day of discharge, after telling

her about the questionable discharge plan and my interpretation of it. She told me to go up to the floor and wait up there to speak to Katherine, the social worker, but Katherine never appeared, only the discharge lady. I didn't get her name, because she was very focused on getting him discharged, and didn't really introduce herself, or really hear what I had to say about the doctor needing to evaluate the Latuda, or really want to know about the possibility of Alex being taken to UCSF Dental School, or about the fact that I was never asked if I were planning to take him home. It was just assumed that I would. There was no discussion about anything because there was no conversation, period. I told her that I didn't come upstairs to take Alex home, just to wait there to speak to Katherine, to talk about why he was being discharged, so she said that they were discharging him anyway, and if I didn't take him she "would just discharge him to the street." Their attitude was something less than cordial, that is, more gestapo: just get 'em out, line 'em up and shoot.

Having been a product of a retail-entrenched family where customer service came up at the dining table just about every other day, I couldn't help thinking how Herrick's discharge of the patient would be tantamount to tossing the customer out the door and then shoving her fur coat box out after her. One might say that hospital stays need to be quick because they are too expensive. In fact, even in the 1960's, the cost of a fur coat would have been similar to the cost of a hospital stay, $1,000 to $20,000. Yet, somehow I don't think my father would have allowed his customers to be treated in that manner. And I don't recall ever hearing of that happening. No, when I officially worked there during one college term, I still remember his whispering in my ear: "See that lady coming in the door? She's your paycheck! Make sure you find out what she thinks she wants then, give her what she really needs." For those 75 years in business, Mirrow's Furs was known to be very customer-service oriented. But, mental health care is not and apparently doesn't have to be. I wonder why that is? And they get away with it time after time. In retail, the customer legally has a few days to return the purchase. In health care, the only legal action is to sue ex-post-facto and the patient would probably have to be near death to get his money back.

I did get a call from Dr. Compton, but I received the message on Thursday, Sept. 24th, the day after discharge, explaining I don't understand what. Even though I did call for my messages on Wednesday evening and hers wasn't among the 5 tapes that I listened to. I remember listening to the messages on Wednesday because I received a few compassionate calls from UCSF Dental School. This one is Dr. Compton's:

> Hi Joan. It's Dr. Compton. I'm calling about Alex. Um, He's somewhat improved with the addition of the Latuda, definitely better than Zyprexa only. I don't know you guys; this is the first time I've worked with him. My understanding from the other physicians that he, is that he doesn't improve more than this, um, and he went to Villa after his last stay, and from what I understand, uh, this is his baseline. Um, so, I'm, you know, happy to hear more from you about it. Um, the plan is… that today is to send him home to you for, uh, his usual outpatient treatment. So, if you have a different opinion about that, um, or would like us to pursue a different line of placement, um, let us know and, uh, and we can, uh, coordinate, um. I'm not sure what type of placement would be open to him. I think the social worker and probably yourself are more familiar with what his options

would be. But, I have him set up for discharge, assuming that you're going to get him at some point today. And if not, please call the unit and the social worker and let them know and we'll go from there.

I have to presume that she called on Wednesday, since that's what she alludes to: "the plan is…that today is to send him home to you…" I really wasn't sure because the phone message I received from Katherine, the social worker, indicated that he was being discharged on Thursday.

I'm presuming that, because I spoke to Veronica in the administration office around 11:30am on Wednesday, Compton may have received a call from her, and then called me. Otherwise, I don't understand why she would call me on the day of discharge instead of in advance of the day of discharge, much less the day after discharge. I only realized he was actually being discharged on Tuesday evening, because Nurse Sydney looked in the computer when I arrived at Unit 4E. And Alberto had already left his message on my tape about the pending discharge sometime during working hours on Monday, after the social worker called him, he said later. When I heard his tape on Monday about his wanting to talk to me "about Alex's discharge," I had dismissed it, because I didn't believe it could be true. How could it be if he were to have the first dose of Latuda that same morning? How could she have known the Latuda was beneficial ("somewhat improved with the addition of the Latuda, definitely better than Zyprexa only") or not, if he only took it hours before she wrote the discharge order? The whole concept of discharging him at that moment was somewhere between ludicrous and unprofessional. And how did she think I would be able to give her my opinion, ("So, if you have a different opinion about that, um, or would like us to pursue a different line of placement, um, let us know and, uh, and we can, coordinate…") if there were not a way to reach her since "she doesn't have a phone" per the man who answers the phones and no one has ever been willing to connect me with her.

The First Week At Home on Latuda

On Wednesday, September 23, day 1 at home, day 3 on Latuda, day 6 on the lower dose of Zyprexa, he called me, "Mommie" recognizing me out of the blue, in a very welcoming way: "*You're* my Mommie!" he squealed to me in the living room. As he walked past me to his room, looking confused, I heard him say, "Then, where's Cest? Who's Cest?"

"She's someone you made up in your head," I said. "Maybe you wanted a different mother."

He hasn't been any more willing to go to groups like the Creative Living Center that moved close to us, but he has been 'going out' consistently, leaving early in the morning for I don't know what or where, and just coming back every few hours to bring whatever he's bought or to get a drink. Saturday he brought home a huge bag of clothing. Mostly girls clothes, however. Trying to start a conversation, I told him he should be a buyer and start a retail store. We could encourage good behavior in elementary school children, I said, by enabling

them to buy the clothing with behavior-mod dollars earned in their classrooms. I showed him pictures of the retail store I used to have and the money we used in my own classroom but it didn't generate much enthusiasm. No conversation; just an "uh, huh". At least he's not holing up in his room so much.

He's been eating more independently, but not eating well. That means not wanting what I have in the refrigerator, but cooking or preparing what he wants, like oatmeal or frozen pizza. The pizza comes out fine in the oven, but since I'm afraid of his using the burners, he just puts cold milk onto the dry oatmeal which doesn't really cook the oatmeal. If I put together a breakfast that I know he would like, like fresh salmon and cream cheese on a bagel with hot chocolate, he just leaves it on the table and puts cheerios and milk in a bowl to eat. Eating my healthy food now means he's less independent. As the week at home progressed, he ate less and less of my home cooked food. I guess that's good for independence but not so good for his stomach.

By the beginning of the second week on Latuda, it apparently was doing its thing and Alex was suffering. That is, it was making him uncontrollably antagonistic. He was waving his hands at me to let me know I should leave him alone and hiding his face with them as though he couldn't stand looking at me. He'd been doing these antics for a few days already. I wrote about it to Brenden.

Tuesday, September 29, 2015
Zyprexa 15mg; Metoprolol 50mg; Amlodipine 10mg; Omega-3 Ethyl Esters 1gm cap (fish oil); Latuda 80mg.

ME

Brenden, Alex is afraid of me. He's been like this for a few days. He is in the back and won't talk to me. (He) says, "You're breaking my star. I can't be around you. You're going to call the police! Tell Brenden to come over and we'll go out! Go away from me!" So that's what's going on. What do you suggest? I think I'll go to the gym and let him be alone for an hour.

ME

Well, it looks like he just took off from the back while I was inside setting up dinner for him. I drove around for a short while but gave up by 8pm and went to the gym. I just came home (9:30) and no Alex. It looks like all this medicine is making him antagonistic. It's almost like he is on 30 mg of Zyprexa. Maybe the 80 mg of Latuda is another med similar to Zyprexa. In that case it would be like doubling the Zyprexa to 30mg. I really think it is similar to Zyprexa. In fact, the pill (itself) looks exactly the same as Zyprexa. I'm not worried that he didn't take the 15 Zyprexa tonight at 9pm because he did take the Latuda at 2pm. I'm up for disappearing the Latuda altogether. What do you think? I'm not planning to let myself get upset because it hurts my head.

Besides writing the discharge orders on the same day that she first administered the starting dose of 80mg, the following information obtained through Google shows that Dr. Compton started the medicine at too high a dose to begin with. And Berkeley Mental Health wasn't

planning to make time to see him until October 6th, so who would be monitoring the effect of the medicine from discharge on September 23rd until his appointment on October 6th? Who was supposed to see if he were doing well or not on the new medicine? I guess that would be me! I would be stuck with the job. But am I not just the dumb family member who doesn't know anything? The one they don't want to talk to? Why would they give me the job to see that their patient is performing better on the new medicine? He would have to wait 2 more weeks to be seen by the out-patient doctor, Dr. Jeffrey Johns at BMH, since he had missed his September appointment because he was hospitalized.

In conclusion, because Compton discharged him prematurely, and Johns couldn't fit him in for 2 weeks, he's not being cared for except by the mother for those 2 weeks. If Compton had followed the pharmaceutical manufacturer's orders for starting the medicine appropriately, perhaps Alex wouldn't be in the pickle that he's in.

The following listings in Google show that Latuda should have been started at 40mg (or less) once daily.

Google listing: **Drugs.com**
Latuda Dosage - Drugs.com

Latuda
What is LATUDA?
An Effective Treatment Option for Bipolar Depression

LATUDA is a once-a-day prescription medicine. It is indicated to treat adult patients with depressive episodes in bipolar I disorder (bipolar depression) when used alone or with lithium or valproate. In clinical studies, LATUDA was proven effective for many people struggling with bipolar depression.

LATUDA is the first medicine approved for bipolar depression that can be taken either:

on its own (monotherapy), or with a mood-stabilizing medication (adjunctive therapy), either lithium or valproate. With LATUDA, as with any other prescription medicine, some people may experience side effects.

The recommended starting dose of LATUDA is 40 mg once daily. Initial dose titration is not required. LATUDA has been shown to be effective in a dose range of 40 mg per day to 160 mg per day [see Clinical Studies (14.1)]. The maximum recommended dose is 160 mg per day.
www.drugs.com/dosage/latuda.html
google listing : **Sunovion ProFile**

LATUDA – Dosing Information - **Sunovion** ProFile
https://www.sunovionprofile.com/sp/latuda-bp/about/dosing.html
Concomitant Use of a Moderate CYP3A4 inhibitor (e.g., diltiazem): LATUDA dose should be reduced to half of the original dose level.
Recommended starting dose is 20 mg per day. Maximum recommended dose is 80 mg per day. Concomitant Use of a Moderate CYP3A4 Inducer: It may be necessary to increase the dose of LATUDA.

google listing : **Medscape**
Medscape mission statement:

To provide clinicians and other healthcare professionals with the most timely comprehensive and relevant clinical information to improve patient care;
To make the clinician's task of information gathering simpler, more fruitful, and less time-consuming; and
To provide physicians with the educational tools needed to stay current in their practice.

MEDSCAPE EDITOR-IN-CHIEF
Eric J. Topol, MD
Director, Scripps Translational Science Institute; Chief Academic Officer, Scripps Health; Professor of Genomics, The Scripps Research Institute, La Jolla, California

From Medscape regarding:
lurasidone (Rx)Latuda

Dosing & Uses
Interactions
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Dosing & Uses

Schizophrenia
40 mg PO /day initially; may increase to 80 mg/day if needed; not to exceed 160 mg/day

Bipolar Depression
Indicated for major depressive episodes associated with bipolar I disorder; may be used as either monotherapy or adjunctive therapy with lithium or valproate

20 mg PO qDay initially; may increase dose if needed, not to exceed 120 mg/day

Dosing Modifications
CYP3A4 inhibitors or inducers
Concomitant use with strong CYP3A4 inhibitor: Do not coadminister
Concomitant use with strong CYP3A4 inducer: Do not coadminister
Concomitant use with moderate CYP3A4 inhibitor: Reduce dose to 50% of original dose, not to exceed 80 mg/day; starting dose is 20 mg/day
Concomitant use with moderate CYP3A4 inducer: It may be necessary to increase lurasidone dose
Renal impairment
CrCl 50 mL/min or greater: Dosage adjustment not required
CrCl <50 mL/min: 20 mg/day initially; not to exceed 80 mg/day
Hepatic impairment
Mild (Child-Pugh class A): Dosage adjustment may not be necessary; use caution
Moderate (Child-Pugh class B): 20 mg/day initially; not to exceed 80 mg/day
Severe (Child-Pugh class C): 20 mg/day initially; not to exceed 40 mg/day
Administration
Take with food (at least 350 calories)
Food substantially increases absorption; increases AUC ~2-fold and Cmax ~3-fold
Initial dose titration not required

Pharmacology
Mechanism of Action
Atypical antipsychotic; precise mechanism is unknown; efficacy suggested to involve mediation of central dopamine type 2 and serotonin type 2 (5HT-2A) receptor antagonism

Absorption
Bioavailability: 9-19%

Peak plasma time: 1-3 hr
Distribution

Protein bound: 99%

Vd: 6173 L

Metabolism
Metabolized by CYP3A4; biotransformation pathways are oxidative N-dealkylation, hydroxylation of norbornane ring, and S-oxidation

Metabolites: 2 active (ID-14283, ID-14326) and 2 inactive (ID-20219, ID-20220)

Elimination
Half-life: 18 hr

Clearance: 3902 mL/min

Excretion: Feces (80%), urine (9%)

Next Section: Interactions

CONTACT WEBMD LLC
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To contact other staff members of WebMD LLC, use the following email template as a guide:
FirstInitialLastName@webmd.net (ignore middle initials and degrees)

And now, Tuesday, September 29th, 2015, Alex has run away again because of being on too high a dose of the medicine. He's both agitated and irritable and can't help himself. And the only difference in his life is the high dose of Latuda. It's too high because the people who make the medicine and research the medicine say 80mg is too high a dose to start with. Why didn't I look this up before Dr. Compton called me? I should have been more knowledgeable knowing that they just don't care.

I waited until 1am to call the police non-emergency line, maybe because I'd called them the night before at 8pm, after Alex didn't appear at dinner time. But, I had to call her back because he came home a few minutes after I called. Officer Neff knocked at the door. I could tell it wasn't Alex's soft, unassured knock; it was a louder, more assertive knock. We spoke for a while and I showed him Alex's picture which had the clothes he would still be wearing 3 days later. I told him, no, he won't get onto public transportation. He made the effort to calm me saying that it was good that he wouldn't go somewhere else, like San Francisco, because he doesn't get on busses or trains. I told him he would be wherever there were people…People's Park, Telegraph. He thought it would more likely be Shattuck. The other places get

cleared out. He put out the word immediately to his fellow officers and before he even left my apartment, one of them called in that he'd found Alex on Shattuck. The Berkeley Police are second to none. He asked me what I wanted and I told him I wanted him just to come home. I figured out that the dose was too high so I was planning to cut the Latuda in half and see how that worked before I stopped it altogether. It was the medicine making him like he is. Nothing else. It's the overdose of Latuda making him like this. But, I didn't tell him what to do; the police can make their own decisions. He told me he'd go to talk to Alex and call me from there. He asked for Alex's phone and told me that he'd give it to Alex so I could call him directly. And he did call me back in a few minutes to say that Alex is OK and doesn't need to go to the hospital. They can't take him anywhere because he's not doing anything wrong, he said. Alex told them he'd come home later. Officer Neff called me and told me to call him. I called Alex twice but he didn't answer.

Then Neff called again after another 15 minutes with Alex to say that Alex doesn't want to come home. So, they're going to take him to the hospital, and not necessarily Herrick. That's up to the paramedics. That's fine. I'm not so fond of Herrick now either. In almost 20 years, only a couple of doctors there have bothered getting information from the parent that they needed in order to make better decisions. Or was it only Dr. Fitzpatrick? And he just left a message after reading my printed word, although, we did talk face to face a few years ago. And I did say a word or two to Dr. Zim in 1996 when I recognized him in the elevator at Herrick. That doesn't really count. I remember his incredulous look when I asked how long it would take for Alex to recover. Dr. Slawsky at John George sat down to hear what I had to say. Of course, Dr. Montandon talked to me at almost every visit he had with Alex. But, they're not at Herrick.

Wednesday, September 30, 2015
no meds last night - the Zyprexa, Amlodipine Besolate, Metoprolol were not taken last night, just the Latuda and Fish Oil were probably taken at 2pm yesterday

At 8am I started calling. The Alta Bates operator said she's "not showing anyone by that name in our computer system." I'm not at all discouraged; Herrick didn't live up to its name. The John George Psychiatric Pavilion emergency room operator said she "cannot confirm or deny if the patient is here, but you can call 510-614-6640 and see if the patient comes to the phone…If he had come to the ER at 2:00am he would not yet have been assigned a doctor." I'm going back to sleep. No, I'd better go to the ER before they do another Tomasini and just overdose him till he's catatonic, like he did in November, 2008. That's not the kind of help for him that the family wants. But, first I have to write a few pages of information pertaining to his recent activities, conversations and medicines to give to the emergency room.

A brief note to the psychiatrist wherever Alex is

Alex is on:

15mg of Zyprexa.

It's working fine at 15mg; he even does OK on 10mg. But, I thought he could use a low dose of another, newer medicine. So, Dr Compton at Herrick was willing to add a new one. She stated that he was looking much better on the 15, (and that was before she added the Latuda) than he looked on the 20mg. that she first raised it to. (p. 188)

So she added the Latuda,

and I was in agreement to add a *small* dose of something that he'd never had, because he needs to be able to do more and have better judgement. But she added too much Latuda—80mg—to get it started. And that was on the 21st of September, 9 days ago. That is, it's 4 times as much as, according to the manufacturer's suggested dose—20mg—one is supposed to get at first administration of the medicine, if another med is being used at the same time that is even a moderate CYP3A4 inhibitor, per © 2015 Sunovion Pharmaceuticals Inc:

> Concomitant Use of a Moderate CYP3A4 inhibitor (e.g., diltiazem): LATUDA dose should be reduced to half of the original dose level. **Recommended starting dose is 20 mg per day.** Maximum recommended dose is 80 mg per day.

80mg has been too much for him. And no one knows that but me, Dr. Mom, Mo. M., because he's been in my charge since they threw him out of Herrick on Wednesday, Sept. 23rd after only 3 doses of Latuda. He can deal better with life with 10 or 15mg of Zyprexa alone or maybe in conjunction with the correct dose of Latuda. He doesn't need all this aggravation. I just asked her for a low dose of a new medicine. I was willing to try it to see if it would enable Alex to do more. I had hope that she would know how much to give him at the first administration of the drug. Please refer to what Dr. Compton said to me when we spoke on Friday, Sept. 18. (p. 186) because it's making him very agitated, angry and frustrated. He's not doing well on it and in fact, that's why he's back on your doorstep. She discharged him without seeing how he even reacted on the new medicine; in fact, she wrote the discharge order the same day as she administered the first dose of Latuda, Monday September 21st. He presented poorly to the police this morning after 9 days of the 80mg of Latuda, and they thought he needed hospitalization. I just wanted him to come home, but the police said he wasn't planning to come home.

He also has high blood pressure now being treated with:

Metoprolol 50mg and Amlodipine Besylate 10mg

(the Amlodipine is up 5 mg since he went to Herrick on Aug 28th). And he's also been taking fish oil which Herrick changed to:

Maxepa or Omega-3 Ethyl Esters 1 GM CAP (MFR: Prasco Labs)1 capsule daily.

Please don't overdose him, that is, don't use Dr. Tomasini's notes because he doesn't need to be comatose! On 40mg of Zyprexa! 15mg has been fine or even 10. On 10 he keeps a little more to himself so that's why I was asking for a low dose of *something new in addition to 10 or 15mg of Zyprexa.* Because he was best on 10mg of Abilify, 100 mg of Clozapine and 17.5 Zyprexa back in 2007 with Dr. Slawsky at JG, but he wouldn't get the blood tests then and won't get the blood tests anymore, so I thought it might have been because of the 3 different medicines that he was better, by getting a little of whatever each medicine has to offer…at low doses of each.

Friday, October 2nd, 2015
I don't know exactly what he took last night.

I hope he took the 15mg of Zyprexa, because he wanted to wait with that one after I returned from John George and talked to the ER Supervisor at 10:30pm. He said he took it. Before I left, I had given him half of the old 80mg of Latuda, the Amlodipine at 10mg, but he didn't take the Metoprolol 50mg. He said he'd take it in the morning with the Zyprexa. But, when the morning came, he said he already took everything. He didn't; there were still 3 in the Metoprolol vial, Thursday's, Friday's and Saturday's. I'm very careful about putting a week's worth into each vial, starting on Sundays.
Alex isn't doing so well, nor am I. He was up several times laughing uncontrollably during the night and I finally gave up on sleep and got up at 4am, too. I would think the mania is because he didn't take the Zyprexa last night, but I can't be sure, because I was in the shower at 11:30pm when he said he took it. When that happens, it usually means he waited intentionally until I was in the shower so he could say he took it. But, last night was unusual with taking the meds, because I drove back to John George at 10pm Thursday where he had been discharged from the emergency room on Wednesday at 6pm. I'm getting out of order here.

When I wrote that synopsis above, I wasn't really sure where he was taken, because neither phone call was conclusive, that is, the Alta Bates ER or the John George ER. It sounded more likely that he might be at John George, so I wrote about 10 pages which took most of the day on Wednesday, and then hopped into the van and drove over there. My cell phone rang just as I was parking. The caller introduced herself as Dr. Lal, the ER doctor taking care of Alex. I said, "Let's hang up and I'll be right in." And there she was, waiting for me, as I entered the main door. This is different, I thought. I'm usually waiting long periods of time for the doctors, if they do come out. I read from her attractive, yet intelligent-looking face, steeped in anticipation, that she, among the others in the vestibule, was the doctor. She looked more like an undergraduate college kid but her jacket said "Dr. Lal" and "Johns Hopkins." Having spent the first 41 years of my life living mostly in Philadelphia, I was familiar with the name, although I didn't know that U.S. News & World Report…"ranked the

JHU-affiliated Johns Hopkins Hospital first in the nation among hospitals for psychiatry." So, one could presume she was a present from home, mana from heaven, as it were. She'd only been working here for a week, I think she said. That was why she wasn't yet corrupted and was willing to talk to me I assumed. I mean, *she* was the one who called *me*! Before I even had a moment to get into the fact that he had been overdosed with 80mg at Herrick (She asked me what 'Herrick' was; that's how new she was to the area.), she told me that she'd reduced the Latuda to 40mg. earlier in the afternoon. She said it like it was just an obvious thing to do. I hadn't yet said anything about his medicines and she didn't want to read the papers I was about to give her. She didn't do anything with the Zyprexa, she said. So, that must have been enough at 15mg. Wow! She wasn't going to raise it like everyone else does. What luck! I didn't have to tell her what to do. I was even more impressed, practically in shock, actually. So, it's true, I thought, it *was* supposed to be started at 40mg as the MedScape and Drugs.com page stated. I mean, I had no experience with it. It's just that the 2 organizations that I'd checked in the computer said the same thing: 40mg to start or even 20mg. per the manufacturer. I'd brought the papers inside that I'd just typed, to give her the recent information she needed (which included the recommended starting dose of 40mg) but we didn't need to discuss that; she preferred to know from me what had been going on, before he came into the ER, that is, she wanted to read me instead. And, since Alex was adamant about not being admitted, she wanted to know if I would take him home. Of course I said I would, although I wondered if he were going to run away again, because the police had said he didn't want to come home. That was probably one of the reasons they decided to hospitalize him, because where would he go if he didn't come home? But, now that he had the right dose in his system for a few hours, maybe he would be better. He was extremely verbose getting into the van, and I put some of it on my phone video. I don't remember how the conversation got started, because I was busy getting the camera working, while trying to be a good listener. Since I can't seem to put the video in here, these are the words he said once he got into the van:

> Spins? When a leaf spins, it produces energy. You know, how spin? How the world spins, and you get ice? When a leaf spins around, it produces energy, and that's the energy that we lack, that, controlling us, not to, um, focus on the right things. We'll go through the whole process and come out a loser—every time, because we're not following the basis of our mind and how we think. We think like a tree. So, we're not following the basis, and they cut our branches all the time, and as soon as they cut our branch, the game's over; it's exit the project, and you lose! And nothing is progress-able. You know, there's no progress made. So, what we're going to do is start from a leaf base—the energy of a leaf spinning. It goes with a lot; it goes with maybe feathers and tree buds and stuff like that. It builds up. It builds up energy… and more energy. One element that's in it, that produces the energy that the world needs, is a saw mill. A saw mill is what energy the world needs. So, it's not basic; it's the most basic energy that we'd all think; that's *mill*. It's a very famous word. The mill energy is what we require now. So, we're going to run with that mill energy and see where it takes us.

So, this is what the first dose of 40mg of Latuda sounds like. I was so anxious, that's the last time I remember seeing my phone; he can't find his either, so maybe he was nervous too. I have to admit that I was extremely careful about driving home with him, especially on the highways, as he'd already jumped out of the van on a highway once before, several years ago. I had texted Brenden earlier to hurry over to

help me, to no avail, so off we went. And we made it home without incident. I kept asking him if I were driving alright, and he kept saying that I could go on the highway if I drove slowly.

But, except for the hysterics from 3am to 7am, he appears much better on the 40mg of Latuda that was started Wednesday afternoon by Dr. Lal. So, tonight will be day 3 on the lower dose. I can't understand why Compton would have done that when the others I've encountered—the JG ER psychiatrist and the CVS pharmacist— both knew it was supposed to be started at at least half that amount. Was it just a mistake? (Is it just a coincidence that High-Dosser Dr. Charles Peter Connor's name is all over Alex's discharge and admitting paperwork, and Dr. Compton said that she consulted with 'other psychiatrists': "My understanding from the other physicians…")
I had no Latuda except for the 80mg pill. I thought the paperwork I received from JG included a prescription. Apparently it didn't. So, the CVS pharmacist spent quite a bit of time researching in the computer, trying to answer my question about whether the 80mg pill is homogenous so I could cut it in half. When I returned to the store at 8pm to get my answer she said she couldn't find the information, but that other customers she knew had cut the pill. I questioned that, because there's no line. But, we did, and he seems OK right now as I leave at 9:45am for BMH to find out why there was no prescription from BMH at CVS when I went there yesterday. I would have thought the hospital should have connected with his outpatient facility to let them know he needed a new prescription or the hospital ER itself would have given me one. I'd already given a message to the case manager, Alberto Flores, yesterday morning and he said he'd call the ER but I never heard back from him. So, I'm heading back to the emergency room now at 10pm, because I can't call to get any information, to see if we can get the prescription from them, or if they already gave us one yesterday and I misplaced it. I already misplaced both phones, so it was likely that I might have lost the prescription as well. Alex accused me of doing so, as I accused him of putting a vial of Latuda in his backpack.

Both accusations were wrong. I spoke to the ER nursing supervisor, who said they "don't give either prescriptions or medicine to discharging patients." That was surprising. How was he supposed to get the medicine the day after Dr. Lal started him on the lower dose? He said that Alex's psychiatrist at BMH would write the prescription. I don't see how he would know to do that since the ER doc didn't call BMH. So, I've been cutting the 80mg pill in half, per the pharmacist.

Sunday, October 2nd, 2015
No meds taken

It seemed like an OK day today for Alex. I gave him all of his money—$20—but he had to either give me $2 back or brush/floss his teeth immediately. He chose the $18. I was home all day and he went to the Ashby flee market where I hope he was eating because he wasn't

eating at home. He said he did. But, I'm in limbo. I finally left home at 5pm to walk on the marina and when I returned at 7pm, after a brief visit at my friend Brynn's apartment, he was not home. I prepared dinner, and when I looked behind the building where he usually sits and smokes to tell him dinner was ready, a strange thing happened. I called his name, because it was too dark to see anything at 7:30pm, and I could hear some kind of sound like something was moving. I quickly left and took the van to scout around on Shattuck for him, but after driving up to University and back, with a few extra turns around the park, I decided to go home to wait for his arrival. At 8pm the streets looked safe. There were plenty of people out and about. That was comforting. Around 9pm I knocked on my friend George's door and asked him if he had a flashlight after telling him about the sound I heard when I called Alex's name earlier. Maybe he was on the ground in the back, trying to answer my call. Who knows? George came with me to shine the light in the back yard because he knew I didn't want to do it myself. No, Alex wasn't there. Thank G-d.

But now, it seems like we're going backwards. Did he not take the medicine last night? Before I left home at 5pm tonight, I'd looked to see if he were in the back yard, and told him where I was going. He was in deep contemplation and didn't want to hear. I offered to take him out to dinner. He wasn't interested. I wondered if he wanted me to go back to the street fair with him to buy the barbecued chicken he likes over there. He had actually suggested that I come over there to eat with him earlier on. But, now he was impatient with my talking so much, telling me he had things to do. I should have realized then that he wasn't OK. Although he wasn't flinging his arms around like he did on the 80mg, the conversation was similar.

Now, it's 11:30pm and he's still not home. Normally, I would call the police around this time, even before. But, when the fire department came last time, the chief told me that I had called them 3 times already for the same thing…that he couldn't breathe. And when the police officer came over the next day, I think he told me something similar, that I had called the non-emergency number 5 times in September. So, I'm a little reluctant to call either of them if I've used up my limit of police and fire calls. It's probably not an emergency to them. Of course it's not. It's not their kid. And their kid probably doesn't have schizophrenia. No wonder Liz, the president of our local NAMI, told me parents just wear hard hats and don't call for help when their psychotic kid hits them on the head. Otherwise, they would know that the behavior of a person who suffers from psychosis, is very unpredictable. Officer Neff seemed to think it was emergent or he wouldn't have finally decided to take Alex to the emergency room. I just asked him to tell Alex to come home. But, he figured that Alex wasn't OK, after talking to him more than just a few minutes, because Alex was able to remember what day and month it was, close enough anyway, which is what they ask first. But, if you hang around him for a few more minutes, anyone can see that his perception of the world is not the same as the norm. Midnight at the oasis. I'll sleep in the living room so I can hear him knock, 'cause I'm triple locking it with the latch in case he might be forced to give someone his key. That thought in the back of my mind that someone may take advantage of him, is always there.

Alex knows he has to take the medicine between 8 and 9pm. Now that's screwed up again. Brenden doesn't answer my texts. He's busy. And my darling next door neighbors, Ben and Samantha, moved last year. Not everyone wants to hear about this stuff. Even George, my friend one house over, looked like he was about to administer the rite of passage to me, that is, that I have the right to pass-age Alex off to a board-and-don't-care. It wouldn't be the first time George told me to get rid of him. I'm grateful for writing; it's the therapy I need when I have no one to talk to.

As I lay me down to sleep at a little after midnight, I decided to call the non-emergency line instead, and asked the police officer if it weren't OK to call too many times. I explained what the fire department said and she explained that it's a waste of time if they come and the person doesn't want to go. That makes sense. So, it's not that you're calling too many times; it's that the person isn't cooperative once the fire truck gets there and therefore nothing good will come of it and they might need that truck for some other emergency where the person is more cooperative.

I feel the same way about getting him to the dentist or the doctor, but I have to be able to devise a plan that works for schizophrenia. These protocols only work for normal people in predicaments. Other than the medicine actually working to give him better judgement, (and so far that's not in the cards), so he could take appropriate care of himself, he's not going to go because his voices tell him not to go. And that's the nature of schizophrenia. Not only doesn't he believe that the doctor or dentist can help him, he doesn't believe any diagnosis they may have come up with. That is, he doesn't think he's sick; he just doesn't think he's mentally ill.

And to insure that he's not going to get served, the fire department says that they are not supposed to go against his wishes—in fact, it's illegal to take him against his wishes—even though he is a danger to himself by not going. So, here is the proof that HIPAA is not helping him to get better, or even to stay alive; it's just helping him to <u>not go where he doesn't want to go</u>…to the dentist or the doctor. He has that right, they say. I say, that's BS (not Bachelor of Science). They are simply not asking the right questions. For instance, they are not asking, "Do you want to live or die?

Of course, Alex in his schizophrenic mind set, is incapable of making those judgements about his own health and someone else should have to make them, someone else who knows him and has his good health in mind. Why? Because you have to know what he really wants: "***to live*** forever." But, no one asks him if he's trying to live or commit suicide. Given that, if Alex could put 2 and 2 together, he would want, indeed yearn for the dentist and the doctor because they can help him to live. But, he simply can't understand that going to get help for his cough or tooth infection, from some stranger, who happened to study in the field for 8 to 12 years, is going to help him get the infection out so he *can* live. He may not live *forever*, but he can at least live as long as possible without a constant health threat that's fixable. His thinking is so confused that he actually thinks he's a doctor.

In regard to the previously mentioned fact that Alex is incapable of making those judgements, where uninformed judgements could kill him, why is the conservatorship process so complicated that it requires over 100 pages of information to explain it? More simple steps should be provided by the court so a parent or other concerned friend would be willing and able to apply to be the ill person's conservator.

Monday, October 5th, 2015
At 3pm: Latuda 40mg (cut the 80 in half); Omega-3 Ethyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg

Alex knocked quietly at 3:00pm the next day, Monday, October 5th, and headed right for the medicine, 21 hours after leaving. He probably felt uneasy, since his body is used to getting medicated at 9pm, and he was 18 hours late in taking it. He stated assertively, his right to go out, then went to his room and slept for a couple hours. There was no remorse for having caused me any anxiety. "You're just my roommate," he said, when I questioned his disrespectful behavior. "Why do I have to call?" I guess this boy's got to go. I can't handle him. I was planning to go to the dentist myself on Monday, but I had to cancel.

And that was the first of his 2 naps on Monday. I couldn't seem rouse him at 7pm, but he did finally get up, just as I was giving up and putting his barbecued beef-potato-broccoli dinner into the refrigerator, and came to the table. Since I refused to give him his $20 allowance because he ran away, he cleaned the plate willingly, thanked me for dinner and went back to sleep for another 10 hours. So, it sounds like he didn't get much sleep when he "stayed at my *friend's place."*
"Oh, who's that?" I pried.
He hesitated. "Sam" he said.

Thursday, October 08, 2015
I know not about what he took yesterday or so far today; it's 10am
3pm: Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg (NO Latuda)

I couldn't write yesterday. Alex got mad and left again. He was angry earlier in the morning, but I didn't call the police, because I don't want him to go to a hospital, because if they get involved, the ball is in their hands. And I don't want him to stay here if he doesn't want to stay here. It's hard to write about what happened. I'll do it later. It's been about 23 hours since he ran out of here yesterday (Wednesday) just because he saw me parking the van in front of the apartment. I hadn't seen him for a couple of hours since he'd gotten upset, and I

thought he'd be better by now, but he still looked upset, so I got back into the van and drove after him for a few blocks, then got out and followed him down the street on foot. But, it was hard to keep up; I can't run anymore. Finally I was close enough to yell across Ashby Avenue to him, saying "You're due to take the medicine in about an hour! The pills are in the medicine box I put into the bag!" that was flung over his shoulder. He said something about, "OK, I'll be back in a couple of years," and ran further away toward Shattuck Avenue. I couldn't keep up the pace, so I walked back to the van a few blocks away. And by the time I started driving around looking, he was already on his way to somewhere. What happened? That was Wednesday at 3:30pm.

It was earlier in the morning that he had freaked out. I don't know what to blame it on except the Latuda. I mean, I could blame it on *myself*, because I *did* turn the stove on, after he directed me not to "cook," but, no, I've done that before and he never did what he did this time. Normally, I just tell him, "It'll just take a couple of minutes to heat up the water. I want some tea." And, he always says OK, I'll wait. I had already finished eating breakfast, when he'd come into the kitchen telling me not to cook or turn on the faucet, because he needed to meditate. What's this? I thought. I'm already use to his telling me he doesn't want cooking aromas when he meditates, but not being able to run the water in the faucet was new. "Don't use the bathroom either," he said. I protested, "No, no, what's all that about?" After he went to his room, I turned the fire on under the kettle and in a minute he came back into the kitchen. "I told you not to cook!" he yelled looking fanatical at me, picking up the hot pot and throwing it into the sink. "I need to meditate; I already told you! So, why are you cooking?!" he screamed uncontrollably, as he continued picking up the burners one at a time, shrieking, "Don't cook, when I tell you not to cook!!" hurling them against the wall and the kitchen table, somehow missing the vases and other paraphernalia I keep there. That was a blessing. The only thing that stopped him were the words "I'm going to call the *police* if you don't stop!" that seemed to come from my mouth. I'm not really sure because I was so upset by the unusual and violent behavior. And actually, my upstairs neighbor, Wesley, was sitting outside on the step right next to my open kitchen window, he told me afterwards, and heard it all. He said that he didn't know what to do so he decided to do nothing. Hearing the word, "police" made Alex sit up and take notice. That is, he actually noticed what he was doing and said out loud, 'though to himself: "What's wrong with me? I usually can control my anger; I don't know what happened." I think I know what was different, that is, what happened. Too much Latuda, from the initial high doses for over a week and all the changes in dosage, were taking its toll. I didn't give him any more today, Thursday, the day after he ran; he just took the other meds. But, he said he did take it yesterday, that is, he took the meds that I had put into his bag, when I reminded him to, on Ashby.

Today I called the FDA and spoke to Maria, a very helpful customer service representative who gave me the following information: She said to call 888-394-7377 customer service at Sunovion for the info about the CYP3A4 inducer/inhibitor. "As far as the aggressive behavior that you're describing, you could fill out a medwatch report to let them know" about the effect the Latuda had on his behavior. "It's on the FDA website…As far as the hospital giving him the wrong dose and discharging him too soon, if they are not taking enough care of him in the hospital, contact the Medical Board of CA, Consumer Information unit: 800-633-2322…To check out Latuda, go to

www.dailymed.nlm.nih.gov." Maria said that "the recommended starting dose from the drug company that we have approved is 40mg. It's been shown to be effective from 40mg to 120mg, but there's no proof (as evidenced from the 6 week trial) that there was any greater benefit at more than 80; there was more risk than benefit."

I had predicted that he would return at least by 5pm today, but I heard the key rumblings in the door at 3pm. Brenden called after I texted him and we both figured from Alex's recent history of staying out all night that he would probably return today. So, I never even called the police to ask them to help find him. I noticed that each time he'd left, he returned a little later, like an arithmetic progression. The first time it was 9am, then 11am, 1pm, 3pm, so I was expecting him around 4 or 5. That's why I decided not to let it get to me. I was able to sleep through the night and keep typing when I got up. As I lay down for a nap around 3pm, I heard him fumble for his key. There went the nap. He was a different person upon entering, from the one who'd left…meek, yet almost jolly. "Hi Joan!" and all that, like nothing had ever happened. Of course, he had much less Latuda in his bloodstream by then. Surprisingly, he wasn't hungry. He showed me the 2 litter soda, bragging that he'd bought it for .99c because he didn't have much money. That was a first. He usually pays top dollar/bottle to the retail store cause. There wasn't any money in the money drawer when he peeked, either. Nor will there be for the rest of the month, I told him. Verbal abuse and throwing things don't sit well with me. I can't deal with it. In fact, the first thing I did yesterday after the incident, while I was still hot, was to go to BMH and speak with one of the clinicians, to report the incident caused by the high doses of Latuda in his bloodstream, and she said she'll let his case manager, Alberto, know that Alex needs a board and care. And I saw Alberto on the street immediately afterwards, and told him I left word with his colleague, so everyone knows. That was Wednesday, yesterday, but I haven't heard any more about it from Alberto as of today.

Friday, October 9th, 2015
Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg

It's just after 9am. I didn't offer him to take any Latuda after he came home on Thursday because of his aggressive behavior on Wednesday morning. Now, I'm not sure I did the right thing. He may not have taken the 40mg the evening of the day he ran away, although he said he did. If he didn't, then he would be off of it suddenly for more than 2 days. That would be an abrupt termination of the medicine and I'm ignorant of whether that would hurt him. I have to call Sunovion. I'm going to pick up the new prescription this morning. I guess we can always start it again at a more gentle dose—20mg. But, I want to see how he is without any...on Zyprexa alone. Give it a rest. Give us all a rest. Brenden said yesterday, before Alex came home, that I should let him be whoever he is, and stop trying to fix him. But, I want more for him. I want him to *be* more, be able to *do* more. Hell, now there are doctors already practicing, who are younger than he is. I really thought he was going to be a doctor. And, the irony is, he thinks he is one. Maybe I told him too many times what my hopes were for him.

I still have to coordinate getting him to the dentist and the doctor before giving up. The doctor he was supposed to see at last week's appointment at LifeLong came out to talk to me, instead, at the appointment time, and said she would be willing to talk to him on the phone, so he could become familiar with her voice, and maybe he would then come in to be seen in the clinic. She was very accommodating. I may go back and ask if I can take her picture so he can be even more comfortable knowing who he would be seeing. He has to be familiar, or have someone he trusts know the person, like his brother knew the dentist, Dr. Arnold. I can work on that. As far as a dentist goes, I'll have to check out the University of the Pacific, since they seem to be already set up to deal with the disabled on a regular basis. Possibly UCSF, too, because Linda at the Faculty Dental Clinic returned my call twice last week to give me the low down on how to possibly get Alex seen there as an inpatient, but I'm thinking that I would have to get him back into a local hospital in order to have the hospital take him there by ambulance and they are not set up to do my bidding just to get Alex's dental health in order. It might have happened last month at Herrick, but they wanted, for their own benefit, to discharge him quickly instead. It should have happened at Villa, where they had the psychiatrist, transport team, social worker and an arrangement with Fairmont Hospital, etc. All they lacked was the *will* to help him.

Will it really be 20 years of this, this coming March? My arithmetic is not so good, thinking this was the 18th year. The psychosis really was brewing even before then, about this time, 20 years ago. I remember bending over my display laid out on the floor for an Advertising Specialty convention coming up in Chicago at McCormick Place. Alex came into the living room saying, "There's something wrong with me Mom; I think I need some medicine. I must have ADHD or something." He was very perceptive, but I was too focused on my new product. I continued cutting out the design for the booth where I would be displaying my Goody Table Designs, so I told him, "You'll be fine Alex. What could be wrong?" We finally gave his new state of being a name, just after his 18th birthday on March 1st, 1996, when he actually looked like a zombie walking across the corn field, stiff and catatonic. Why did he get this? Nobody seems to know. In the beginning, they just pushed the old neuroleptics into him that weren't even invented for what he was diagnosed with, because they don't really know much about what he has.

I have to stop writing and start doing something else, something more attention getting. What? A sit in? Like the documentary film on the 1st floor of the Ed Roberts building in Berkeley, depicting what took place to help get a law passed for the developmentally disabled, to end "discrimination in education, employment and services from organizations using Federal money."

> The demonstration's purpose was to press the Carter administration to fulfill a pledge of his candidacy. He promised to sign drafted regulations for Section 504 of The Rehabilitation Act of 1973 that had languished without regulations for over three years. The Rehab Act was passed over President Nixon's veto but Section 504 was the controversial piece of the law, promising Americans with disabilities an end to discrimination in education, employment and services from organizations using Federal money. It met opposition from hospitals, universities and schools.

We all entered the building and ultimately settled in for the duration until regulations were signed. For 28 days, the demonstrators lived on the sixth floor of the Federal building to pressure the Carter Administration to sign the promised regulations. I was not one of the heroic scores of people who lived within the difficult circumstances of the Federal building full time, I commuted back and forth to the demonstration in order to fulfill my responsibilities at home to my wife and infant son. But thoughts of that monumental accomplishment come to mind this month as we celebrate Ed Roberts Day.

Ed Robert 1984 Ed didn't stay at the Demonstration at all, he was very busy in Sacramento with his job as head of the California Rehabilitation Department. I stayed several nights and I recall helping to get Hale, a man with severe cerebral palsy out of his wheel chair and bedded down on the hard carpeted floor. We became a community supporting each other in genuine and humble ways.

Today, the broad-reaching Americans With Disabilities Act is grounded in the principles of Section 504. Our society has become more inclusive although we have a long way to go. My own brother Mark, who has severe cognitive disabilities, has been a bellwether of that change. He has moved from a hideous institution, where he languished in the most violent conditions from 1963 to 1981, to supported living thanks to the progress of law and my own advocacy. In many ways, Ed Roberts set the stage for Mark's life change, which would not have been possible without the 504 Demonstration. Thanks also to those brave individuals whose tenacity and personal sacrifice 36 years ago have helped to make a more just society for all of us.

Courtesy of: http://mn.gov/mnddc/ed-roberts/jeffmoyer.html

But, Schizophrenia is not included in Developmental Disabilities. I learned that when I called the phone number that Dianne Feinstein referred me to in her kind letter of last March 13th: 916-654-3454. I dropped Senator Feinstein's name initially, thinking it might help me get the information that I wanted. The young woman who answered said, "Who is Dianne Feinstein?" After that, it was all downhill. I took a few notes during the telephone conversations:

3/13/15
I called California Health and Human Services Agency according to Senator Feinstein's letter.

1600 9th St. Suite #460
Sacramento, CA 95814
916-654-3454

They are over Social Services, Residential care facilities and a 3rd one that I couldn't quite catch. Ashley answered at H&H and I explained that I'd already called this number late yesterday and another young lady gave me to the Office of Developmental Disabilities and they said they couldn't help (because they are not about mental illness.) I called Ashley back (to let her know what happened) and she transferred me to Social Services. Denise in social services said: "It's a medical facility, we handle the non-medical." She gives me the number 916-558-1784 to the California Department of Public Health, a recorded line which says call 916-541-5555, press 1 for certified nursing assistant, 2 for vital records, 3 for genetic disease, 4 for

licensing or a complaint. I pressed 4 and the live person said, "There's another licensing and certification section for mental health: 916-651-3907." She transferred me to them: "This number is not in session. Code FAC" was the recorded message.

"Health problems? Call County Health Department." I can't remember where I heard that message, somewhere along the line, but I wasn't about to start with the county because I already did that, and ended up back at Berkeley Mental Health, who knew all along that it was they who should have helped me, and they didn't.

I called Ashley back at H&H (again). She went to her director who looked it up and said to call the Licensing and Certification Department, she said, who has jurisdiction over Villa Fairmont at the East Bay District Office: 510-620-3900. Ashley added that I could write a letter to this office regarding my concerns:

Secretary Diana Dooley
California Health and Human Services Agency
1600 9th St.; suite 460
Sacramento, CA 95814

I called 510-620-3900, the Dept. of Public Health. But the lady at that number said they don't take complaints for mental health…only skilled nursing, home health agencies, hospice. She gave me 2 other numbers for mental health complaints to the Dept. of Mental Health:

916-440-5600 –It sounded like the squeal of a fax machine.
916-327-8378 –A recorded voice said "California Department of Health Care Services Licensing and Certification." There was a recorded message asking for the caller to say what the unusual occurrence is, the complaint, address and telephone number, date and time of occurrence and details of the unusual occurrence. I started speaking and it cut me off in less than 10 seconds, so I called again and just talked consistently to see if it would do that again. No, it let me talk longer, so I called back and made notes as to what all it wanted to hear and then I called back again and told them what they wanted to know.

Should I deduce from this treatment that the California Dept. of Health Care Services Licensing and Certification is a very humanistic department and that they will do everything they can to handle the situation? Somehow I don't think so, but at least I got the number of the department at the state level and I can proceed from there. There had to be someone who deals with mental hospitals at the state level even though some of the people insisted that it was only at the county where decisions about licensing and certification are made. I wonder why it's such a secret that few know how they could be reached. And did I really reach them? Will someone actually listen to the message I left? I'm not sure.

Berkeley Mental Health had 5 numbers that didn't get results on their fake site. And that's why I haven't been able to get any help from them. They're there but they're not there. And they are the ones that the county points to who are supposed to be in charge of helping their own clients get the services the client needs. And BMH didn't get back to me until I wrote to the county who told them it was their (BMH's) job to get back to me.

In the end, there was no live person to speak with about my son's dental dilemma that is complicated by mental illness. So, after several phone calls, I ended up leaving a message on a tape, 916-327-8378 and never received a phone call in reply. And that was that. No help.

I've had enough of the incompetence of the mental health system. It doesn't even deserve capitalization or a font as big as the other words. 20 years is definitely enough! In the beginning, I was under the illusion that clinicians knew what they were doing and that they would help him, but slowly the journals about Alex's illness and limited capacity became journals about the system's illness and limited capacity. Not only was it immensely difficult to find help; not only are there no medicines that really work; not only does no one care about what causes the demise into schizophrenia; *they don't care, period*! And, apparently, they don't have to do anything to justify their positions as psychiatrists, and no one is the wiser, especially when the patient has no interested family, friends or money. How long has this state of affairs been allowed to go on? Forever, apparently.

Why else would they allude to discharging him because he's "at his base line," when they don't really know what his base line is? Herrick's psychiatrist, Dr. Compton, didn't know or care what went on at home or at other hospitals, so they can't know and obviously don't care to know, or have to know what went on at John George in 2007 when he was the best he could be on 17.5mg of Zyprexa, 10mg of Abilify and 100mg of Clozaril. That was his baseline! But they don't know that. Up until I met Dr. Lal, a recent graduate of Johns Hopkins, now employed at the John George Psychiatric Pavilion's Emergency Room, I realized that psychiatry has been primarily a non-caring profession. Lal was one of the few doctors in these past 20 years who *asked* to speak to me, who *called* me, without my seeking her out. Dr. Slawsky and Dr. Montandon were 2 others. Why wouldn't the physician seek out the parent to get the information that only the parent knows? They must not need to know. They must not be responsible for knowing anything about their patients. They simply see what they see and deal with it on a temporary basis, like an emergency room. I was told more than once that that was the case. That's why doctors can give their patients the same medicines that didn't work before, creating a vicious cycle of poor care, while they excuse themselves by saying, "That's his base line." (Translation: He doesn't get any better.) In conclusion, that's why doctors don't seek out information from the parent. They don't want or need to know, because if they knew, they wouldn't be able to use the *baseline* excuse. Who knows their logic? Maybe they still see the parent as the culprit. They need to be made responsible to get information from the parent ***by law***. HIPAA doesn't state that they can't *get* information.

What I Want

I'm not as concerned when Alex is out and about during the daylight hours, as long as he's not laughing hysterically or feeling aggressive. This morning he left after breakfast and returned only after I finally left for the Y, because he was home at 7pm, when I came back. What a

relief. Unpredictably, he went out again. I was afraid he wasn't planning to come home again, so I drove in the direction in which he took off, and found him checking out at his favorite corner store. I told him he was already 3 hours late for taking the medicine. He said he'd walk home and take it, but I wasn't convinced, and followed him in the van, I was so sure he'd take off again. He said he wanted to walk without my following him. So, I drove up ahead. All of a sudden, I couldn't see him in my rear view mirror. I lost contact. Then, I began to think that was just a ploy so he could escape. I drove around some more and finally gave up and gave in to whatever would be.

There he was, right at home when I arrived, smoking in the back yard. I guess I'm too anxious, seeing things that aren't really happening. He had already eaten the food I'd prepared earlier and left in the refrigerator for him. He seemed content, was pleasant, took his meds (at least I thought he did, including a lower dose of Latuda-20mg) without contesting, and sailed off to sleep shortly thereafter. My goal was to try the lowest doses of more than one medicine, so he might get the benefits of more than one medicine, if they are, indeed, different. Now I have hope. But, I'm alone in this. That is, I'm only one person.

As Henri Montandon, M.D., Ph.D., has already stated (p. 38): "…we have this opportunity to come together and help one another…" so I would hope, too, that not only *psychiatrists*, and *organizations* who support clinicians dealing with the mentally ill, but the *colleges and universities* who teach future clinicians, and *political incumbents* who represent the people, as well as organizations like NAMI who support the family, should all come to the table on a more frequent and on-going basis, to delve into the issues that would help the mentally ill to recover, ***"people have not realized that we have this opportunity to come together and help one another."***

There are a plethora of issues like the ones listed (p. 70/71) in the notes from the Advocacy Meeting last year. It's not a matter of just *listing* what needs doing. Meeting attendees need to *choose the categories that each is interested in*, that were listed and *prioritize them*, so that the people who are interested in this issue of how to help the mentally ill recover, can actually work on their area of interest in the months between meetings*, by each group taking on an assignment* to work on until the next meeting, so that we could move forward. "Everyone should be taking on a mental health issue." I agree with Darrell Steinberg's statement, everyone needs to be involved, and not just in support groups, but in making change happen. *Everyone* means *each of us* with an investment in mental health reform. *We, the People, can all author bills* to give to Congress. In case it's not clear, my issue is:

> **a *mandate* for the doctor to have to communicate and work together with the parent** or other concerned family member (who has not previously been proven to be a detriment to his/her patient.)

Monday, October 12, 2015
Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg, Latuda 20mg

A representative from Sunovion called back to get more information and then transferred me to their pharmacist. I had left a message on their phone over the weekend. Linda, the pharmacist, said to call Eli Lilli to see if Olanzapine is a CYP3A4 inhibitor or inducer; if it's a *moderate* inhibitor, start the Latuda at 20, if it's a *stronger* inhibiter, it's not recommended that Latuda be given at all…As far as decreasing the dose, they don't recommend cutting it…It should have a longer trial before it's discharged.

Wednesday, October 21st, 2015
Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg

A thought passed my mind that I should just quit and move somewhere else, and this week has so far showed me I would be a fool not to just give up, and let Alex do his thing until death do we part, which is probably not far off. Even though we've caught up with the timing of his medicine this week, that is, he's finally taking it every 24 hours, like it's supposed to be taken, he's still not OK. I've got to get back to the Alta Bates ER tonight because Alex told me he doesn't feel well and needs to go there. Then he took off before I could get back into my car to find him. He said he was going to go downtown first, so I did the regular street sweep looking for him for an hour. He hadn't been seen at Herrick, according to security and the urgent care medical office I stopped into. He hadn't yet arrived at the emergency room at Alta Bates, when I stopped there as it was starting to get dark, 6:45pm. So, I drove around down town, and now it's 9pm. I'm going back. He should be there by now. His last words to me were that "I don't feel well." I'm not surprised; I'm just surprised it took so long for him to not feel well. He's been eating potato chips of all kinds for breakfast, lunch, dinner and snacks. He hasn't wanted my cooking since Latuda at 40mg. He knows he can do what he wants to do now. He has complained to the police and Dr. Lal at John George, saying that I'm too controlling. He's already told me and the Alameda County IHSS intake worker that he doesn't need a caretaker. So, I guess I've been fired.

Gee, I'm way off the time track. We're already in the 20th year of schizophrenia that will end on March 1, 2016. My math is worse than I thought. As far as the Metoprolol, Alex has been getting that at 50mg for a long time, and before that it was Atenolol at 50mg. But, someone added the Amlodipine Besylate at 10mg at Herrick last year, and apparently that's the reason Johns told Alex yesterday, that he doesn't need the Metoprolol, too. The first time I wrote about Amlodipine was Sept. 6, 2015, so he had to have had it prescribed just before then, because he was at Herrick under the care of Dr. Compton at that time, because Johns didn't ever prescribe anything new on his own. But, all of a sudden, Dr. Johns doesn't want the Metoprolol for Alex. But Alex's blood pressure was always better *with* the Metoprolol, and every hospital gave it to him, and if Johns doesn't want the Metoprolol for Alex, I don't want the Johns for Alex. I'm in the process of getting a private psychiatrist for Alex, so it doesn't really matter what Dr. Johns says. I wrote to the President of NAMI East Bay, Liz Rebinsdorf, last night in that regard, and she returned my e-mail today:

> Good morning Joan, I'm out of town right now…but perhaps you can contact someone at the county's psychopharmacology dept - in the past, they've been very helpful as consultants - I don't know who's there now, and they wouldn't be there on the weekend. My non-pharmaceutical thinking is that one doesn't fool around with high blood pressure, and that should be questioned. Cogentin works to counter side effects and perhaps that isn't necessary. Fatty acid meds may not be crucial. I think you're at an untenable position with BMH and you shouldn't deal with them without a knowledgeable person there who can mitigate the conversation - someone who can express your viewpoint and questions in a rational, non-emotional manner. I don't believe the BMH folks are rascals and thieves but you're at a donnybrook with them - and have been for some time. Give a call to CASE (I think the acronym stands for Community Advocates for Special Education) - they wouldn't necessarily know this territory but could perhaps recommend an agency or someone to accompany you to meetings. I don't have any names to recommend. To be frank, right now, your emotional involvement, knowledge and assertive advocacy is not working for you and that process needs to be modified; BMH is treating you as a difficult challenging parent and that is not helping Alex. Liz

Sent from my iPad

On Feb 26, 2016, at 11:58 PM, JOAN <JoanOfArt44@comcast.net> wrote:

Hi Liz,

I'm attaching the last of the journals and on the last few pages you can see what's going on with Dr. Johns at BMH. He has missed his appointments with Alex for the past few months, but none-the-less, he is telling Alex to discontinue taking 3 medicines at once: cogentin (benztropine), metoprolol for his blood pressure and the omega 3 fatty acids. He hasn't been without metoprolol since a few years after he got schizophrenia. Every doctor that he's seen in the different hospitals has kept him on the high blood pressure medicines. Johns just doesn't like that I reported him to the Compliance Officer. I need a second opinion as to whether it's wise to go off of 3 medicines cold turkey. Does that sound right to you? It sounds like something that should be done in a hospital setting, not at home with me.

Earlier this week, when he wouldn't take his benztropine because Johns had it delivered without telling Alex or me, Alex wouldn't take it because he said, he didn't order it and it must be for me. And not taking it twice in one day, caused him to be highly agitated, causing me to have to call the police-rather the neighbor called when Alex absolutely exploded. That had to be from not taking it the night before and in the morning of Tuesday. The police took him to BMH instead of the ER where he stayed till he calmed down. They had to put him in cuffs. I don't want him going off of that again in that same way, cold turkey, not while I'm around. Plus, he's stopping his blood pressure med and the fatty acid...all at once. I need somebody new. BMH stinks.

After the LifeLong medical doctor, Dr. Herb, refused to see him on the 8th, after I finally got him to go, they made another appointment last Monday, but Alex's feelings were hurt, apparently, and he wouldn't go to that appointment, so he couldn't get the blood pressure med from the medical doctor and the previous Thursday, while I was at CVS, the pharmacist told his assistant that Dr. Johns did call but only said he didn't want to prescribe the Metoprolol anymore for Alex's pressure. I was there to pick up the Benztropine, but Johns wouldn't order that either through CVS, because he decided, without consulting with us, to have it delivered. It's all on the last several pages.

I would appreciate if you know someone who I will have to pay out of pocket, someone in Berkeley that Alex can walk to. Who knows; maybe he would get in the car. I'm looking and I've called several but they don't want the severely mentally ill.
See you on Monday, if I"m still alive.

Thank you so much,
Joan

Dear Liz,

Thanks for your thoughts. I'm not sure about the lady you refer to from Marin NAMI. Was that the one sitting to your left? I thought she was a little too distanced from her family member. She had helpful things to say to other people, but nothing much about her own son. A few of them were too distanced even though their sick kid was on the street. That's hard to believe. No, I'd be out for long hours looking for him. Except for last Saturday.

He was on the street again last Saturday night, and apparently, the reason I couldn't find him, he said after he returned, was that he spent the night in the Alta Bates ER on his own volition. Why doesn't he just tell me where he's going? I usually check there, but this time I didn't. I followed him soon after he bolted, but not immediately, and not for long, deciding that he predictably returns around 3pm the next day. I felt I had to be home in case he came home on his own. That's what's happened the last 7 or 8 times. The first time I found him at 9am, the second at 11, then 1:00pm and 3:00pm is the latest he seems to arrive home. So, after I waited at home all night and Sunday until just after 3 pm, and he hadn't returned, I headed toward Ashby Av, so I wasn't home when he did arrive, as projected, soon after I left. Although I'd planned to stay home and wait, this time, I changed my mind and went out, only because I had just spoken to the police officer (I can't find his card) who arrived soon after I reported him missing on Sunday around 2. I had waited 18 hours, from the time he bolted, before I reported him missing. I thought it would be easier to find him before dark settled in.

Unlike the other officers, this one looked annoyed and suspicious. He asked me why I called so soon, if Alex usually comes home at 3pm. I said it was because he hadn't taken medicine for 2 days and I didn't want him to act out. He wondered why I wasn't out looking on my own, rather than calling the police again. He wondered why I kept calling the police. I told him I hadn't called them at all after the last 2 runs. He wondered why I didn't place him elsewhere, like most of the other parents he encountered, some of whom even got restraining orders for their sick kid, he said. He actually asked to look through Alex's room, and, of course, I let him. I wasn't sure if I had to, that is, he didn't show me any paper stating that he had permission to look in the closet. But, I didn't want to get on his bad side. He had the gun, not I. I showed him into the room and he stood for several seconds, feet astride, taking it all in. I said the boxes on the shelf were for my business. He didn't seem interested, so I didn't go any further about Goody Table Designs. He just turned on his flashlight to look more carefully into the closet. I got the feeling he was looking for contraband or something that he could find to put Alex in jail and end these time-wasting phone calls I was making. It was slightly embarrassing because I hadn't vacuumed the throw rug next to Alex's bed of his recent cookie fest.

I told the officer I needed to be home, because I thought Alex lost his key based on the look of the kitchen window, when I returned from doing laundry. Alex had climbed through the window sometime before he ran, because the window was slid open and stuck in the open position, open all the way, 2 feet wide. It was exactly 7 pm when he ran just as I was arriving home to give him the hoagie I promised I'd get from IB's. I was taken aback that he would run again. He wasn't angry or anything. But, I couldn't run after him because I had to figure out how to close the kitchen window. It wouldn't budge. And it was dark already. Fortunately my friend George in the house next door came to the rescue. And by the time he was able to pry it loose, so it could close, Alex was long gone.

I knew it was all about the fact that he's had so many different doses of Latuda, starting from the high of 80 to 40 to 20 starting September 21st, and ending almost a month later. That was the wrong order of dosing, but that's what they do in the mental wards...start too high. Why do they do that? I think it's because the doctor just wanted him out because they don't get paid enough money from Medicare or Medi-Cal, because she wrote the discharge order the same day that she started the first dose of the new medicine. So, she discharged him to the care of Dr. Mom. They should give me some credit for being a Dr. Mom, a colleague. And there was no follow-up appointment yet scheduled for Alex at BMH to monitor the effect of the new medicine. So, I had to do it, and the Berkeley Police were my Official Social Father-Replacement Guardian-Angel Workers. He finally got an appointment with Dr. Johns for 2 weeks later. My older son, Brenden, insists that it's because I tried to tell the doctor what to do, and since administration was the one who told her to call me, she had to do it. She didn't like that, Brenden keeps insisting each time we discuss the issue. But, she did it. At any rate, Dr. Compton said she read my letter, would start him on a new medicine and suggested Latuda, (as I suggested that she try *a low dose* of something new,) and wrote the discharge order the same day as he received the first dose. I know that, because the case manager at BMH left a message on my phone that Monday, to talk to me "about Alex's impending discharge." How would he have known if Herrick's social worker hadn't called him to let him know? So, that was the problem: the same day she started the Latuda at twice the suggested dose, she wrote a discharge order. So, she didn't follow manufacturer's directions using the high dose, and she discharged him to no one's care except Dr. Mom's. So, excuse me for demanding some input since I'm being mis-used as a physician.
So, that's my issue with the mental health system. And I have to be involved because of their misguided, almost malevolent treatment of patients. I can't and won't give up, Liz. I didn't realize that this is really the 20th year of this craziness, and I don't mean Alex's craziness; I mean the system's craziness. Besides, as much as I'd rather be doing the business that I finally had to put on the shelf 18 years ago because I couldn't do both, I can't give up, because I made a pact with someone when I got cancer in 2001, that I would take care of Alex if I could live to do it. So, I'm still breathing. So, I'm still taking care of him. But, thanks for all of your caring, Liz, and all the work that you do for everyone.

Fondly,
Joan

From: "Liz" <tunkiliz@sbcglobal.net>
To: "JOAN" <JoanOfArt44@comcast.net>
Sent: Friday, October 16, 2015 8:12:22 AM
Subject: Re: liz from NAMI EastBay here

At the support group, that woman from the Marin NAMI was a bit officious and overbearing but her refrain about "letting go" is really true. You have been so involved with Alex, to the point of being in charge of all the meds details - it's perhaps just too much and he might benefit from not living with you and having to take care of himself. Rather than telling you to just let go, perhaps it would be easier for you to engage in some new project...away from mental illness.

Sent from my iPad

On Oct 16, 2015, at 12:04 AM, JOAN <JoanOfArt44@comcast.net> wrote:

Yike, Liz you really do soooo much-- toooo much. Maybe I should/could take notes for your support meetings? i'm a note taker by nature. Then you won't have to strain to remember. And I'm available for anything else you may need. I think I'm going to kick alex out. He ran away again tonight. I can't hack that. It's because his medicines are changing too much. I stopped the new one last night, Latuda, that the doctor at Herrick gave him a few weeks ago. She started it too high, at 80mg and then discharged him the same day, and she was supposed to start it no higher than 40mg, I discovered when I looked it up on the manufacturer's website, maybe even at 20mg. it should have been started. It depends on whether his Zyprexa is a "CPT3A4 inhibitor/inducer." No one around here seemed to know--the CVS pharmacist, the BMH psychiatrist. If it's even a moderate inducer or inhibiter, he shouldn't have gotten Latuda at all, the Sunovion pharmacist told me. So, I stopped it last night after having cut it to 20 for a week, and he left this afternoon to parts unknown. But, I have hopes that he's going to return at 4 or at least by 5pm tomorrow, so I'm not planning to be as upset as I was the first 5 times he's run since Aug 28th The last time he stayed out all night, he came home at 3pm (last weekend) He seems to come back in an arithmetic progression. I was shocked to hear how many of the folks last night had kids who've lived or are still living without housing. Housing is number 1 priority. There should always be box cars or some other kind of cheap housing arrangement for the homeless, so they can be safe.

I've always thought those kinds of containers like they use on ships to transport imports and exports, could be bolted together in interesting configurations in a "condo complex" near the services they need so the homeless can be off the street. It's disgusting. All these companies have sooo much money. It's a shame that housing isn't mandatory for everyone.

Joan
And thanks for the heads up about mixing housing with other needs.

From: "Liz" <tunkiliz@sbcglobal.net>
To: "JOAN" <joanofart44@comcast.net>
Sent: Thursday, October 15, 2015 7:13:06 PM
Subject: Re: liz from NAMI EastBay here

Hi Joan,.... yeah, I generally write a short note to new support group attendees the day after, but I also generally know who is who and their issues and send them specific information - but last night !! - I was so confused and I didn't know but 3 names so I just sent out a generic note. I was exhausted at the end - did not expect that many people. Re your work, the housing group is dedicated solely to housing and I don't know if you saw

Laverda Allen in action, but she is focused only on this and can be blunt and not nice if she feels people are off-topic, so I don't want you to get attacked by bringing in the multiple issues facing all of us. Liz

Sent from my iPad

On Oct 15, 2015, at 5:02 PM, JOAN <JoanOfArt44@comcast.net> wrote:

Wow! Liz, that was a very nice note. I guess that went out to everyone there? I don't remember seeing a letter like that right after a meeting before. It's a great idea to put all the information out to everyone. Although I've been coming for a long time to the support groups, I don't know all the information, and your writing it down in an email is really helpful.
Thanks,
joan
PS: Were you about to tell me last night that I shouldn't have sent my journal to those people on the housing list? I think email is a great way to send information. They can use it/ read it if they want or just delete it. No harm done. I couldn't quite see on the last housing email when the next meeting would be. Do you know?

From: "Liz Rebensdorf" <tunkiliz@sbcglobal.net>
To: tunkiliz@sbcglobal.net
Sent: Thursday, October 15, 2015 11:13:30 AM
Subject: liz from NAMI EastBay here

Thanks for coming to the NAMI EastBay support group last night. It was an unusually large group and I was concerned that some folks left without having a chance to share their stories....hence this note with my e-mail address in case you want to contact me. So many sad situations with so few slam-dunk solutions - but it does help to know you're not alone. I'm attaching our Sept/Oct newsletter and refer you to our website at www.namieastbay.org for more information about what's going on with our group. And I'll put your names on our electronic mailing list for newsletters - next one comes out end of Oct. In the meantime, here is information about some resources we talked about last night: 1-IHSS - In Home Supportive Services - available for elders and disabled adults, 510-577-1900, alamedasocialservices.org. This service is located in every county. 2- Wellness Centers - access through BACS (Bay Area Community Services) at www.bayareacs.org

->Mental Health Services ->Wellness Centers. 3- Private case manager, John Whitty, can be reached through john.whitty@rocketmail.com, 415-793-5120. 4-Bonita House - www.bonitahouse.org ->Services ->Berkeley Creative Wellness Center. 6-We will be offering a free 12-week Family to Family class Jan 21-April 7, downstairs - need to pre-register with me. Feel free to contact me via e-mail. Liz Rebensdorf, president, NAMI EastBay

Thursday, Oct 22nd, 2015

I've always thought the medical profession used too high of a dose of all the medicines. Now here's proof that lower doses are better. Brenden and Monica just sent me this article in The New York Times that came out 2 days ago, October 20th, 2015:

HEALTH

New Approach Advised to Treat Schizophrenia
By BENEDICT CAREY, OCT. 20, 2015

More than two million people in the United States have a diagnosis of schizophrenia, and the treatment for most of them mainly involves strong doses of antipsychotic drugs that blunt hallucinations and delusions but can come with unbearable side effects, like severe weight gain or debilitating tremors.

Now, results of a landmark government-funded study call that approach into question. The findings, from by far the most rigorous trial to date conducted in the United States, concluded that schizophrenia patients who received a program intended to keep dosages of antipsychotic medication as low as possible and emphasize one-on-one talk therapy and family support made greater strides in recovery over the first two years of treatment than patients who got the usual drug-focused care

The report, to be published on Tuesday in The American Journal of Psychiatry and funded by the National Institute of Mental Health, comes as Congress debates mental health reform and as interest in the effectiveness of treatments grows amid a debate over the possible role of mental illness in mass shootings.
Its findings have already trickled out to government agencies: On Friday, the Centers for Medicare & Medicaid Services published in its influential guidelines a strong endorsement of the combined-therapy approach. Mental health reform bills now being circulated in Congress "mention the study by name," said Dr. Robert K. Heinssen, the director of services and intervention research at the National Institute of Mental Health, who oversaw the research.

In 2014, Congress awarded $25 million in block grants to the states to be set aside for early-intervention mental health programs. So far, 32 states have begun using those grants to fund combined-treatment services, Dr. Heinssen said.

Experts said the findings could help set a new standard of care in an area of medicine that many consider woefully inadequate: the management of so-called first episode psychosis, that first break with reality in which patients (usually people in their late teens or early 20s) become afraid and deeply suspicious. The sooner people started the combined treatment after that first episode, the better they did, the study found. The average time between the first episode and receiving medical care — for those who do get it — is currently about a year and half.

The more holistic approach that the study tested is based in part on programs in Australia, Scandinavia and elsewhere that have improved patients' lives in those countries for decades. This study is the first test of the approach in this country — in the "real world" as researchers described it, meaning delivered through the existing infrastructure, by community mental health centers.

The drugs used to treat schizophrenia, called antipsychotics, work extremely well for some people, eliminating psychosis with few side effects; but most who take them find that their bad effects, whether weight gain, extreme drowsiness, or emotional numbing, are hard to live with. Nearly three quarters of people prescribed medications for the disorder stop taking them within a year and a half, studies find
"As for medications, I have had every side effect out there, from chills and shakes to lockjaw and lactation," said a participant in the trial, Maggie, 20, who asked that her last name be omitted. She did well in the trial and is now attending nursing school.

Doctors praised the study results.

"I'm very favorably impressed they were able to pull this study off so successfully, and it clearly shows the importance of early intervention," said Dr. William T. Carpenter, a professor of psychiatry at the University of Maryland School of Medicine, who was not involved in the study.

Dr. Mary E. Olson, an assistant professor of psychiatry at the University of Massachusetts Medical School, who has worked to promote approaches to psychosis that are less reliant on drugs, said the combined treatment had a lot in common with Open Dialogue, a Finnish program developed in the 1980s. "These are zeitgeist ideas, and I think it's thrilling that this trial got such good results," Dr. Olson said.
In the new study, doctors used the medications as part of a package of treatments and worked to keep the doses as low as possible minimizing their bad effects. The sprawling research team, led by Dr. John M. Kane, chairman of the psychiatry department at Hofstra North Shore-LIJ School of Medicine, randomly assigned 34 community care clinics in 21 states to provide either treatment as usual, or the combined package.

The team trained staff members at the selected clinics to deliver that package, and it included three elements in addition to the medication. First, help with work or school such as assistance in deciding which classes or opportunities are most appropriate, given a person's symptoms. Second, education for family members to increase their understanding of the disorder. And finally, one-on-one talk therapy in which the person with the diagnosis learns tools to build social relationships, reduce substance use and help manage the symptoms, which include mood problems as well as hallucinations and delusions.

For example, some patients can learn to defuse the voices in their head — depending on the severity of the episode — by ignoring them or talking back. The team recruited 404 people with first-episode psychosis, mostly diagnosed in their late teens or 20s. About half got the combined approach

and half received treatment as usual. Clinicians monitored both groups using standardized checklists that rate symptom severity and quality of life, like whether a person is working, and how well he or she is getting along with family members.

The group that started on the combined treatment scored, on average, more poorly on both measures at the beginning of the trial. Over two years, both groups showed steady improvement. But by the end, those who had been in the combined program had more symptom relief, and were functioning better as well. The researchers expect to have lowered average doses in the combined program but had not yet finished analyzing that data.

"One way to think about it is, if you look at the people who did the best — those we caught earliest after their first episode — their improvement by the end was easily noticeable by friends and family," Dr. Kane said. The gains for those in typical treatment were apparent to doctors, but much less obvious.

Dr. Kenneth Duckworth, medical director for the National Alliance on Mental Illness, an advocacy group, called the findings "a game-changer for the field" in the way it combines multiple, individualized therapies, suited to the stage of the psychosis.

The study, begun in 2009, almost collapsed under the weight of its ambition. The original proposal called for two parallel trials, each including hundreds of first-episode patients. But that plan was changed due in part to recruiting problems, said people familiar with the project.

"It's been a long haul," Dr. Heinssen added, "but it's worth noting that it usually takes about 17 years for a new discovery to make it into clinical practice; or that's the number people throw around. But this process only took seven years."
Correction: October 22, 2015
An earlier version of this article referred incorrectly to the conclusions of the study. Though it studied a program intended to reduce medication dosages, the researchers do not yet know for sure if dosages were lowered or by how much. Therefore, the study did not conclude "that schizophrenia patients who received smaller doses of antipsychotic medication and a bigger emphasis on one-on-one talk therapy and family support made greater strides in recovery." (The study did conclude that the alternative treatment program as a whole led to better outcomes.) The article also erroneously attributed a statement to Dr. Robert K. Heinssen, who oversaw the research. It was scientists familiar with the project — not Dr. Heinssen — who said that the study's original proposal, calling for two nearly identical trials, was changed in part because of recruiting problems. (Dr. Heinssen said that one trial was redirected, but did not say why.) And because of an editing error, the article misidentified the institution of which Dr. Heinssen is the director of services and intervention research. It the National Institute of Mental Health, not the Centers for Medicare & Medicaid.

A version of this article appears in print on October 20, 2015, on page A1 of the New York edition with the headline: *New Approach May Alleviate Schizophrenia*.

Are my observations finally validated? Aren't they saying that less medicine is better? plus, the talk therapy, of course. Alex didn't even get to talk to a psychiatrist at Kaiser in the first 2 years, but that was because he wouldn't go to the appointments I made before he was officially diagnosed, and even now the doctor at BMH sees him around every 6 weeks, so there's not much talk therapy going on there either. I had made an appointment with a doctor in the old Kaiser building, even before Alex was officially diagnosed, but I had to cancel.

He wouldn't go. Then, Brenden was able to go with him to one other appointment. It was the end of 1995. But, the burden of any talk therapy was on me. Once he started looking like a zombie walking across the field, I called the psychiatrist and he just told me to call 911. And then the medicines started rolling, in huge doses: Haldol. Prolyxin. Navane. Cogentin. This was right before the new medicines were introduced in 1996. Aliosha Zim, MD, talked in a very loud voice into Alex's ear as he lay in bed at Herrick in an immovable condition from the overload of medicine. I stood by his bedside watching. "Alex! I know you can hear me," I remember the doctor yelling.

I could feel something was amiss even months before then. Alex, himself, told me something was wrong that October '95: "I must have ADHD or something. I need Ritalin," he called from his room as I worked on my booth design laid out on the floor. I blew it off. I couldn't hear it, so focused was I on introducing my new product at McCormick Place that next week. "Come on, you'll be fine. You must not be feeling well today." That was exactly 20 years ago, as I'm writing this. I was so focused on Goody Table Designs and on creating a booth to display them at the Chicago Premium Convention, I didn't want to hear anything that might deter me from going. The Too Good Gourmet, Inc.® cookie boxes I bought in the nearby San Leandro factory, that were designed to look like houses, barns, trains and airplanes, et. al., still fill my closets. I finally did get around to emptying them of the cookies, some years later after I noticed that a few bags inside the boxes had been opened with telltale crumbs on the floor. A dozen Set by Number® tablecloth maps still lay folded in their boxes on a shelf. I can't seem to throw them out and let go of the possibility of being in business. After all, it was Alex, himself, who motivated me to design the first centerpiece…that is, my love for a little boy that caused me to put together a table filled with 4 circles of dancing cupcakes and chocolate racing cars speeding around the table on Wright® popcorn highways for his 4th birthday party at nursery school. Never could I have imagined that I would be anxiously waiting 33 years later, for this same boy to come home, burdened by an illness that can't be fixed, after staying out all night in the streets.

Talk therapy. Another scene comes to mind of Alex sitting in the waiting room, anxiously looking forward to talking to his first psychiatrist at Kaiser after he was diagnosed in 1996. But the doctor, in less than 10 minutes, pushing him out of his office, while mumbling, "Mishigina!" a little too loudly, so, of course, I could hear, sitting just a few feet away from the door. The doctor said nothing to me and never asked me to come into his office. So that's what "talk therapy" looked like in 1996, at Kaiser Permanente, anyway. Psychiatrists must not be trained appropriately to deal with serious mental illnesses, just the "worried well."

The Hofstra North Shore-LIJ School of Medicine's study was only with patients in the early stages of schizophrenia. I wonder that there was not a concomitant study of patients who've had schizophrenia for a longer time. Are they to just be forgotten? Registered hopeless? 'Though I came to the same conclusion in regard to low doses being better for the patient, it took me a longer time than the five years for this study, to see the light. Why? I made the mistake of presuming at first that psychiatrists knew what they were doing. And, after

observing his behavior over time, I learned that he needed a smaller dose of 1 or perhaps 2 or even 3 antipsychotics to get whatever he could get out of each of them. I only came to that conclusion from observing him on Abilify, Zyprexa and Clozaril in 2007 after discharge from John George Psychiatric Pavilion in little more than a week where he had been administered the lower doses. A Richard Slawsky, MD, put him on each of 10, 17.5 and 100mgs respectively. He seemed much better then, but since he still refused the required blood tests, after discharge, the Clozaril had to be discontinued. Typically, hospital physicians overloaded him with high doses, and since I'm not a doctor, they habitually ignore what I have to say.

I wonder if kickbacks from pharmaceutical companies—for using bigger doses of their medicines—is built into the system as a motivator. I wouldn't be surprised, because I know from my own experience that pharmaceutical manufacturers wine and dine doctors over long weekends in lovely places. I, myself, was at such a dinner in Ft. Lauderdale as a young lassie with a doctor who I met as I was getting out of my car in the Hilton's parking lot. He needed a date; I was out to dance. I think I wrote about this several books ago. It was a fairly large affair, maybe a dozen tables of 5 couples at each. We were given a talk about their new medicine and shown a film introducing it to the physicians. My date was flown in from Texas, and after the event he offered me a job if I happened to find myself in Houston. I remember it was a Saturday night, because he had plans for golf on Sunday, all paid for by the pharmaceutical company—hotel, flight, food, golf.

I need to write to The New York Times.

> 10/24/15
> public@nytimes.com
>
> Thank all of you for setting the record straight!
> Inbox
> Joan Miro <joan.miro6420@gmail.com>
> Attachments8:02 PM (7 minutes ago)
>
> to public, medicine, nimhinfo, NIMHpress, nimhreferral, appi
>
> The article in your HEALTH section, "New Approach Advised to Treat Schizophrenia" by BENEDICT CAREY, OCT. 20, 2015, was very much appreciated and long overdue. As a parent of a 37 year old with this debilitating disease, I'm thrilled to hear that the Hofstra School of Medicine (Thank you Dr. Kane!) has made the effort that can motivate change in clinical behavior so our beloved family members are set free from any more Medicinal Lobotomies. In my 20 years of observing and writing about my son as he is "served" by the mental health system, I have been deeply concerned about this on-going question of why doctors would want to keep doses higher than necessary. And to be succinct, I would have to conclude

that physicians have been high-dossing because they think they, themselves, need to serve other groups or organizations, other than the health of their patients.

I would like to share the most recent of my yearly journals with The New York Times because, as my son's first psychiatrist, Henri Montandon, MD, stated: "people have not realized that we have this opportunity to come together and help one another." (p.38) Please feel free to use the information in the document in any way possible that will promote better mental health care.

My hope is that other studies will be done for those who have had the disease longer than 2 years. I have not yet given up the hope necessary to eradicate this horror, and I have faith that Congress will, indeed, soon put it on the front burner.

Sincerely,
Joan Miro
Joan.Miro6420@gmail.com
JoanOfArt44@comcast.net
510-418-8568

P.S. I am interested in doing research on the etiology of schizophrenia, if anyone knows who is working in that area. (p. 19).

CC: John Kane, chairman of the psychiatry department at Hofstra North Shore-LIJ School of Medicine
Chair
John M. Kane, MD is Vice President for Behavioral Health Services of the North Shore - Long Island Jewish Health System and Chairman of Psychiatry at The Zucker Hillside Hospital. He is Professor of Psychiatry, Neurology and Neuroscience and holds the Dr. E. Richard Feinberg Chair in Schizophrenia Research at the Albert Einstein College of Medicine. Dr. Kane received his B.A. from Cornell University and his M.D. from the New York University School of Medicine. He currently directs the NIMH-funded Advanced Center for Interventions and Services Research in Schizophrenia at The Zucker Hillside Hospital. He has been a member of the Board of Scientific Counselors for NIMH, and he has served on the council of the American College of Neuropsychopharmacology. He has chaired the NIMH Psychopathology and Psychobiology Review Committee as well as the Psychopharmacologic Drugs Advisory Committee of the Food and Drug Administration.
Dr. Kane is a recipient of the Arthur P. Noyes Award in Schizophrenia, the NAPPH Presidential Award for Research, the American Psychiatric Association Foundations' Fund Prize for Research, the Kempf Fund Award for Research Development in Psychobiological Psychiatry, the Lieber Prize for Outstanding Research in Schizophrenia, the Heinz E. Lehmann Research Award from New York State, and the Dean Award from the American College of Psychiatrists.

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Fax 703-907-1091
Email: appi@psych.org

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nimhinfo@nih.gov
NIH is the nation's medical research agency—supporting scientific studies that turn discovery into health.

Tuesday, October 27th, 2015
Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg, Latuda 40mg

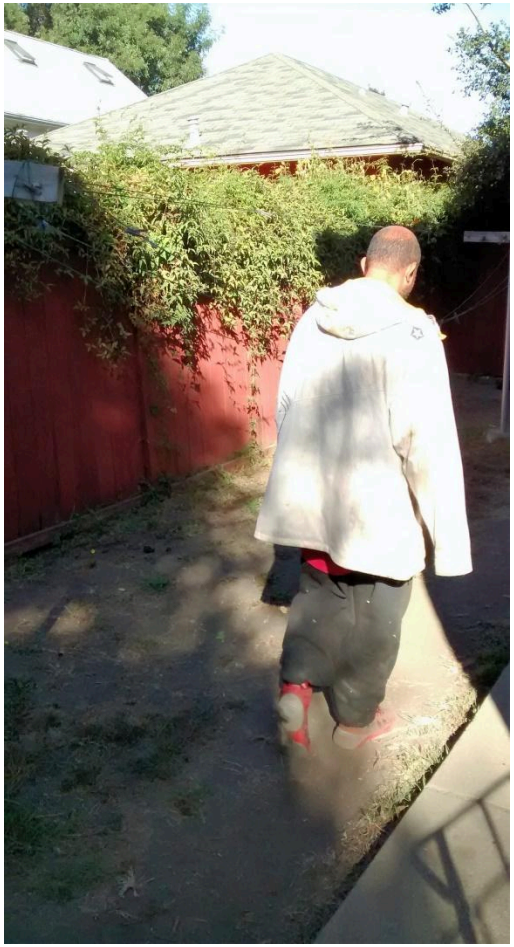
While the good news has come in, the bad news is going out. That is, Alex has run away twice this week and it's only Tuesday. He says he stays at his friend's house, Sam, that is. I don't recall Sam and I don't think he exists, but, I guess it's possible. He stays overnight somewhere. I do know that; but it may be in a doorway or behind a tree on campus. He left again yesterday after taking a shower the night before and said he had to leave. He didn't want to be here. He wanted to live his life. He told me on Sunday when he returned that he went out to a club, then to a concert, then to someone's house. He had fun, he said. So, he left again on Monday after a good night's sleep. How could I say no, if he wanted to go? I guess I could have denied him his $20. But then, how would he eat? And this time, he did ask for his medicine, which I gladly gave him for Monday night. The problem was, that he showed me the vial of meds he said he took over the weekend, when he last ran, and it had a Latuda, which he's been off of for over a week. So, he took Latuda at 40mg on Saturday night. So, when 9pm came on Sunday I thought I'd best give him another 40mg. So, we're back with the Latuda again. He's had time away from the higher dose, so he doesn't have those agitated symptoms and now we'll see how he does on the recommended starting dose of 40mg. He's definitely exhibiting independence ever since the initiation of the Latuda. I guess that's good. He wants to go out and socialize. That's good. Staying outside all night isn't so good, but, who knows, maybe he does have some shelter. In any case, he so far comes home unharmed at or before 3pm the following day. It's 1:17pm on Tuesday and he left at 3:30pm on Monday. I'm sorry that I only gave him $15 because he refused to take the fish oil on Monday evening. Nor did he take the Amlodipine until this morning because he wanted a new one from the pharmacy, not the old one, the last one in the vial.

Thursday, October 29, 2015

Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg, Latuda 40mg

So far, so good. My blood pressure is feeling a bit high from his activities last night, but I'm still standin'. He was smoking or meditating or pacing in the back yard for many hours yesterday. Then I gave him his $20 before I left for the gym at 5pm, and he was still back there when I returned at 8pm. I finally egged him on, when my neighbors in the apartment #4, who have to see him if they look out their kitchen window, returned from work after 8pm. He came in after some coaxing and took his meds, then left "for dinner."

I triple locked the door at 10pm but was awakened at 1am by his knock. Is that the result of his newly found independence? He wants to come and go as he pleases. That may be good for him but I can't hack it.




I triple locked the door at 10pm but was awakened at 1am by his knock. Is that the result of his newly found independence? He wants to come and go as he pleases. That may be good for him but I can't hack it.

I wrote a memo to Alex's psychiatrist, explaining about the new form that I'd already given to the BMH receptionist. IHSS only allowed one week to get it back to them. That's a little tight since I don't really have access to the doctor. But, coincidentially, Dr. Johns, with his two kids in tow, actually passed by me as I was leaving and he was coming to the YMCA. I had his letter in my hand on the way to the post office across the street. I had gone into the Y just to ask my friend to look up his address for me and there he was. Of course, even face to face, when I asked if I could give him the letter, he said "No, I can't take it now." He knows his rights.

To: Jeffrey Johns, MD

Date:

10/29/15
From: Joan Miro, Alex Anderson's mother

Re:

new IHSS papers

Another set of papers for IHSS requiring your signature and acknowledgement, that I gave to Sharon at the reception desk a couple of days ago, were received from IHSS on Monday, 10/26/15. I'm enclosing the information here, too, just to be more certain that you would receive them because I didn't get to BMH until a few minutes before 4:00pm on Tuesday, 10/27 and Sharon looked at me with admonishment, and told me, "The office is closed." I reminded her of the time and asked her what the best way was to get papers to you quickly and she said she would give them to you. The enclosed is another copy of the same papers from IHSS.

I want to tell you why IHSS is sending these additional papers because it may not be clear. The IHSS worker, Ms. Bills, came to our apartment on the 19th of this month and Alex, in an agitated manner, told her he didn't need any caretaking, doesn't want any money, doesn't eat my food and can do everything for himself. As you may have heard, I had slowly lowered the Latuda since I wasn't really sure if the Zyprexa was a CYP3A4 inhibitor/inducer and really couldn't get the info from the Lilly website since it only mentioned CYP3A. He has been running out overnight for 24 hours every 3rd day since he first got Latuda at Herrick at too high a dose.

Back to Ms. Bills: Alex's tense manner indicated to her that he actually might need some help, even though he declined any, and she understood from me that I'm the one who does his laundry, cooks, cleans and gives him the medicine. Since he, as he so stated, doesn't eat my food, and I didn't get into the details of the issue with her in front of him, I want to make it clear that since the Latuda was started in mid- September, albeit erratically, he's now feeling more independent and he *hasn't* been eating my meals as they come off the pan or out of the oven at meal time. It came to my attention that, for other reasons of his own, he is able to eat the food after I freeze it in individual portions, which he then takes out of the freezer whenever he

wants to, (he says he 'put' them there) then leaves the food out to defrost, or places the container in his backpack and takes it with him for whenever he's hungry. This has been a change since the initiation of the Latuda.

Everything else is the same in regard to the "caretaking" that he says he doesn't need. He doesn't do his own laundry, I still do it. He doesn't clean up, I still do. And I still monitor the medicine, unless he leaves for the night, and then he says he takes the meds that I've packed into a strip with one night's medicine for him. I'm not sure if I should be doing that, but I think it's better that he has the medicine with him, rather than not having any to take when he goes out all night. In a way, I feel like I'm supporting his all-nighters by letting him have a one-night's supply, but if he's going out anyway, I would rather he take the meds at the right time and I hope he does. He says he does.

So, the above is what the form they sent me is about: another way to receive IHSS services even though the client is declining. Thank you for your help. They have to receive the forms before Oct 2nd, (this coming Monday) and I can pick them up Monday and drive them over to the IHSS office on Oct 2nd unless you plan to mail them on Friday, Oct, 30th. Sorry for the short notice, but I just received the forms this week.

A recent New York Times article is enclosed. Based on the information, I would like you to lower the Zyprexa a little more before restarting any more Latuda at a lower dose, given the Zyprexa isn't a moderate inhibitor/inducer. I'm not 100% sure since I wasn't able to connect with a Lilli pharmacist.

Friday, October 30, 2015
Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg

Gee, I just received a very nice email reply to my letter from the NIMH:

Thank all of you for setting the record straight!
Inbox
x

Joan Miro
The article in your HEALTH section, "New Approach Advised to Treat Schizophre...
AttachmentsOct 25 (5 days ago)

postmaster@hofstra.edu
Your message to medicine@hofstra.edu couldn't be delivered. medicine wasn't f...
AttachmentsOct 25 (5 days ago)

Joan Miro
Forwarded conversation ---------- From: Joan Miro <joan.miro642...

AttachmentsOct 25 (5 days ago)
NIMH Info <nimhinfo@iqsolutions.com>
10:12 AM (3 hours ago)

to me
Dear Joan:

Thank you for your email and phone call to the National Institute of Mental Health (NIMH). NIMH is part of the National Institutes of Health (NIH), an agency of the U.S. Department of Health and Human Services (HHS). NIMH conducts and supports research on the brain and disorders of mental health.

Thank you for sharing this New York Times article with us. We appreciate your thoughts and input on the schizophrenia study conducted by the Institute. We have forwarded your comments to the appropriate NIMH staff.

We also appreciate learning about your son's story, we can direct you to other organizations with whom you may wish to share it. Please note NIMH does not endorse any organizations or agencies.
National Alliance on Mental Illness (NAMI)
Toll-Free: 1-800-950-6264
Website: www.nami.org

Mental Health America (MHA)
Toll-Free: 1-800-969-6642
Website: www.nmha.org

Schizophrenia and Related Disorders Alliance of America (SARDAA)
Toll-Free: 1-800-423-9432
Website: www.sardaa.org/

We hope this information is helpful. If you have additional questions, please feel free to contact the NIMH Information Resource Center at 1-866-615-6464 or 301-443-4513, or email us again at nimhinfo@nih.gov.

Respectfully,
NIMH Information Resource Center
National Institute of Mental Health
Website: www.nimh.nih.gov
U.S. Department of Health and Human Services
National Institutes of Health

SENSITIVE/CONFIDENTIAL INFORMATION
The information contained in this e-mail is confidential. It is intended only for the addressee(s) identified above. If you are not the addressee(s), or an employee or agent of the addressee(s), please note that any dissemination, distribution, or copying of this communication is strictly prohibited. If you have received this e-mail in error, please notify the sender of the error and then destroy the document. Thank you.

From: Joan Miro [mailto:joan.miro6420@gmail.com]
Sent: Sunday, October 25, 2015 11:03 PM
To: public@nytimes.com
Cc: medicine@hofstra.edu; nimhinfo@nih.gov; NIMHpress@nih.gov; nimhreferral@mail.nih.gov; appi@psych.org
Subject: Thank all of you for setting the record straight!

The article in your HEALTH section, "New Approach Advised to Treat Schizophrenia" by BENEDICT CAREY, OCT. 20, 2015, was very much appreciated and long overdue. As a parent of a 37 year old with this debilitating disease, I'm thrilled to hear that the Hofstra School of Medicine (Thank you Dr. Kane!) has made the effort that can motivate change in clinical behavior so our beloved family members are set free from any more Medicinal Lobotomies. In my 20 years of observing and writing about my son as he is "served" by the mental health system, I have been deeply concerned about this on-going question of why doctors would want to keep doses higher than necessary. And to be succinct, I would have to conclude that physicians have been high-dossing because they think they, themselves, need to serve other groups or organizations, other than the health of their patients.

I would like to share the most recent of my yearly journals with The New York Times because, as my son's first psychiatrist, Henri Montandon, MD, stated: "people have not realized that we have this opportunity to come together and help one another." (p.38) Please feel free to use the information in the document in any way possible that will promote better mental health care.
My hope is that other studies will be done for those who have had the disease longer than 2 years. I have not yet given up the hope necessary to eradicate this horror, and I have faith that Congress will, indeed, soon put it on the front burner.

Sincerely,
Joan Miro
Joan.Miro6420@gmail.com
JoanOfArt44@comcast.net
510-418-8568

P.S. I am interested in doing research on the etiology of schizophrenia, if anyone knows who is working in that area. (p. 19).

Actually, I wasn't expecting any replies to my email from last Monday. So, I was astonished to see, not only a letter thanking me for sending my note, but a list of 3 organizations, 2 of whom I was not even aware of. That was very nice. And, as soon as I finish the laundry, I'm going to send a journal to all 3 of them. In fact, maybe I'll send them the last 5 journals, if I can find them in the cloud.

Tuesday, December 29th, 2015
Zyprexa 30mg, Depacote 1500, Amlodipine ?, Metropolol 50

As of 9pm last night, Alex has been on the 4th floor at Herrick Hospital for exactly one week starting Monday, December 21st. I don't think that things are boding well for Alex. At first it appeared that he might be in good hands when I received a call the very next day from Dr. Robert Dolgoff, who I remembered had given a talk to NAMI a couple of years ago, and went to Harvard so he has to be pretty smart. But, I don't remember his telling me in our phone conversation that he was leaving in a few days and that there was going to be 2 other psychiatrists to replace him until he returned on January 4th. He just told me to call him if I needed to and gave me his office number. He'd already promised to keep the dose at 15mg, and was even willing to add the Depacote that Alex needed so badly, that BMH wouldn't agree to, so I didn't think anything had to be monitored. I was pleased and impressed that he had gotten in touch right away, and wanted to know what I knew, and agreed to put the Depacote back in place. I wasn't prepared for what was to come.

When he first said that he was going to raise the dose to 20mg, I advised him that, although Dr. Fitzpatrick insisted on leaving it at 20, when he discharged Alex in early September, 2014, he presumed that Villa doctors would adjust it downward in due time, but it didn't actually happen until 5 months later, January 2015. I informed him that high doses of Zyprexa were already shown to make him agitated. At 20mg he didn't know who I was and at 30mg he didn't care who I was, even at 27.5, and 40mg put him on the precipice of catatonia. Dr. Dolgoff said he "would leave it at 15 for now." I asked him if he would lower the Zyrexa to 10mg. and referred to the Hofstra Study, to which he replied that he'd think about it. I explained that at 10mg. Alex acted no differently; the only difference was that there was less medicine in his body. I thought that when he said he "would leave it at 15 for now," that meant that he would leave it at 15 for now. However, I was soon to find that he did raise it to 20mg the very next day. He kept it at 15mg on Tuesday night and raised it on Wednesday. To clarify for myself, I made the following list of doses that were administered early on, pertaining to the Zyprexa:

Dec 21st…Monday…Alex admitted at 9pm to the floor and the ER doctor was willing to give him his regular meds right before he left the ER…15mg Zyprexa
Dec 22nd…Tuesday…Dolgoff called in the afternoon consenting to keep the Zyprexa at 15mg
Dec 23rd…Wednesday…Dolgoff raised Zypexa dose to 20mg

Dec 24th…Thursday…I wrote a letter contesting his raising the dose after saying he would not
Dec 25th…Friday…I gave the above-stated letter to Dianne at the front desk and addressed the envelope to both Dolgoff and Fisher, after learning that there was a new doctor, who replaced him, and sent a copy of the letter to Dolgoff's office on MLK Way.

The letter I wrote to Dr. Dolgoff that he would not see until his return next year:

12/25/2015

Robert K. Dolgoff, M.D.
1749 Martin Luther King Jr. Way
Berkeley, CA 94709
Dear Dr. Dolgoff,

I appreciated your calling the first day that my son Alex was admitted to Herrick. When we spoke, you told me you would keep the Zyprexa at 15mg for now, after I protested about raising it, and would consider lowering it to 10 later. And on day 2, before you left for your holiday, you raised it to 20mg. I don't understand. Was it because, "My colleagues would think I had poor clinical judgement?" I put that in quotes because my Kaiser physical medicine doctor said the above to the judge when I took Kaiser to the arbitration table about why they made me wait 4 years, 3 of which in dire pain, before being willing to give me an ortho-surgery consult, after which it was revealed that I needed an immediate laminectomy/fusion in 2011. It sounds like the practice of thinking colleagues are more important than patients, is not limited to medical doctors.

My son's life is at stake. *He* is the patient. And need I remind you that the *patient* is the customer. I've noticed, too often, that doctors have somehow learned to think otherwise, as was revealed by the comment to the judge above. It's just by chance that I am familiar with customer service from more than a buyer's or sales person's perspective, having heard it discussed at almost every family dinner of my growing-up years, since my family owned a women's wear department store, Mirrow's Furs, for 70 plus years. Telling the customer one thing and doing something else would not have been acceptable. "See that lady coming in the door?" I still remember Dad advising me, when I did my co-op experience there as a design student at Drexel. "She's your paycheck! Find out what she thinks she wants, and give her what she really needs."

If you read the *New York Times* article (I left ½ dozen with Dianne) published on October 20th, 2015, regarding the Hofstra study that would come out the following day in *The American Journal of Psychiatry*—funded by the National Institute of Mental Health—it states that the study…"call(s) that approach into question." What approach?: Using "strong doses of antipsychotic drugs…" More specifically, "In the new study, doctors used the medications as part of a package of treatments and worked to keep the doses as low as possible—in some cases 50 percent lower—minimizing their bad effects."

20mg of Zyprexa was the highest dose that Elli Lilly researched, as related to me in 1997 by Fillipe, one of Lilly's pharmacists. Therefore, one would think that 20mg. would be the highest dose allowed to be used. Not so. It is even used at higher doses by psychiatrists who are apparently allowed to do their own research? At 30mg. I've seen my son severely agitated and at 40mg. practically catatonic. He sat immobilized on his bed at John George Psychiatric Pavilion after a Dr. David Tomasini, MD incapacitated him with 40mg in November, 2008. And Alex couldn't move for a week,

even to go to meals, after being transferred to Villa the following month, his nurse at Villa told me, until a more compassionate phychiatrist, Dr. Lawrence Novis, MD lowered it again at my request.

You noticed, I heard you say on Tuesday, that I have left a few journals at Herrick over the years, but I've actually been documenting my observations about my son and the 'help' he's been getting since 1996. There are 20 journals now written. It's been 20 years of this "revolving door" treatment. The revolving door, a quote by a Dr. Wright, MD and attorney, at John George: "He'll be back." So, it appears that psychiatrists know that the medicines don't work. Therefore, do they raise them to the highest so the patient will be quiet? Because incapacitating them is better for who? The neighbors? The doctors? But, I repeat, the *patient* is the customer!

He only asked me to call the paramedics to be seen by a doctor because his back hurt. Dr. Johns at Berkeley Mental Health said he was waiting for the Latuda to get completely out of his system in 6 months, before he would lower the Zyprexa to 10mg. So, I don't understand why the doctor in the Alta Bates emergency room turned it into a psych admit because the back x-ray didn't show anything. She was about to send him home with pain meds, before I arrived in the ER to inform her that I really needed him to be checked medically for an abscess because he was diagnosed with 3 abscessed teeth in April and the dentist said the infection would spread. In addition to that, the underside of my shower chair was dirty and I didn't know he was taking a bath so I thought the back pain might be from an anal abscess. Everyone knows people have back pain due to a multitude of reasons. I believe he's in back pain. He looks like he's experiencing back pain even though he's walking. He's in pain. And it's not in his head. He told me that again last night on the ward. My own laminectomy wasn't performed after seeing anything on an x-ray. A cat-scan and MRI were taken. And the Stanford graduated physical doctor wasn't motivated to get the appropriate pictures taken just because I begged to see a surgeon. She wasn't motivated until I sent her the message: "I thought torture went out of fashion with Guantanamo." I don't know why that did it, but that taught me that I have to be more aggressive to get doctors to pay attention because, as Kaiser's attorney, Mr. Anthony, declared: "She's a Stanford graduated doctor!" I only imagine he was implying that she has to be right because she went to a well-respected university. That may often be the case, but I think the parent also has to be respected for what they know about and have done for their child after observing and caring for him most, if not all of his life.

I want to meet with you and whoever else is interested in discussing Alex's case. He was best on 10mg Abilify, 17.5mg Zyprexa and 100 Clozapine back in March, 2007 and Dr. Richard Slawsky was able to discharge him from John George after only a week there. But, at that time he refused blood draws for the Clozapine after discharge and only consented to them in November of 2009, so he could come home to live. On April 30th, 2009 when he was discharged from Villa, I told him he couldn't come home unless he got the blood draws and stayed on Clozapine. He thought about it for several months in a board and care and begged to come home that November. All was well for a few years until something bad happened at John George again, where they took him off the Clozapine for more than 3 days and started him on a high dose 150mg on day 4 instead of starting over at (the recommended) 25mg per the pharmaceutical manufacturer. He was having heart problems after that so he didn't want Clozapine again.

I would hope you would incorporate a *low* dose of another medicine—not particularly Latuda— in the plan, once Alex is on 10mg of Zyprexa. The background (from my journal) of his Latuda initiation is as follows:

Monday, September 21st, 2015
Zyprexa 15mg; Metoprolol 50mg; Amlodipine 10mg; Omega-3 Ethyl Esters 1gm cap (fish oil); Latuda 80mg. (p. 35/36)

Oddly, but in keeping with the nature of the Mental Health System, Alex's discharge order was written the very same day as the first dose of the new medicine, Latuda, was administered, Monday, September 21st, 2015. How do I know this? I received a phone message on that same Monday, from Case Manager Alberto Flores, at BMH, stating that Herrick's social worker, Katherine, had called him so he wanted to call me "to talk about Alex's discharge." I ignored it, thinking he had heard wrongly, because I knew the 80mg of Latuda had just been started a few hours before he called that same Monday, so any discharge would be unlikely, because Dr. Compton would want to watch her patient's reaction to it for at least a week to see how it was working and then decide whether to adjust it or discontinue it. I have to apologize for my inability to understand the doctor's logic. Apparently, since she lowered the 20mg of Zyprexa to 15mg on Friday the 18th, after talking to me, she thought he was well enough to go home (surprise!) even without the Latuda so she didn't need to follow up and monitor the Latuda.

It wasn't until a week after Dr. Compton's starting him on twice the recommended starting dose that I researched the Sunovion Pharmaceuticals' website to find that 80mg *was* twice the recommended dose. I looked it up because Alex had become so angry and agitated. I don't know why I believed that she was going to do what was in his best interest. I had asked for a low dose of a new med and she gave him the new med, but a high dose. 80mg is the highest dose that the FDA recommends. I didn't need to tell Dr. Lal at the John George ER, a recent Johns Hopkins graduate, that it was too much, because she told me first, when I arrived to pick him up from the ER where the police had determined that he needed to be, when they found him on the street after one of his overnight run-aways. After the Latuda was started on the higher dose, that Monday in September, and even on the 40mg, he continued to run away approximately every 3rd or 4th day, leaving in the afternoon and returning 24 hours later. This went on for about a month and a half before I cut the 40mg pill in half and then finally stopped it altogether. That was very scary. He hasn't run away overnight since. Altogether, 12 runaways. I got the feeling the police were ready to arrest me for bothering them so much, so I stopped calling them and just waited and prayed. Independence is not what it's cracked up to be, not when you're mentally ill with schizophrenia.
I look forward to hearing from you about a prospective meeting before any more medicine changes occur. Something needs to be done about his dental abscesses. They were identified and not treated since September, 2014. That certainly could cause back pain if the infection went to, e.g., his kidneys. It's been 20 years and he's no better because no one doctor has taken care of him during the whole time. I would like to be on his team to get him better. I'm sure he is physically hurting even though he may not be able to verbalize accurately what it is. I hope the physical issues, possibly caused by the dental abscesses, won't be overlooked while he is in your facility, because you have everything necessary in order to get them taken care of. He's feeling physically ill because he is physically ill.

Sincerely,
Joan Miro 510-418-8568 2736 Grant St Berkeley, CA 94703 JoanOfArt44@comcast.net

I also enclosed pages 197-206 from this 2015 journal to give him information about the Latuda because I told him it didn't help, that it made him agitated. I've been told by the various nurses who I asked that they didn't restart him on the Latuda. Thank G-d for small favors.

Is it still December 29th? I wrote the above at 5am and now it's 11pm, so I guess it is still Tuesday. What I didn't write is that the new psychiatrist, Dr. Trautner called at 9am, because he apparently heard that I pitched a fit at the end of visiting hour, as soon as I was told that there was another psychiatrist who raised the dose to 30mg. I had asked Patti to let me speak with the nurse manager, after Patti told me the dose. After explaining what I wanted to the manager—for her to call the doctor so I could speak to him—she immediately told me to

leave—"Get out!!"— rather than answering my request in a reasonable tone or with a reasonable explanation. I wanted an opportunity to talk to him before they would administer the higher dose of 30mg in another hour, because I was obviously the only person who knew that 30mg would be detrimental to Alex. They don't have the information in their own notes and they apparently don't communicate with other non-Alta-Bates facilities. I knew the doctor had to have a phone so he could be reached in emergencies. And this was an emergency! Not only did the medicine get turned up the 5mg by Dr. Dolgoff, but his third replacement raised it another 10 notches to 30mg after I had only a few days ago complained in a letter to Dr. Dolgoff that he, Dolgoff, wasn't doing what he said he would do…keep the Zyprexa at 15mg! Kessler, MD, his second replacement, must have read Dolgoff's notes and kept everything the same, but apparently not Dr. Trautner. Of course their raising or lowering doses is not illegal. They're the doctors. It's just immoral because they are doing it *without knowledge* of what went on before in other facilities when the dose had been raised to 30mg. Why does the patient have to suffer because the doctor chooses not to know? I guess Dr. Troutner has his own ideas because he went to medical school so he thinks he can do to my son what has already been done and didn't help. Why didn't he didn't call me first to find out that 30mg would be harmful? He apparently didn't even read that 30mg wasn't to be used at this time…or EVER#!!#! He finally did call me at 9am after the higher dose was administered the night before. I had just gone back to sleep at 8am so I wasn't too coherent and my phone wasn't either because it shut down, but he called again, interested enough to find out why I had pitched a fit last night about the upward turn of events.

I didn't take notes so I don't really remember what I said to him because he seemed to be doing most of the talking until I said that I needed to tell him why the 30mg dose is too high: because it was already used on Alex at least a couple of times before. Early on in the first decade, some outside doctor turned it up to 30 and Alex was very annoyed, angry and frustrated. Then at John George and Villa in 2008 and 2009 the same thing happened, and the same result was achieved: Agitation! Anguish! Frustration! I do remember saying that if he goes a little higher than 30, Alex will be catatonic again. He asked me if I were a physician. I replied that I was not but if I had wanted a PhD, I certainly could have opted for it with over 200 semester hours of classes past my teaching credential. He said that I sounded knowledgeable. What I didn't say was that I wouldn't want to have 'Dr.' in front of my name because then I would be part of the problem! Why didn't he call me BEFORE he raised the dose? Why didn't Dr. Dolgoff tell me that there would be 2 psychiatrists replacing him that wouldn't read the notes I would presume Dr. Dolgoff left for them to read? Why wouldn't Dr. Fisher have given the next doctor the letter and journal that I left for both Fisher and Dolgoff to read? Why did he think he can play G-d and do whatever he wants to do to my son—without doing the proper research—when what he wants to do has already been done…with bad consequences. Why do we have to go through the same thing repeatedly? What's his rush to go in and do *anything different* without knowing what's been done before? He said, Dr. Trautner, that he could give Alex another medicine that would reduce or take away the Acathesia that I said Dr. Fitzpatrick said he might get at doses over 20mg. Why would I want Alex to get yet another pill to eliminate a disturbing side effect just so Dr. Trautner could raise the dose further when I already saw that raising it is not going to help Alex. It would harm him, making him more agitated. I told him, "I don't want my son to suffer," alluding to what higher doses do to his brain. He repeated, "I don't want him to suffer either."

In retrospect, not having gone into this much detail and not wanting to argue on the phone, I would/should have said: Why didn't you talk to me first if you don't know that he already had been given 30mg, and 30mg didn't help him? It produced agitation and frustration. Didn't you just say you didn't want him to suffer? Well, suffer he will, if he already suffered the first and second time that he took 30mg of Zyprexa. You just don't know that he did suffer, and that the doctors had to start over at a lower dose, because you don't have access to the records at John George or those of the other psychiatrist in 1998. And you don't have access to what happened after Dr. Connor raised the dose to 30mg and discharged Alex in 2013 after which he couldn't do anything.

It's not going to be any different this time. If you don't know, you're supposed to ask!!!!!!!!!!!!!!!!!!!!!! Just because it's not in your chart at Herrick, that doesn't mean he hasn't already had 30mg. You know he's been at other hospitals in the last 20 years. You know he has a doctor in the community. Ask BMH. Any intelligent person who has completed years of schooling is supposed to have learned how to *ask*: "Has he ever been on 30mg? Do you know? What effect did that dose have?" If you don't have time or inclination to do that, then don't change the dose until you have the necessary time to do the homework!!!! And who does one ask? Well, you could call the other hospitals. Or you could call the BMH physician. Or you could ask someone who lives with him who has been observing and documenting what medicines he's taken and how they have affected him for 20 years!!!! And I'm always available by phone. After 60 years of taking all kinds of classes, including a half dozen in psychology, I've learned that *asking* is the difference between being a good student and a poor student. Communicating with the family who knows your patient, so you can get all the information you need to make better decisions for your patient is necessary, before you do any damage. He doesn't need a repetition of what didn't work before.

But I didn't say all of that to Dr. Trautner, because he decided somewhere along the line that he'd had enough conversation, and if he couldn't be the one to make the judgements on his own, based on what *he* saw and had access to, in order to do what *he* wanted to do, whether the patient had already been subjected to that medicine before or not! because *he* was the doctor, (blimp imprinted in big letters: "EGO," seen in sky) then he would reduce the dose to 15mg and discharge the patient even though the patient had other needs that Dr. Trautner didn't even know (or care) about.

Come on people! As Henri Montandon, MD, Ph.D., has already stated (p. 38): "…we have this opportunity to come together and help one another…" so I would hope, too, that not only *psychiatrists*, and *organizations* who support clinicians dealing with the mentally ill, but the *colleges and universities* who teach future clinicians, and *political incumbents* who represent the people, as well as organizations like NAMI, who support the family, should all come to the table on a more frequent and on-going basis, to delve into the issues that would help the mentally ill to recover, because ***"…people have not realized that we have this opportunity to come together and help one another."***

Wednesday, December 30th, 2015
Omega-3 Ethyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg, Benztropine 1mg am, 1mg pm.

Dr. Trautner called in the morning to let me know that "You can pick him up any time you like. His back pain is gone." he said. "I talked to Alberto Flores, the case manager at BMH, and we concluded that he's at his base line."
I said, "No doctor has been interested in the whole picture. Although you said 'I don't want him to suffer either,' not helping him to get the infection out of his body is making him suffer." He needs to go to UCSF or Highland where they can remove the teeth that are infecting the rest of his body for over a year now. That may be why his back hurt to begin with. The infection could have gone to the bladder or the kidney. I wouldn't be surprised. "I would like you to get an ambulance to take him where he needs to go."
He said that they only deal with psychiatric issues. "Herrick won't do that." I say, what happens if the mind is connected to the body? A mind/body connection isn't exactly new news.
I didn't get a chance to tell him that I had only 2 days earlier consulted with an oral surgeon, Dr. Knowles, DDS, MD, in Alameda whom Dr. Sharma, DDS, had referred Alex to on October 7th, last year, but Villa wouldn't/couldn't deal with his dental needs either, while they detained him in their facility from the beginning of September, 2014 until April 14th, 2015. Dr. Knowles told me that Highland or University of the Pacific only required 2 doctors' signatures attesting to the fact that the patient was unable to make his own decisions in order to do the oral surgery.

None of the doctors have been interested in seeing the big picture so that Alex could be properly helped. There wasn't time to explain all of this on the phone to either Dolgoff or Trautner. But, if, as Trautner said, it's true that he doesn't "want him to suffer…," the only way he won't is if doctors acknowledge that the brain, teeth and the rest of the bodily organs are all one entity, with one organ having the potential to have an effect on another, and therefore, call in or send the patient out to, other specialists when necessary to prevent the patient from suffering needlessly. His dental health has caused his physical health to beg me to take him to the emergency room. His physical health, "a broken back," according to Alex, with no findings on the x ray to support that claim, then caused him to be admitted to mental health. The ER doctor had to know that his "broken back" symptom, simply meant "my back *feels* like it's broken because it hurts so much that this is what broken must feel like, but I don't really know if it's *broken* because I didn't go to medical school. I'm just telling you that it hurts so badly that I couldn't get out of bed to even go to the bathroom," so it feels like it must be broken. The ER doctor used Alex's own misdiagnoses of "broken back," to admit him illegally to the psych ward.

On the other hand, if only because Dr. Dolgoff was willing to re-prescribe the Depacote, the admission was worth-while. Because I don't want another situation to transpire whereby 2 men in a truck, who stopped to ask Alex for directions, and thought Alex was ridiculing them: "You laughin' at me?" and were about to get out of their truck and beat him up, when I overheard and intervened. But, BMH did not want to start the Depacote again, saying that he had refused the quarterly blood test, even though I asked them to resume it on more than several occasions. I spoke to Alex about it yesterday and he said he "couldn't have the big needle. That hurt too much. But if it was like a small prick on the finger…" it might be do-able. So, it's all about how you talk to the patient.

The doses in the hospital toward the end of his stay were the following:
Dec 28th…30mg Zyprexa
Dec 29th…15mg Zyprexa…Nurse tells me Alex said he "doesn't know that woman" when she tells him she's on the phone with his mother. This is the day after he got the 30mg Zyprexa.
Dec 30th…15mg Zyprexa…I picked Alex up and he walked while I drove home, meeting him at home at the same moment. He jumped into the shower singing and making noises that sounded like he was riding a bronco or perhaps just thrilled to be home.
Dec 31st…15 mg Zyprexa…Alex is home, eating well, sleeping later than 7am, talking and happy and leaves around 2pm to go downtown near campus for a few hours to celebrate the new year.

Except for the fact that he's still laughing too much, he is feeling better. The nurse, the day after he got the higher dose of 30mg of Zyprexa, related to me on the phone that when she mentioned to him something about his mother, he replied that he "doesn't know that woman." And that's what he always says at 20mg or above. Yet, since I picked him up yesterday on the lower dose of 15mg, he's already called me "Mom" a few times. It's important to me that he knows who I am especially if I am living with him. At 30mg. he was always too agitated/angry/frustrated, just like when he took the high dose of the new medicine, Latuda, more recently. That was medicine that created an Alex at his most agitated:

> It was earlier in the morning that he had freaked out. I don't know what to blame it on except the Latuda. I mean, I could blame it on *myself*, because I *did* turn the stove on, after he directed me not to "cook," but, no, I've done that before and he never did what he did this time. Normally, I just tell him, "It'll just take a couple of minutes to heat up the water. I want some tea." And, he always says OK, I'll wait. I had already finished eating breakfast, when he'd come into the kitchen telling me not to cook or turn on the faucet, because he needed to meditate. What's this? I thought. I'm already used to his telling me he doesn't want cooking aromas when he meditates, but not being able to run the water in the faucet was new. "Don't use the bathroom either," he said. I protested, "No, no, what's all that about?" After he went to his room, I turned the fire on under the kettle and in a minute he came back to the kitchen. "I told you not to cook!" he yelled looking fanatical at me, picking up the hot pot and throwing it into the sink. "I need to meditate; I already told you! So, why are you cooking?!" he screamed uncontrollably, as he picked up the burners one at a time, shrieking "Don't cook, when I tell you not to cook!!" and threw them against the wall and the kitchen table, somehow missing the vases and other paraphernalia I keep there. That was a blessing. The only thing that stopped him were the words "I'm going to call the *police* if you don't stop!" that seemed to

come from my mouth. I'm not really sure because I was so upset by the unusual and violent behavior. And actually, my upstairs neighbor, Wesley, was sitting outside on the step right next to my open kitchen window, he told me afterwards, and heard it all. He said that he didn't know what to do so he decided to do nothing. But, hearing the word, "police" made Alex sit up and take notice. That is, he actually noticed what he was doing and said out loud but to himself: "What's wrong with me? I usually can control my anger; I don't know what happened." I think I know what was different, that is, what happened. Too much Latuda, from the initial high doses for over a week and all the changes in dosage, were taking its toll. I didn't give him any more today, Thursday, the day after he ran; he just took the other meds. But, he said he did take it yesterday, that is, he took the meds that I had put into his bag, when I reminded him to on Ashby.

Today I called the FDA and spoke to Maria, a very helpful customer service representative who gave me the following information: She said to call 888-394-7377 customer service at Sunovion for the info about the CYP3A4 inducer/inhibitor. "As far as the aggressive behavior that you're describing, you could fill out a medwatch report to let them know" about the effect the Latuda had on his behavior. "It's on the FDA website…As far as the hospital giving him the wrong dose and discharging him too soon, if they are not taking enough care of him in the hospital, contact the Medical Board of CA, Consumer Information unit: 800-633-2322…To check out Latuda, go to www.dailymed.nlm.nih.gov." Maria said that "the recommended starting dose from the drug company that we have approved is 40mg. It's been shown to be effective from 40mg to 120mg, but there's no proof (as evidenced from the 6 week trial) that there was any greater benefit at more than 80; there was more risk than benefit."

We are both endangered when Alex is under the influence of too much medicine. *He* with his high blood pressure and *me* being at his mercy. I wonder that there is not a way for every hospital in Alameda County, to provide access to a specific website in order to share information *BETWEEN* hospitals, just like Kaiser facilities are able to share information between other Kaiser facilities across the state. What's the difference? I would imagine that plenty of people, if asked, would give permission for their information to be shared between unrelated hospitals, if they frequently enough find themselves at more than one hospital, as they may if they're not on a Medicare Advantage plan. As I concluded in last year's journal:

Information Sharing

And what about the sharing of information between facilities? Why is information only made available to the particular hospital in which the patient resides for that particular period of time? with the exception of a brief discharge summary faxed from the previous hospital. The patients, themselves, should be the focus of the information retrieval system within each state or county. When they leave that state, they can always take their CDs or print-outs with. But, while a patient is in any county, given that we are now in a new state of affairs with internet availability, a telecommunications method should be set up whereby each patient's information retrieval system could be made available on the cloud to every facility, no matter what facility the patient is presently in. If banks can keep their information from hackers, than there has to be a way for hospitals to keep their information safe as well, only to be shared with cooperating facilities within some predetermined bounds. Steve Case, co-founder and former CEO of AOL says "innovation is collaboration." That should just as well apply to health care where "partnerships, engagements on the policy level, and perseverance" are the groundwork to make excellent healthcare happen. "If you want to go quickly, you go it alone; if you want to go far, you need a partnership," he said on Washington Ideas Forum recorded by C-Span. (pp 122-123)

If there is no access to needed information, and hospitals are going to put the burden of providing information to physicians on the back of the family—because the family is the only group of people who know the patient intimately—then physicians need to ask the family for what information they need, like Dr. Dolgoff did, *before* they do to their patient what has already been proven to be harmful. "DO NO HARM!"

I've written about this same issue regarding talking to the family for several years and in several different journals. The following is from last year's *Journal #19*. (p. 120 of 2014/15)

> There simply has to be a law that makes doctors own up to what their plans are, and have to talk to the parent about their intentions and get information from the family member who has the information. And they should have to be responsible to get all the information about their patient from whatever sources are available. And that means the parent, if their patient lives with the parent at any point in time, *especially if there is no sharing of information between facilities.* They shouldn't have the privilege to do whatever they want to our children, especially when they haven't worked with the patient before, and don't know his or her history. They don't know what medicines at what doses have helped and what hasn't. There's no way she (Dr. Dovale) could have known whether to go up or down on the Zyprexa and that's why she didn't go up or down on her own. She just left him alone like her predecessor, Freeman, M.D., left his meds alone. She could only judge by what he looks like, says and does. She might just as likely have increased the Zyprexa to try to get him out of the almost psychotic state that 20mg put him in. You just can't tell from looking if it's too much or too little. The only thing one can conclude is that he's not OK at that dose.
>
> Only the mother, who was also the caretaker, knows from all the times before, that less was better and that higher doses were bad. I had to negotiate with his BMH psychiatrist, Dr. Tran, to get him down to 10mg. only by reducing it by 2.5mg. every 3 months, because that's how she insisted it would have to be lowered. And I insisted on lowering it, because he wasn't so great on the higher doses. He wasn't so human, so alive or so communicative at any dose above 15mg. *The higher doses of Zyprexa were as devastating as the disease itself*, and affected him noticeably. *He couldn't take a shower for almost two years, from the time of discharge on 30mg. from Herrick in January, 2013 until mid 2014, when I was able to get the dose back to 15mg.* And what did Dr. Tran say about that? "Well, they take too many showers in America…" Tran would normalize whatever I said that Alex was doing. If he were dressing weirdly, she would counter with, "Yes, I know. My sister-in-law is always complaining about how my brother dresses, too." Never-the-less, it was worth reducing it, just to see how low we could go, so he might actually be able to *think*. Why do psychiatrists want to go high? I mean, what motivates them? These medicines affect the brain. Do they want people to be sick from the medicine as well as from the disease? I really wonder what their intentions are for going up on meds. Dr. Connor at Herrick, took it right up to 30mg and thought Alex was OK. He most certainly wasn't. Then Alex was discharged from Herrick. Collins didn't see how Alex was for that whole year and a half thereafter: easy to anger, agitated, not taking showers, not brushing his teeth, not eating well, not writing, not walking, not jogging, not talking much, until he was down to the 17.5mg. He couldn't even watch TV! He simply could not focus on anything but the movies in his head. And Dr. Tran at BMH wouldn't agree to lower the meds more frequently than 2.5mg every three months! It was hell to live with him! And Thomasini, M.D., at John George even went higher with the Zyprexa…to 40mg. so Alex couldn't even talk or move. He was just short of catatonic, but not quite as bad as the Haldol overdose at

this same Villa 17 years ago, thanks to Economy, M.D. and Segalove,M.D. On that combination of Haldol, Prolyxin, Zyprexa and Cogentin he was actually diagnosed as catatonic in the Kaiser Hayward ER! Those psychiatrists hurt not only his brain, but his body, and were able to get away with their crimes.

Doctors' intentions should be investigated. The colleges where psychiatry is taught, should be investigated. What do professors teach? Do they even discuss with their students how doctors are supposed to get the best information, the most accurate information, before making decisions about people's lives? Are they taught the importance, the necessity for getting the information? Or do they tell them just to wing it as many doctors are doing; or do they recommend that physicians collaborate with the people who know the patient? I mean, is doctor/family/patient collaboration important enough to even be discussed in the university classroom setting?

I wrote to Brenden who went out of town for the weekend.

ME

Guess what! I had to stop everything and say a prayer at dinner last night when Alex actually sat down on a dining room chair and ate dinner with me eyeball to eyeball. In addition to that, he has been addressing me as 'Mom" without thinking about it first and is talking about things in the here and now more, so he seems to be connected better. Maybe it's the addition of the new bi-polar med that he used to have that BMH wouldn't start again. And one of the docs prescribed another med, Benztropine, that I only found out about when I was handed the prescriptions at discharge. That one is new. Don't know about it. Have to find out.

When I told Alex that I was invited to a friend's house on New Year's Eve, he asked me to keep him company, instead. Brynn said she was having a few other people, and they're probably just doing what we were doing anyway, watching TV and talking, so I stayed home. He hasn't watched TV at all for several months because he's been so preoccupied (right after getting out of Villa, just a few months after I bought him a new TV). So, even though Alex's newest physician, Dr.Troutner, started the 30mg without either consulting me or reading Dolgoff's notes, and the nurse manager refused my request to call him before it was time to give the increased dose and instead called security to escort me out, something went right at Herrick. It has to be the additional new medications, so I'm grateful to Dr. Dolgoff for insisting on the Depacote even after I told him BMH wouldn't start it again because they couldn't get Alex to consent to blood tests, according to Nurse Peggy.

BRENDEN

Wow! That sounds awesome. Hopefully you can figure out the balance and keep it up. So, they finally put him back on Depacote? That's good. Glad to hear he is doing better. I hope you're feeling better too.

Now that I've researched the Benztropine, I'm not sure of its benefit, since it's apparently a generic of Cogentin, one of the medicines in the cocktail at Villa on May 7th, 1997, when Dr. Economy, with Director Segalove's permission, tried taking him off the, then, new med, Zyprexa, in order to put him back on Haldol, for their own benefit. Alex had been started on Zyprexa originally at Alta Bates in early 1997,

and Villa's decision to take him off the Zyprexa, soon after he was transferred there, in order to put him back on Haldol, put him in a coma, instead, for 10 days. (The addition of Haldol without first reducing the Zyprexa, Cogentin and Resperidol caused the overdose.)

I hope the New Year brings more sense to the way hospitals handle getting the important information about patients and try to get both past and current information from *wherever they need to get it* in a timely manner, so mistakes aren't repeated and patients don't have to be put through the same traumas as they had to suffer the first time.

Monday, January 5th, 2016
Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg; Benztropine MES 2mg; Depacote 1500mg.

Things are continuing to improve with the 2 additional medicines. The uncontrollable laughing is diminishing in both frequency and duration. His demeanor is pleasant almost always. Since discharge New Year's Eve, on the 15mg Zyprexa, plus 1500 Depacote and 2mg Benztropine MES, he's still sitting down on a chair at the dining room table. Tonight we really had a nice dinner. He talked. He stayed a little longer at the table even though dinner was over. It was no longer like feeding the animals. He ate everything and had a second portion of macaroni and cheese. It was the first time we actually had a conversation in a long while.

At night, Alex took another blanket from my room to keep warmer. He'd been sleeping only with one blanket that he "bought" for himself, he told me, and had been refusing to use a second one, so I would have to sneak another cover on him after he fell asleep. He often enough let me know that I wasn't allowed to do that, but I would tell him that he was too cold, so I would anyway. I had to; it was my job. He insisted that he wasn't allowed to have more than one blanket, (according to whoever has command of him.) But, tonight I went into his room and commented that he must be feeling better if he's decided on his own to stay warm at night. He didn't reply, but he heard me and understood what I meant. So, things are looking up.

The voices now allow him to watch TV, and he did watch again, even though I had to leave after dinner for a little shopping. He's taking the medicine on time, although he complained that one of the white pills is "scratching his foot," so he instructed me to "get new medicines." He wouldn't tell me if it was the foot with the sore on it. He still needs to see a general practitioner.

Alex still refuses to brush his teeth at night, but does do it in the morning. This is as good as it gets with these medicines at these doses. Hopefully, a very low dose of one or two new medicines, different medicines, as the Hofstra study suggests—maybe 50% lower than the

starting dose originally recommended by the manufacturer—could be used to give Alex more motivation for doing more activities, like Depacote enabled him to laugh less, watch TV more, keep warm at night, take more frequent showers, and use a tooth brush in the morning.

What if the benefits of individual antipsychotic medicines could be tapped into, at doses 50% to 75% less than what pharmaceutical companies have been recommending up 'till now? Could manufacturers not have a personal reason for recommending higher doses? Are they not taking in more money by simply selling more medicine? I'm hopeful that by reducing doses of antipsychotics, my son will be released from their grasp, a bondage that doesn't allow him to get into a car, bus, train or plane, thus, isolating him in his room; that didn't allow him to take showers for almost 2 years, go into the YMCA, go out to dinner, sit down at our dining room table, go to school, make friends; and won't enable him to have a conversation about anything other than his invented stories put into his head apparently by the Greek Gods.

With lower doses…new medicines…who knows? Maybe patients will be able to experience a more colorful panorama of the world and be able to find their places in it. Perhaps more medicines and newer psychotropic medicines at lower doses than now recommended will do the job needed to make possible consumers' better functioning in the real world. We have to keep in mind that *patients* are the customers, not clinical staff, pharmaceutical manufacturers, psychiatrists, police, social workers or parents. The part played by others is to do their jobs to facilitate patient recovery. To reiterate Dr. Henri Montandon's hope for working to achieve recovery: ***"…people have not realized that we have this opportunity to come together and help one another."***

Are we going to take this opportunity now, before it eludes us, or continue along this dead-end path holding the severely mentally ill hostage forever? Are we going to make up our minds to ***stop abusing the mentally ill*** by ignoring their ***need for medicines that work*** well enough so they can have decent lives in normal communities? Are we going to ***stop blaming and ignoring the mentally ill*** for being mentally ill? Are we going to ***discover the causes*** of mental illness in order to research intelligent, appropriate cures? Are we going to ***end isolation*** by creating clean, well designed, activity-focused housing and other community groups that are age appropriate? Are we going to ***share information*** within counties or states so that bad outcomes at hospitals don't have to be incessantly repeated? Are we going to ***make it mandatory for doctors to get information from the parent*** when they don't have current information about their patient in their own chart or can't get it from other hospitals? Are we going to ***fund research*** on a national level that can accomplish all of the above? I hope so, because only then is recovery possible.

Tuesday, January 19th, 2016

Alex is in the hospital again. Yesterday, he ran out of here as I came home from the laundromat at 5pm to check on him and put dinner together before returning to the laundromat again, to put the clothes into the dryer. He never came back. I wasn't thinking that he wouldn't come back until I saw he wasn't home after I finally got home at 6:30. He's usually home at 5 or 6, but before 7pm at the very latest, getting his last smoke in the back. So, I start getting anxious at 6:30pm. I couldn't call the police because they'd already informed me that I call too many times. With the Latuda, he had run away a dozen times, but would return before 24 hours. So, I waited and just texted Brenden:

ME

Monday, January 18th.

Did you come over tonight and take Alex out? He's not home yet. I stopped home at 5:00 between washing and drying and he went outside then. Is he with you? He didn't say anything, just left as I came in from the laundromat.

Are you there? Is this going to be an all nighter?

BRENDEN

No, I did not come by. I am at a game right now.

ME

OK, I guess he's tired of being alone.

Can you stop here after the game? Is it in Berkeley?

BRENDEN

It's in Oakland. I'll call you when done to see how things are.

ME

Did you forget me?

BRENDEN

I called and txt you. What's up now? I'll call you.

Tuesday, Jan. 19th.
Hi Mom. Is Alex Back? He must be, with this rain.

ME

He never came home. I'm going to call Alta Bates ER. Maybe he went there.

BRENDEN

OK, let me know if you need me to come over. That is crazy. He was out all nite.

ME

He did go there and he's at Herrick now she said.

BRENDEN

Wow. I guess that is good news. Wonder why he went there instead of home.
Did you check there last nite? I guess that is always a good place to check.
At least he is not out in the weather. Hopefully they don't over medicate him. But they probably think he needs more if he keeps coming back to the hospital.

ME

I don't want to 'hope'. We need to go there today when the doctor is in and have a presence. When are you available?

BRENDEN

Sorry just seeing this. I wld just need to take off work. Maybe like 2:30.

I went to the printer to update the doctor with the latest information and went home again to get the meds then spent around 3 hours sitting in the hall outside the unit waiting for the psychiatrist to appear. Dr Stanger, Dianne, the receptionist on 4E, told me was his name. I wasn't about to wait 3 or 4 days before talking to him like I had to do with Compton, Fitzpatrick or Connor. She must have told him I was in the hall and he came out to let me know he would talk to me after he asked Alex if he could. I said, "Someone else already said you could talk to me." He wasn't impressed, as evidenced by the fact that he ignored my comment, and went inside to see Alex and do other things. I hoped he'd talk to us at the end of his shift because I didn't want Brenden to have to leave work early. I wanted to tell the doctor what Alex has been up to. Luckily he was one who apparently worked afternoons and Brenden arrived before 5pm just as Dr. Stanger came out to get me. He looked a little put off when he saw Brenden; somehow men are more threatening. None-the-less, we all went into the unit, but Alex refused to join us. He couldn't be talked into going into the small meeting room, although Stanger was trying to talk him into coming in to the meeting. He was really off kilter, telling the doctor a little too arrogantly that he didn't have to come in to talk to him. He went off about the "lava" and the "children" and a bunch of his other stuff that this new doctor had not yet heard.

It was just because he hadn't had any meds last night or probably in the morning either, because the doctor assigned to him didn't arrive until afternoon. I don't understand why the ER doctor doesn't have to give him the meds when they have a record of what he took last time and not too long ago. Patti told me he did get some in the morning, but they wouldn't have given him the Zyprexa, because he takes it at night. Therefore, he wouldn't have had any Zyprexa for 48 hours. Of course he was psychotic. Dr. Stanger looked more shocked than simply surprised that Alex sounded the very definition of psychotic. He talked back to the doctor very aggressively about the volcanoes and the lava and the space ships. Everything! He was not able to come into the little room because he had more urgent things to take care of, he said. The doctor didn't insist; he just wanted to see what he was dealing with.

The room was closet like, with a few chairs set up against the walls, and the 3 of us went in. Brenden and I walked around the computer that was already set up on a small table with wheels, and Stanger sat right down to blast away at the keyboard about what he had just seen and heard. We weren't a part of the process. He looked up at me only when he needed to fill in a word to finish a sentence authentically, about what Alex said or did under the influence of a certain medicine. I was allowed to reply with only that answer, "He was comatose on May 7th, 1997 at Villa Fairmont on a combination of Haldol, Cogentin, Zyprexa and Resperidol…for 10 days." He would rebut if he thought my assertion was incorrect: "Comatose?"
"Well, maybe it was catatonic. It was a sitting-up coma. He couldn't move anything but his eyeballs. If you put his hand up, it would…" He cut me off, and looked down at the typed page again, fingers blasting away. Dr. Stanger wanted information from me, but only when he was ready to process that particular piece of business that he wanted to put on the page. So, I was just helping him do his report. When I started talking about Alex having back pain on the last admission, potentially because of an abscessed tooth, he looked at me crazy-like. So, I continued to try to explain how I knew it could be possible—that the infection went to his kidney or bladder, potentially causing the back

pain—because of my own headaches that were caused by an infected tooth. He had had enough and glared at me yelling between clenched teeth: "I don't care about your headaches!" Hmm, another caring psychiatrist, I couldn't help thinking. So, Brenden and I learned fairly quickly to keep quiet while the leader typed and to wait until he asked a specific question. Actually, Brenden was quiet the entire time. I needed him there just for a masculine presence, (+2) anyway, so I might have a little more clout than is usually afforded a woman (-1) who is single (-1) and elderly (-1) without a Ph.D. (-1). So, we were still 2 points behind going into the fray.

Toward the end, Dr. Stanger picked up the 81 stapled pages from journal #20 that I had given him earlier, flipped through in 2 seconds, commenting that it was wordy or some such, then put them aside having already determined that it was too much information. I remember thinking, that's fine, I saved the $3.00 just stapling them; he didn't deserve the cost of binding. He probably wouldn't have glossed over them at all if I did make it look like a book. Psychiatrists don't like people writing about what they do. I'd already experienced the antagonism and fear, from Alex's first psychiatrist at Villa Fairmont, Dr. Nicholas, M.D., who actually verbalized his disenchantment with my journaling on day 1 of Alex's September, 2014 admission:

Journal #19
(p. 29)

> …since Dr. Nicholas changed it back to 20mg., after only a few weeks on the 15mg., Alex kind of lost any motivation to do anything except for meditating and flying his spaceship. Then, Dr. Nicholas quit. And oddly, he quit right after I notated that it looked like his changing it upwards to 20mg came right after he received my memos—which he told me on day 2 that he didn't like. Why didn't he like my writing? He didn't want notes made about his work, he said, and sending them to people in power.

(p. 93)

> Nicholas' disenchantment with me was made clear on Alex's second day when he got upset seeing that I write and send letters to the powers that be. What a great way for him to get back at me.

Stanger wanted details about what Alex said and did at every point in time, and what meds he was on and when, so he could fill out his forms. I was happy to be able to give him the information from memory, but I would have been more accurate in describing exactly what Alex would/could do under the influence of each med, if I had felt comfortable enough to ask him to pass me the journal, but I didn't, so he didn't get all the information. I could give him the dates that he did a few activities under the influence of a particular medicine, but there were more things he did that I couldn't remember to tell the doctor, like when he was able to sit down at the table under the influence of Depacote, he was also able to do other things all of a sudden:

> (p. 82) …like Depacote enabled him to laugh less, watch TV more, keep warm at night, take more frequent showers, and use a tooth brush in the morning.

In any case, he said he would not raise the Zyprexa. We'll see. He's going to add something else that starts with an S: Saphris, the vial says. We'll see. At a low dose. 5mg. he said. We'll see. Normally one starts with 10mg, he said.

Wednesday, January 20, 2016

What a surprise to be awakened by a Dr. Star from the emergency room at Alta Bates, calling to see if Alex were home. He said he took care of Alex in the ER on Monday. I asked why he didn't know that Alex was admitted to Herrick since he was the one who did the admitting. I also asked if he gave Alex his medications on Monday night. He said he couldn't reply because that was confidential information. Of course, I already know that they don't administer medication because on all other admissions when I was with Alex they didn't, unless I pressed them and presented the vials to the nurse. Only then would they give him their own. I wondered why emergency room doctors aren't concerned with giving needed medication, and don't apparently have to give patients, especially psych patients who are dependent on antipsychotic medications, the medication they need. It was 10:30pm when Alex was admitted into the ER, according to what Dr. Stanger read to Brenden and me at 5pm yesterday, and 10:30pm is an hour and a half after he normally takes his meds, so the first thing I would wonder is why they don't ask the patient if he took his meds when they come into the emergency room. There must be a reason. They know that medication is normally given to patients in the morning and again at night in the psych wards. And knowing that a patient had walked in at 10:30pm, after walking around in the rain for 5 hours, he probably hadn't taken any meds. So, of course, by 9am, after not having the medication for another 10 ½ hours Dr. Star found him very psychotic and admitted him to Herrick. So, by keeping him off of his Zyprexa, at the very least, and keeping him off of his high blood pressure medication for those 10 ½ hours after Alex was without medication from 9:00pm when he normally takes the 7 night meds, he's looking at a patient at the time of admission who has been without meds for 12 hours. Of course, he took meds in the morning on that Monday at approximately 9am, expecting to take them again at 9pm when he was out in the rain and probably thought he could get them at Alta Bates, but he didn't, so by the time of admission on Tuesday, January 19th, he'd not taken any meds since 9am on Monday, January 18th…a 24 hour period. Of course he would be psychotic! That is why he could be admitted to Herrick. Alex was and definitely would be, gravely disabled after so much time being kept from taking his due medication. My question is, is that the technique that is taught in medical school? To keep psych patients from their medication in the emergency room, so they can be admitted to the hospital's psych ward? It works.

So why was Dr. Star calling and asking me if Alex were home when it was he alone who strategized to get him admitted just the day before? And my second question is, if it were easy to call me, and he had the number, why wouldn't he have called me 24 hours before, before he admitted Alex to Herrick, to let me know that Alex was there. If he had asked Alex if he could communicate with his mother, Alex would

have said yes, because he has already written so, and they have it in their charts. Instead, they use the HIPAA as their own means to disassociate with any interference from the family, yet the doctor has the nerve to call home 24 hours later to show that he is some kind of compassionate person. I say he's not, he's just curious about who would be a roommate to a patient like the one Alex presented by 9am, all strung out from not getting his needed medication the night before. He ought to be fired. But, then, they wouldn't have any doctors.

Thursday, January 21, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 1mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 10mg.

He already raised the dose? I spoke to Alex's nurse, Sydney, to find that the Saphris was already raised to 10mg or 5mg-twice a day. I hope I didn't sound too annoyed since I didn't want to take out my antagonism on Sydney. He's one of the nicest nurses there. I asked him to call Dr. Stanger to remind him that he said he would keep the Saphris at 5mg. He did call and got the answering service and the doctor returned the call in a few minutes. There you go! The last time I wanted to call an off-duty doctor for the same reason, I'd asked Patti, the social worker, to ask the charge nurse to call the doctor. That was a mistake. Instead, the charge nurse turned on me yelling, "Get out!" and called security to escort me off the unit. Apparently, a regular nurse can page the doctor, if they want to be accommodating, but the charge doesn't have to be. So, the charge nurse just didn't want to make the call and get yelled at by the doctor. Doctors do have phones even when they're off the unit. What a surprise. Unfortunately, Stanger told Sydney that the medicine will stay at 10mg/day, Sydney told me after Stanger called back. I pointed to the plastic sign on the wall that declared some kind of mission statement about Alta Bates and its concern for integrity along with some other of its promises that probably don't amount to a hill o' beans either. And I left.

Sunday, January 24th, 2016

I'd found out at the last NAMI support meeting about a group of mothers who want to change things in the mental health system. That sounded good to me. One of the founders of the organization, Candy, called me and invited me to come to a meeting which was coming up soon. I arrived at Patricia's house, albeit a little late. Getting there was a problem because I didn't know where I was going, didn't have a map because my internet was down and my Berkeley maps were just of South Berkeley, and didn't have a phone because I had already run out of money for the month and still had a week to go until my Social Security check would kick in.

The door was open and everyone was already sitting around the dining room table and didn't stop talking to greet me, except for Brynn's friend, who looked up and smiled since I'd only the night before told her about the meeting. I decided to take notes about what they were trying to accomplish and conspicuously set up my computer. Parts of the various conversations follow:

Mothers' and Others Meeting notes submitted by Joan Miro 1-24-2016

Comments around the table at Patricia's house ranged from what is not being done by Alameda County, how consumer organizations have taken root, to what mothers would like to see happening:

Alex Brisco former Director of Public Mental Health, Alameda County, is ground 0 for consumer empowerment. There are consumer organizations that have been funded. Within these organizations you aren't allowed to say "mental illness." That would mean there's *something wrong with us*. If you have mental health issues it means your illness is caused by families. "What did you do to make your child sick?" is the current thinking among some in the mental health system as well as consumer organizations and it is an erroneous belief that schizophrenia is caused by family.

We have to discern between serious mental illness—which is bipolar, schizophrenia or schizo-effective disorder—and others that are not as serious like depression and family issues. It's a different lived experience and not meeting the needs of serious mental illness.

Prop 63 – whereby the money would come from taxing the millionaires—was supposed to go toward people with severe mental illness. And consumer advocates got them to fund voluntary programs instead. The Senate passed prop 63 so it can be used for Laura's Law.

Abu…the only male at the table, spoke up saying we have to "get people on the track. Continue this motion…How do you go from here? 1421… I'm trying to find my niche...Prop 63. The report from Sacramento projected 2 billion dollars for one year. But it's misappropriated…First politicians count the numbers."

We need a new name. Already have another group for Laura's Law. *Voices of Mothers and Others*. Mothers show up. Why is a man here? (He) would be someone who could tell us what goes on inside Alameda County. (We're) sickened by the fact that Villa closed so many beds. Nobody knew. Where do we most need attention? We need a bigger John George and a bigger (_____).

Had no idea why this is so hard. A moderate program, less coercive.
Candy and I got stuck on Laura's Law. No one is tracking outcomes of which programs are more effective. There are many.
Abu has a lot of practical knowledge about how things are going on now.

How does this group relate to the Path for Help group? This is Candy and my (Patricia's) group: *the Mothers*. Another family group is (_____).

Steve Bishop is meeting with us. (He's) fixated on Laura's Law. Linda M., and Dianne Arroner were working with us. And we started meetings with public officials and called it *United with a Path for Help*. One of the reasons that we separated from the other groups…they can only go so far on a conflicting positon.

(Some) Mothers wanted to be more forceful. Others didn't want to ruffle people's feathers.

After a couple of Board of Supervisors meetings they decided they would not take a vote. They told Behavioral Health that you need to make more of a plan. And they came back with 9 *Volunteer Programs*. We said volunteer programs don't address the issue of the serious mentally ill. So, they were supposed to take a vote on the 5 person. You've got to get the family members and consumers to come together. All the stake holders in the county met for 3 month (with) anyone who was contracted with the family. County said you're supposed to get 4 representatives. The Behavioral Health didn't support Laura's Law. It was a bogus process. The consensus was 9 in support… and 4 against and most abstained.

Our Behavioral Health Care has just focused on (_____), they haven't focused on (_____).

(Our need is for) More Supported Housing rather than Independent Living. Need a power group to get more media attention.

Patricia has been speaking to Holly Madir at East Bay Express. Any way that we can get information out to the public (is worthwhile). It's good to write up op eds and get this published. Go to meetings at Board of Health and Board of Supervisors and Behavioral Health.

There are not a (large enough) number of people present. There's a *Family Dialog* that meets the first Wednesday of each month at 5-6:30 at 2000 Embarcadero Cove. (That will be Feb. 3rd)
The Family Dialog has been and is the starting point. The families shouldn't have to beg. We should recommend.

Rosa Warner speaks (for us. But she's not saying what we need her to say.) We (parents) don't have representation. It's not a question of her credentials. In order to represent family needs, she needs to (_____). She works for Alameda County Behavioral Health Care (and doesn't really represent us).

We're disgruntled with Berkeley City Council setting the tone; it's personality driven.

The Consumer Advocates are strong. Who are the people at the top? Alex Brisco, Manual's boss, for one.

We educated the Board of Supervisors. Each supervisor has a health aide and they are opposed to Laura's Law. It takes education to understand about *Involuntary Admission*. Ginny, a health person, would never let us meet with a group. She doesn't know the facts and doesn't want to (_____) her parents out. They make the decisions.

Parents haven't been there to take the lead. The other things that happen at Board of Supervisor meetings (_____).
Parents never had the numbers.
A new law just came out and Evonne went to a meeting for the PEER group. Evonne said she wanted to attend. You just have to show up. *FERC* is a resource agency for families…not an Advocate. Rosa is in charge of FERC. The *PEERS Group* (pool of consumer champions).

(We have to) formulate a plan to take to the *Family Dialogue* meeting on the 1st Wednesday of each month at Embarcadero Cove (2/6/16). You have to be invited into the group. Direct the problem to Manuel.

Why do they meet behind closed doors? The Brown Act states that you have to allow people into public meetings.

There were 6 core people from United from Path to Hope who go to meetings.
Organizations that are supposed to represent families should be getting money and stipends, too.

Meet before Manuel's meeting. Start the conversation with a dialog. Marc Ramon at FERC is a good family advocate. There are jobs on the FERC meetings.

We have 2 major things to present at the family dialog meeting.
The best medical care for our severely impaired children is top on the list.

The plan is to close down John George and use respite care instead. Nate Miley (_____).

We have a lot of pastors, downtown merchants who showed up at the Nov. meeting.
The 5-person Board of Supervisors voted in favor again of (_____).

Murphys Law to have funding for AB686 to allow you to see a psychiatrist.

Can we get some support from other organizations, like law enforcement organizations?
And other board. Joe Biden talked about ( ).

There's a lot of mentally ill people working in the government. "I personally know nut jobs that work in the government…I worked in the drug rehab area and the programs are written by PhD's…But, there's mental illness going on in the organization, too…Fred Frieze, for instance, was in a mental hospital where high officials are in the hospital, too."

(Finally) attention is being paid to mental illness…because people aren't getting the help we need.

We share some ideas with consumers. There are some treatments. Some medications are miraculous. Medication saves many consumers.

The group brainstormed some of the things that they want to do: (not in order of importance)

1. Get hospitals to share information about patients within the state or county so that bad outcomes don't have to be repeated
2. Have a meeting with Manuel
3. Bring the Rosa situation forward
4. Increase AOT from 5 to 30
5. Have family involvement on the committee
6. Build publicity-a diverse crowd needs to know who we are
7. Make arrangements to go before the board of supervisors
8. Tell them what we want them to do
9. Have an education meeting
10. Get advice on an approach to the board: Ask someone who can help us with something concrete. Is there a legal way to have your own (_____)? Could we approach the city council and bootstrap to create a pilot program under Laura's Law? The law says we need county approval. We want to go back to the board and have a pilot of our own. You approved it in principal. Find an attorney to advocate. Get ready.
11. Increase amount of beds at John George and Villa
12. If we find the date, ( )
13. Come up with our own Slogan: e.g., *treatment not jail*

13 Keep going to the Board of Supervisors meetings.

14. What support is there for the family?
15. (Fighting) Family stigma
16. SB 114 County needs to give director- no longer Imminent Danger
17. How hospitals deal with alcohol and drug related mental illness
18. Change the definition and interpretation of criteria for admission
19. Stop the bias against females/mothers
20. Identify judges who might help us
21. Diversify our constituencies
22. Identify what groups that will collaborate with us, come to our meetings – e.g., public defenders, especially male groups
23. Write a mission statement
24. Write goals
25. PR—Write a packet of information to give out
26. (Disband with) imprisoning the mentally ill
27. Housing problems regarding the mentally ill

After editing and printing up the above minutes of the meeting, I wrote a letter to Patricia to let her know that I wouldn't be joining her group since she was so snide with me when I tried to read *my* ideas of what we need to work on as a group of mothers. I wasn't impressed with the way she ran the meeting either, because it was the opposite of how the Housing meeting was run. People were just talking around

the table without any form of order or idea of what needed to be talked about. There were no motions, no declarations of what needed to be covered, no prioritizing…nothing. It was just a group of women around a table who didn't know each other, had no idea of how to discuss business in an orderly manner, what business was in need of discussion, or how to go about coming to any decisions. I don't have time for that. And she didn't have the courtesy to hear what I had to say. I didn't have much to say because I was the only one with a computer, so I occupied my time mostly taking notes. As usual, I didn't come back with a retort when she indicated that she didn't want to hear me read my conclusions, so I wrote her a letter that I mailed with the minutes, which weren't really minutes, just notes for my journal that I was willing to share with her.

Dear Patricia,

Thanks for having the meeting and starting a mother's group. It's impressive that you've done that.
Enclosed are the notes that I took from your meeting, but I left spaces (between parentheses) when I didn't hear what was said; maybe you could add. Of course, it's on my computer, too, but unfortunately, my internet access just went down and I have to get Comcast over here to fix it, so that's why I printed and delivered the notes for you.

I couldn't put names next to the individual comments, because there were no name tags worn, and I didn't know anyone's names, and I didn't want to interrupt since these weren't official minutes. That's one of the problems I have found with groups, except, of course for the Commission and the MH Board, attendees don't wear name tags. And people don't usually have a built-in time to socialize and get to know each other. Sometimes I get the feeling that leaders don't want people to know each other, like at NAMI meetings. So, you might want to add the names to the comments, if you know them…or not.

You gave me an idea to maybe start my own group since the items that were talked about at the very last part of the meeting are not what I want to focus on. So, thank you for that. I intentionally brought my last 2 years of journals to the meeting because I knew I wanted to read what I had concluded after 20 years of watching the mental health system do its damage. I presumed you would want to make a list of the things you wanted to tackle and I wanted to add to that list what I found needed tackling. In addition to that, sometimes it's hard for me to remember everything, but I know where to find the information when it's written. Another benefit of writing and editing is that one puts a lot of thought into what one writes, and it can be presented orally in a more concise way than just hoping I'll remember what I want to say. I apologize for not knowing I wasn't supposed to read, but what I tried to read aloud to the group, before you cut me off, are the things I was interested in joining your group for, with the intention to fix:

> To reiterate what needs to be done to bring to fruition Dr. Henri Montandon's hope for working to achieve recovery: ***"…people have not realized that we have this opportunity to come together and help one another."***
>
> ***Are we going to take this opportunity now***, before it eludes us, or continue along this dead-end path holding the severely mentally ill hostage forever? Are we going to make up our minds to ***stop abusing the mentally ill*** by ignoring their ***need for medicines that***

work well enough so they can have decent lives in normal communities? Are we going to ***stop blaming and ignoring the mentally ill*** for being mentally ill? Are we going to ***discover the causes*** of mental illness in order to research intelligent, appropriate cures? Are we going to ***end isolation*** by creating clean, well designed, activity-focused housing and other community groups that are age appropriate? Are we going to ***share information*** within counties or states so that bad outcomes at hospitals don't have to be incessantly repeated? Are we going to ***make it mandatory for doctors to get information from the parent*** when they don't have current information about their patient in their own chart or can't get it from other hospitals? Are we going to ***fund research*** on a national level that can accomplish all of the above? I hope so, because only then is recovery possible.

However, your intention to cut me off, so that I couldn't finish what I had to say, for your own personal reasons, is the antithesis of Henri's comment and the reason we are getting together to begin with, to try to be heard and to work together. Just to let you know, more than half of the people at your table had already heard the words I read, either at a NAMI support meeting, a housing meeting or at a mutual friend's house where I was excited to share what I had concluded after so many years of researching what needs to happen. On none of those 3 occasions was I interrupted; in fact, the facilitator took notes, the friend made copies and there were only acknowledgments of agreement at NAMI. Best wishes in your work to help the seriously mentally ill.

Sincerely,
Joan

Wednesday, January 27, 2016

Things are not going too well at home. The new medicine that Dr. Stanger gave Alex in the normal 10mg starting dose is showing both good and bad effects. On the good side, he was able to walk over to BMH to talk to the receptionist about whatever was on his mind. He has never been willing to go inside that building before. Now he wants to be more independent and be in charge of taking his own medicine. The Saphris didn't take away his motivation to watch TV or take a shower or sit at the dinner table. Those activities came about after he took the Depacote. So, he's still able to do those things on Saphris; it didn't take those abilities away. On the other hand, wanting to be more independent and be in charge of taking his own medicine is more of a problem than a benefit. That is, I don't think I can depend on him to do it accurately, and that's why I made a list of the medications so he can check each one off as he takes them. But, he won't. I even drew a picture of, and wrote the names of each medication on a plastic plate, so that he could see which ones are taken in the am on one side of the plate and which in the pm on the other side. He smiled when he saw the plate, but he won't use it. I already caught him a few times taking the morning fish oil at night, and I was quick enough to stop him. But, I couldn't stop him from taking too much of the Benztropine. On the first night at home, he took a 1mg tablet of Benztropine twice, even though he's only supposed to take one - 1mg tablet at night. He had taken the one I gave him, but then he insisted on taking the one he keeps in his backpack, too. I couldn't talk him out of it. He had to because the hospital told him to, he said. I had to call poison control to see what might happen. The man said he'd be OK. He

insists on keeping the new medications in his backpack, away from my authoritarian hands. *Wanting* to do it himself is a point for independence, but being *able* to take the meds himself, is another story. He wouldn't let me write the words "a.m." or "p.m." on the vials as I used to, because he said the pharmacy already writes it in their brief description typed on the vials. But, after we found 2 vials where the word 'morning' or 'evening' was not indicated, he finally saw that it doesn't always appear, and wrote the word himself. So, we're not there yet. And I don't know if we're going to get there.

The main issue regarding too much medication finally showed its head last night. This Saphris has to go, at least at this 10mg dose. That's clear. We were both standing in front of the dining room table, a metal table with a clear Plexiglass top, when he placed his heavy, dirty backpack onto the table. I asked him nicely to take the backpack off the table because he always leaves it outside either on the ground or cement when he's smoking out back. Then he transfers the dirt onto the dining room table. But, he said, he wanted it on the table so he could unzip it and take out the meds. I asked him to put it on the file box behind the chair or in his room on the floor because I explained, it was too dirty to be placed where we eat. Either he didn't understand or like the idea, so he tried to show me who was boss by lifting the backpack up high and slamming it back onto the glass table top. After the first time he slammed the table, I felt threatened because he seemed out of control, so I smacked him on his arm, kind of defensively, so he would know I wasn't afraid of him. I wasn't about to run and hide to show him I was scared. Nor did I want to call the police to put the decision into their hands. None-the-less, as far as I was concerned, it wasn't OK to slam the table with a big, heavy back pack filled with bottles, cans, food, and medicine vials. At that point I was cursing, but it was Dr. Stanger I was cursing, for the extra 5mg. that he snuck into the prescription so he could protect his blimp-sized doctor's ego. He promised me he would keep it at 5mg. but did just the opposite. Alex stared at me wide-eyed, yet unemotionally, while he raised the weighty backpack and slammed the table 5 more times. I could sense that he presumed he could take over by exhibiting aggression. Wrong! I stood my ground, screaming and punching him once more. He didn't like that. I didn't like it either, but it was both automatic and defensive. I couldn't simply stand still and do nothing, nor could I move away and pretend it didn't happen. I needed to stand my ground. I needed to watch him take his medicine to make sure he would take the correct ones. It was scary. I think I threatened to throw him the hell out! I think I said he could get out now! I think I said I don't want to live with him anymore! I think I declared he was an idiot! I think I said I was going to call the police! It was sometime after this interaction that he finally pulled open the zipper of his backpack to take out the meds and took one after the other while I watched without knowing what he was taking. I was too upset to look, nor did he want me to. He wanted to do it himself. So much for independence. I would have to live with the result of any mistakes and I wasn't about to have this happen again. He remained mad and didn't apologize. I remained mad and scared as evidenced by my abdominal muscles tightening up. I reminded him that he didn't say he was sorry. He went into his room and I slammed his door saying a few more things that I can't remember less than 24 hours later. Locking myself in the second bedroom, instead of taking my usual place on the sofa, we divided up until the morning. And that's how it went. By morning, I was still on his case until a meek apology finally emanated from his lips.

Tonight, I tried to explain that the doctor raised the dose too high. I tried to explain how all the doctors like to high dose him. I tried to explain how it works. That the pharmaceutical companies like to sell drugs…the more the merrier. He listened, but he doesn't believe me. He wants to think that *the doctors care*. He wants to think that *they are doing the best for him*. He's very hopeful and positive and thinks that *everyone has his best interest in mind*. That's not what I've seen.

I let him know that he took the meds so late in the morning that we would have to wait until 11pm to take them again. He wasn't fighting me; he was tired. And when he fell asleep by 10:30pm, I let him sleep a little longer while I snuck the backpack that was next to his bed into the kitchen, to quietly remove the Saphris and Omega so he would only take them in the morning. I hid the packages of Saphris under the coffee table and tucked the Omega into a kitchen drawer. When I awakened him for the meds at almost 11pm, he placed the backpack on his desk where he said he preferred taking the meds from now on. Good, I thought. It's dark in his room, because he'd taken the ceiling light bulbs out months before, so there was only one floor lamp. He opened the vials one by one, spilling the pills into his hand so he could choose the one he wanted, then swallowed each single pill with the water I'd put on his desk, and noticing that the Saphris wasn't among them, commented, "They must have taken them."
"Yea, they probably did," I said, as he went back to bed. And that was that; so far so good. While he's sleeping I'll slip the Omega and Saphris containers onto the floor near his bed so he can think they fell out. He's not going to take 5 more Saphris on my watch.

Thursday, January 28th, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 2mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg.

Good News: Alex has been sleeping a little longer on the new bunch of meds so I have no fear that he'll go outside before the legal time of 7am. Today it was 8:30am when he left. So that's a break not to have to be defensive with the neighbors. Bad news: When he does go out, he's a little noisier due to the 'cold' he got at Herrick. His cough is worse; lots of phlem. And he feels hot, so hot that he's been turning the heater off. That sounds like a fever to me.

I've been pressuring him, telling him he won't get any money, if he doesn't see a doctor this week, or at least make an appointment to see one, and there's only 2 days left. He said he'd only go to BMH to see a doctor, not the other newer building where they "do crack cocaine." I can't believe that I didn't remember that there actually is a doctor, Dr. Herb, who'd already seen him twice before at BMH, before he'd even switched out of Kaiser. She works for the same company, LifeLong, that he now belongs to. Apparently he remembered seeing her. I

can't believe I didn't think about her. She's the answer to the doctor problem. Anyway, I made an appointment for him for Feb. 8th at 11am. Dr. Herb was sweet and very customer focused, willingly coming out to the curb to do an exam in my van, since he wouldn't/couldn't step over their precipice. But that was then, and now he has been going into the building since this week as a result of the Saphris. I spoke to Nurse Peggie yesterday and she said her eyes almost fell out of her head on Tuesday when she saw him come into the waiting room. I did all I can do to make it register in his brain, that he won't get any more money starting in February, if he doesn't see a doctor or go to the appointment. He sounds pretty sick, but he won't acknowledge it, and hasn't said one way or another if he'll see even Herb at BMH.

Having finally caught whatever Alex was giving away, I spent all day in bed. That was fortunate, because the night was soon to unveil a new plan for my energy. Alex didn't want the concoction of vegetables and meat that I was making for dinner, but as soon as I cleaned up the kitchen, he decided I could make him some pancakes. Both pre and post pancakes, he was going outside to smoke, and I went out to check on him when it was getting towards 7pm to find that his backpack with all the medicines was standing alone at least 30 feet from where he usually sits in the back of the building. It was too dark to see if he were even there and it didn't sound like it, so I took the backpack inside and put it in his room. Usually, he places the backpack next to where he smokes, and I really thought he'd gone out somewhere else, because it was parked in front of apartment #4 instead and he sits behind #4. I didn't want it there because anyone could have taken it or someone might have thought it had a bomb in it. I looked through it to check on the bomb status and it was then that I got a plan. I would remove all the medicines and put them in a weekly pill holder for him. I felt I could convince him to change the way he takes the meds since he goofed up by leaving the bag in a precarious place. I removed the vials and hurried outside again to my van, hiding them while I got everything I needed to carry out my plan: list of meds, plate with drawings of meds, pill holder. Then I saw him coming out from behind the apartment building where he smokes. I closed the van door, locking myself inside. He went into the apartment without noticing me, but came out soon thereafter. He came over to the van asking if I knew where his medicines were. I was already on the non-emergency phone with the police, asking the officer to send a police officer over, in case there might be a problem. I was expecting that he would get upset. After explaining in a whisper what was going on, while Alex was already standing next to the van looking at me through the window, I began to be uncomfortable, and more so when the police officer on the phone didn't sound convinced that anything required their services.

I cracked open the window so Alex could hear me and started explaining to him what was wrong: The backpack sitting alone. My not seeing him nearby. The medicines outside for the taking. The possibility of someone thinking there might be a bomb. Alex didn't think anything was wrong. He just wanted his medicine. My voice was starting to climb as I repeated what bothered me: He already had taken too much of some medicine and not enough of another because the medicines weren't counted out. The medicines weren't organized. The containers weren't all marked. They needed to be counted out and placed in a stick for the week. He didn't agree. He liked taking them the way he liked taking them. We went over and over. He insisted that I open the door. I told him to stop insisting. I wanted him to change his

ways when it came to taking medicine. But, behind it all, I wanted to make sure he wouldn't take any more Saphris at night. I already could see that the 10mg of Saphris was too much for him because through all the discussion about what I wanted, he didn't get out-of-control angry having only had 5mg. I was the one getting loud. He remained calm because he'd only had the correct 5mg of Saphris during the 24 hours of yesterday. So, I slid the door open and gave up. I gave him the vials of medicine after getting his agreement about not taking the Saphris tonight. He agreed. But, all of a sudden, as I handed over the Zyprexa, he said that the Zyprexa was no longer good. I had done something to it. It needed to be replaced. Someone "switched it". He would have to run to the hospital to get a different one, he said. And he left. That was around 8pm.

Now it's 1:30am on Friday morning and I'm still putting into place what happened and why. I had followed him to the Alta Bates ER. By the time I arrived, he was already sitting in the waiting room, and didn't look too pleased to see me. I placed myself in a different area where I could still see him. I knew he was angry at me because he told the triage nurse that he didn't know that woman, (me) and that they shouldn't talk to her, the triage nurse said. And not only did his nurse ignore me, no one even told me when they discharged him at 10:45pm. I was still sitting in front of the door where he would have come out of at 11:15pm when I finally got up and picked up their phone to speak to the charge nurse. No one answered. They carried their rendition of HIPAA a little too far, ignoring me completely so that I couldn't give them the information that they needed to know. But, when he arrived home, he did say that they gave him one Zyprexa in the ER, and a new prescription for the rest, because that's what he came in for, to get the Zyprexa that had been "switched." The whole time I was messaging Brenden about the ordeal:

ME

We're back in the emergency room again.

BRENDEN

Alex is back in ER? or You? For what?

ME

Alex. He said the Zyprexa was switched, so he walked to the ER. And I followed him. More happened…that's been going on since last night but I can't write it all. He did something last night that scared me.

BRENDEN

So, are they going to admit him? Send him to Herrick? Do you think things are crazy due to adding the other medication?

ME

Yes, the anger he displayed 2 nights ago was from too much of the Saphris. So, last night I was able to sneak the Saphris out of his back pack and he didn't take it and he was already better today…not angry.
He's mad at me because I told him not to take that med again tonight but he doesn't understand.

The doc said he would give him half…5mg. Isn't that what he said? So, he gave him 5 and the next day he gave him the regular 10mg. That is not what he said he would do. He was deceitful, Dr. Stanger, saying he would keep it at 5 and the next day raising it to 10mg. So he was on the regular dose anyway.

The Hofstra study report in the NYT said that when 50% to 75% of meds are used there is a better outcome.
Apparently psychiatrists don't have to read studies. I'm not feeling well today. I caught Alex's cold or whatever he has. This has been an upsetting week and I have a low resistance to begin with.

BRENDEN

Yes, he said 5. Did Alex go home with you right away after adding the Saphris? Maybe he needs to stay a few days when they change his meds to get monitored…in case it doesn't work.

ME

He's not letting the nurse talk to "that woman;" his mother is dead, he told them.

BRENDEN

Is Alex getting admitted? Do you have to stay there?

ME

Of course he needs to stay in the hospital after they change meds, but that's not hospital policy, because that would make sense for them to observe him at least for a few days (on the new meds). And apparently, they are not mandated to do what makes sense.

That's just one more problem with the system. They try something new and let the mother suffer with the result.

BRENDEN

Wouldn't he have to stay if he doesn't have the choice to go home to you? Or do they just kick him out and put him on the street?

ME

They just kick him out or get a Board and Don't Care.

I don't know anything because he's not letting them talk to me. And I don't even know if he is taking his meds.

I'm trying to reach Jay, the charge nurse. Maybe they would talk to you. No one is picking up the phone. If I can only talk by phone then you could call. The charge nurse never came out even when I asked for him.

The number is 510-214-2500. But you would have to call me first to learn what happened. A nurse just came out to say he was discharged. I can't believe it! I've been sitting here the whole time and they are telling me he came out the door a half hour ago and I'm sitting right next to the door.

BRENDEN

Can they lie like that?

ME

I went home in between texting.

I'm home and he's home. They didn't even tell me they discharged him. By the time I arrived home, he wasn't home but he came home a minute after me, thank G-d. So, that's it. I told him not to take the Saphris as he was about to and he didn't contest. Who knows if he will when I'm not looking. He didn't have it last night so I don't think he should have it again until we see how he is on the lower dose (5mg) that the doctor said he would give him. OK, so that's it. He's in bed. He didn't take it, think G-d. He just wanted the hospital to give him new Zyprexa.

And you know what? I think that through all this aggravation, he didn't get upset because of the low dose he took last night. He was annoyed but he was calm and collected.

BRENDEN

Well, I hope things work out for tonite. Good nite.

ME

That's a blessing. Thanks for the communication. Nighty night. Please do stop over the next time I don't return communications in the future. I want to be cremated so there is no trace of my ever having been on this planet.

Friday, January 29th, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 2mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg.

He was good today after 2 days on the lower dose of Saphris. I let him know that it was the last day for him to be able to make a doctor's appointment or he would lose all his money for the month of February. He was supposed to go to BMH to make the appointment, but it was raining all day and he didn't want to go. Since I'd already made the appointment, I just called them on speaker phone from Alex's room, so he could think he was making the appointment, and they repeated for him that he had an appointment on Monday, February 8th, at 3:00pm.

Thank G-d for the pharmacists at CVS in Berkeley. They are extremely customer focused. Alex started getting upset because he didn't want to walk the mile in the rain to give the prescription that he'd gotten in the ER to the CVS Pharmacy. After a lot of mulling over whether he could trust me, he finally asked if I would bring it over there. He didn't really trust that I wouldn't "switch it" as he said I did before. That was why he had gone to the ER to begin with. But, with no better options, he let me do it.

Sunday, January 31, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 2mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg.

I texted Brenden after experiencing a non-threatening, normal weekend with Alex.

ME

Just letting you know that he's been better since the ER. He just wanted a new vial of Zyprexa because he thought I "switched them," when I took his meds into the car. I didn't really elaborate about that scene. No time. I thought it was an

opportunity, when he left his backpack in the back unattended and in view of the street, for me to take the meds out and demand that he not take the Saphris at night. He hadn't taken it the night before, when he had lifted his backpack up high and banged it on the dining room table top 5 times, and I had retaliated by punching him on the arm once, as a defense measure. Fortunately, he didn't hit me back. He scared me and I retaliated immediately in self-defense, and to show him that I would stand my ground and not be intimidated. So, he did listen after he saw that I wasn't going to accept that kind of behavior. He didn't apologize till the morning but he did listen and not take the Saphris that night that he banged the backpack. If that had been a glass table top, it would have broken.

All that really happened was that the 2 cups of tea spilled all over. He had been on the 10mg of Saphris for a week at that point, so I explained that it was the high dose of Saphris that had made him so angry, when I simply had asked him to put the backpack on the floor…it wasn't he who was at fault, just his being overdosed with meds, that did it. So, he heard me and went along with only taking it in the morning. So, he's been much better since he came home from the ER and asked me to get the new prescription filled at CVS, and I did what I could because they won't have that particular kind of melt-in-your-mouth Zyprexa 'till tomorrow. The pharmacist was able to fill it only because it was a different kind of Olanzapine because his old one wasn't yet up for renewal. So, I gave the pharmacy 30 pills of Zyprexa, that I had saved up from the times he was hospitalized, for her to re-bottle to make them look new. She did all the typing and put them in a new bag and he was then willing to take the "old" meds that I gave the pharmacist to repackage.

And tomorrow, I have to go back there to pick up the new melt-in-your-mouth meds.

So, that's what the ER visit was all about. And he's been more conversant, pleasant, comical, helpful—better than on just the 15mg Zyprexa— on the lower dose of the new med for about 5 days. So, I hope you enjoyed your weekend.

BRENDEN

Oh cool. Glad to hear that he is doing better. So, is he still on 5 Saphris or none? It's interesting that he fights to take the meds, when he used to fight not to take them. Be careful being physical. He could just hit you by accident if it becomes a reaction.

Weekend was OK. I'm back in school this semester. So, between my website and school, that's my weekend. But, things are moving forward for both, so that is good.

ME

I can imagine that you are very busy. How did it go from last semester? Do they grade with A's and B's in grad school? Or just pass and fail."

Yes, he is still on the 5mg dose. He really wants to be independent. He asked me tonight when he will be able to take the meds on his own. I said as soon as you are willing to get better organized and keep a record of what you take…before you take it. I drew a picture on a plastic plate of each medication with its name underneath, so he could see what he's taking and not make mistakes. He likes to do it fast for some reason, and he's made a few mistakes already, like taking the fish oil more than he's supposed to. If he does that with the Zyprexa, it will be a bad outcome. He caught himself last night and spit it out. I have to be there to get him to read the vial each time.

But, all is well. Keep up the good work. It's great that you are doing all that. I wish I had looked at a degree instead of just taking classes, I think. I have over 200 post baccalaureate semester units, but no degrees other than B(ull) S(hit). It would give me more credibility fighting these characters, if there were credentials after my name. Maybe it would garner me some respect. Anyway I'm glad you're getting them.

Monday, February 01, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 2mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg.

Alex continues to be progressing in a positive direction, eating my food even though he says occasionally that he can't. Yesterday he ate all three meals at home. I guess he eats what he likes or what he's in the mood for. This morning he ate the breakfast sausages with a bagel, kind of an oxymoron, but he didn't want the fried white fish for lunch, the same fish that he loved the other day. I should have known. He always liked a change of menu. Still sick in the chest, he takes a lot of naps, coughs, spits up a lot of phlem and feels warm. He will only drink hot chocolate that I slip cough medicine into a few times a week, so it's not having much effect. His appointment with a medical doctor, Dr. Herb, isn't for another week. I'm trying to get him to the urgent care clinic of the same company, LifeLong, but he keeps insisting he can't go even though they rent space on the 1st floor of the Herrick Hospital building, where he feels at home.

Other than smoking in the back yard and coming inside to recuperate, he doesn't do much. I guess meditating is something. He does do that. And he talks to himself or to someone who I can't see. I guess that's something, too. I hope he doesn't do it outside. Brenden got him a little computer that holds discs and he can watch videos on it…X-rated no doubt. That's about it. I have to write to Jerry about hiring an attorney.

Thursday, February 4th, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 2mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg.

Alex has been predictable at these doses. He's eating at least one decent meal at home and is able to look at TV programs. He talks a little bit during the day. He's OK. As long as he's not running away and staying out all night, I can't complain. He's still praying out loud to himself a little too much. "On heal many" is an expression that he can say several times in one minute. And the smoking outside is too much, too. Other than that, I won't complain. He's conversant at times, watches TV and finds it amusing—I think that he finds it more amusing than it actually is. He's been low key, helpful. For instance, he did the dishes tonight when I said I wasn't feeling well. He was pleasant when I was in his room to check if he were covered and woke up to tell me I could cover him with the red blanket. Most of the time he tells me to take the second blanket off. He must realize that I do that each night.

Super Bowl Sunday, February 07, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 2mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg.

Alex watched quite a bit of Super Bowl entertainment during the day. I was grateful for what they had on TV. He looked excited, like it was getting through to him. His brother, Brenden, came over for brunch to see him. Oddly, Alex kind of ignored him and wouldn't sit down to eat with us. Brenden offered to walk around with him, but he didn't want to push it, so he just stayed at the table and had brunch with me. I asked Alex why he didn't spend time with Brenden, after Brenden left, and he replied that he "wasn't sure it was really Brenden. He looked dirty." Now I'm not so sure that the Saphris is working. He is talking out loud too much.

I made an appointment a couple of weeks ago for Alex to see Dr. Herb at Berkeley Mental Health instead of Dr. Nguyen at LifeLong. They're both LifeLong; they just use different offices to serve the patients. There's an urgent care clinic, too, that LifeLong rents on the 1st floor of the Herrick building. I had toyed with Alex going there but he would never do it. And so far, he is planning to see Dr. Herb because he's already seen her twice while he was still a Kaiser patient.
He's been a LifeLong patient for 3 or 4 months already, but hasn't been willing to be seen at the Ed Robert's Campus. I don't know why I or anyone else at BMH didn't think about Alex seeing Dr. Herb earlier. Finally, it dawned on me a couple of weeks ago that he could and should see her because he's willing to go to the BMH building. I need to write her a note about his health so she can read it before she sees him.

2/7/2016

Dear Dr. Herb,

I'm happy that I finally figured out that Alex could see you at BMH, since he wouldn't go to the Ed Robert's building after checking it out with Alberto Flores, when I switched him from Kaiser to LifeLong last September. He's not comfortable with places he's not familiar with, so I told Dr. Nguyen, after she called several times to try to introduce herself to him, that he was more willing to see you at BMH. I'm kind of concerned that no one else thought about having Alex see you at BMH, because I didn't put it together for a few months that you were from the same organization. When you call the LifeLong number they just arbitrarily fit you with a doctor at the Ed Roberts Campus.

I need to tell you a few things, and I'm sure Alex won't want me to come inside BMH with him so let me clarify a few pieces of recent history regarding his physical health from my journal:
It was in September, 2014 that he was taken by Villa Fairmont to Eden Hospital where the ER doctor found he had a tooth abscess, and on October 7, 2014, that was confirmed after another trip to his dentist, Dr. Sharma, DDS, in Berkeley. All this while he was detained in Villa, without their following through on taking him to the oral surgeon, Dr. Knowles, who Dr. Sharma referred him to. Villa finally discharged him on April 14, 2015. The following week my other son and I took him to a Dr. Arnold, DDS, on MLK Way, who said he now had 3 abscessed teeth which were no longer dormant from the antibiotics administered in September, 2014, by the ER doctor at Eden. Alex's regular dentist, Dr. Sharma had written a letter (enclosed) to let Villa know that his teeth had to be taken care of urgently. The Villa administrator didn't consider it urgent so they declined any

responsibility to do what the dentist recommended. By April of last year when they discharged him, and Dr. Arnold took over his dental care, I, myself, could not get him to Dr. Arnold's
oral surgeon, Dr. Kalleil, to whom he was referred. It was after that that several things happened to Alex that may have been related to the diagnosed infections:

1. He was having a *very* difficult time breathing by September 2015 as I indicated (in my journal) his brother on 9/11/15:

   He won't go to a doctor even if it's close, and his lungs are getting much worse. I had to call 911 twice yesterday becz he couldn't get a breath and was running around the apartment trying to get some air, but after what seemed like most of a minute he started breathing again. When the ambulances came, he wouldn't go, so they wouldn't take him. I'm sleeping lightly listening to his breathing. He has to see a doctor. He promised he would if he could walk but it doesn't look like he's owning up to the promise.

2. The next day I was able to get him into the Alta Bates ER and he was admitted to Herrick. There were 3 episodes of his inability to breath for more than 30 seconds in September. Herrick nurses gave him some cough medicine while he was there for a psych admit. I wrote a note then to the doctor and this is part of that note:

   My *main issue is to make sure he keeps breathing until someone comes up with a medicine that actually works (for his schizophrenia diagnoses), that gives him a chance to live normally in this world. Who knows if it will happen tomorrow or in a decade or ever? And that's why I finally called the police for a well-person check. He is having a great deal of difficulty between the coughing and the infections that have been active inside 3 or more of his teeth that are predicted to have already invaded the bloodstream to go wherever they may go. The last dentist he saw in April, Dr. Arnold, said that when the infection is on the bottom tooth, it usually goes to the lungs. And he's been coughing a lot for the past several months.* ***His*** *main issue is that he's not in this world. He really thinks he's in the sky flying a space ship and "saving all the children."*
3. Last December 30, he was discharged again after another week at Herrick, having been admitted because his back hurt and he couldn't move (to the point that he urinated in bed because he couldn't get up to walk to the bathroom). I wondered if, again, it had something to do with the infection that the teeth were purported to send into the blood stream perhaps to organs that could cause back pain. These are some of the observations I made at that time while talking and writing to his psychiatrist at Herrick, Dr. Trautner:

   "No doctor has been interested in the whole picture. Although you said 'I don't want him to suffer either,' not helping him to get the infection out of his body is making him suffer." He needs to go to UCSF or Highland where they can remove the teeth that are infecting the rest of his body for over a year now. That may be why his back hurt to begin with. The infection could have gone to the bladder or the kidney. I wouldn't be surprised. "I would like you to get an ambulance to take him where he needs to go."
   He said that they only deal with psychiatric issues. "Herrick won't do that." I say, what happens if the mind is connected to the body? A mind/body connection isn't exactly new news.

   I didn't get a chance tell him that I had only 2 days earlier consulted with an oral surgeon, Dr. Knowles, DDS, MD, in Alameda whom Dr. Sharma, DDS, had referred Alex to on October 7th, last year, but Villa wouldn't/couldn't deal with his dental needs either, while they detained him in their

facility until April 14th, 2015. Dr. Knowles told me that Highland or University of the Pacific only required 2 doctors' signatures, attesting to the fact that the patient was unable to make his own decisions, in order to do the oral surgery.

None of the doctors have been interested in seeing the big picture so that Alex could be properly helped. There wasn't time to explain all of this on the phone to either Dolgoff or Trautner. But, if, as Trautner said, it's true that he doesn't "want him to suffer…," the only way he won't is if doctors acknowledge that the brain, teeth and the rest of the bodily organs are all one entity, with one organ having the potential to have an effect on another, and therefore, call in or send the patient out to, other specialists when necessary to prevent the patient from suffering needlessly. His dental health has caused his physical health to beg me to take him to the emergency room. His physical health, "a broken back," according to Alex, with no findings on the x-ray to support that claim, then caused him to be admitted to mental health. The ER doctor had to know that his "broken back" symptom, simply meant "my back feels like it's broken because it hurts so much that this is what broken must feel like, but I don't really know if it's broken because I didn't go to medical school. I'm just telling you that it hurts so badly that I couldn't get out of bed to even go to the bathroom," so it feels like it must be broken. The ER doctor used Alex's own misdiagnoses of "broken back," to admit him illegally to the psych ward.

In conclusion, I would hope you would be willing to:

1. Check him for any infection that may be in the blood or possibly have already invaded other organs by this time.
2. Fix the cough and whatever other lung issues may have developed.
3. Send him to Highland, UCSF or U of P to have his teeth taken care of. I'm told that they can put him to sleep. I can make the arrangements but it has to sound important, i.e., he has to be told by a doctor that he needs to get his teeth fixed. I already went to UCSF and they are aware of the situation so I would like to request that BMH or LIFELONG be willing get him into an ambulance or some other official transportation to go to UCSF where I've already connected with a dentist,

Dr. Justin Becerra, DDS, and a psychologist, Dr. Linda Centore, PhD, in the:
Advanced Education in General Dentistry
Department of Preventive and Restorative Dental Sciences
UCSF School of Dentistry
707 Parnassus Avenue
San Francisco, CA 94143-0760
Tel: 415-476-9656
Fax: 415-502-8399

They can't do it in their office, but they know how it can be arranged.
Thank you for helping my son return to better physical health. I don't see why he has to suffer physically just because he's mentally ill and can't make good judgements. If it's true, as the Oral Surgeon, Dr. Knowles, DDS, MD, told me last month, that doing surgery against the will of a mentally ill patient, only requires 2 doctor's signature, I wonder what kept both Villa and Herrick from providing that care. They had all the doctors necessary and they knew that he had poor judgment due to the schizophrenia and the last psychiatrist he had at Villa had even changed the information officially in a letter to the conservator Renzi, in February of last year, to state that Alex *could not* make his own medical decisions. So, one can only conclude that they don't care about the seriously mentally ill. I wonder if anyone, except the parent, does. I hope so.

Sincerely,

Joan Miro

510-418-8568
joan.miro6420@gmail.com
JoanOfArt44@comcast.net

CC: Dr. J. Johns, M.D.

Monday, February 8th, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 2mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg.

This is just going from bad to worse. Determined to get everything accomplished after I finished my morning cooking, cleaning and writing, I made up my schedule to fit everything into the afternoon:

Noon…Home-Finish the LifeLong form for Alex's appointment with Dr. Herb
12:30…Kinko's- to print the letter to Dr. Herb
1:00…..Van- to type letter to Yvette Katuala to report Dr. Johns for breaking appointments
2:00…..Van- pay consumer cellular bill on phone
2:45…..Home-make sure Alex is ready to go over to BMH appointment
2:55…. BMH-deliver letter to desk before Alex's 3:00 appointment with Dr. Herb
4:00…. PO-Mail bills
4:30….YMCA bring membership form to desk before working out

After all this time, I didn't take into account that the Mental Health System is so out of step with customer service, it's beyond repair. How did I not plan for that well-documented fact? I mean, last Friday, when I received the phone message from the receptionist, Tahira, at BMH that there was a problem with Alex's insurance, it was followed with a second message, "Never mind, Nurse Peggy cleared it up." Could I not expect that the problem was cleared up? But, upon arrival at 2:50pm with the letter for the BMH receptionist, Robin, to give to the doctor, everything still looked like a go, so I left when Alex presented at the door, because I knew he wanted to handle his own business himself, and in fact, had asked me at home not to come. Leaving abruptly, I looked through the window to be certain things were moving in

the right direction. But they weren't. There seemed to be a problem and he was turning toward the exit instead, so I reentered the waiting room.

Robin said his appointment had been cancelled after all. I just couldn't believe it. I was stupefied. When I get like that, I insist on knowing what happened because I don't feel comfortable being confused. It sounded like someone out and out lied. What Tahira said they'd already figured out on Friday was still the same problem on Monday...whether or not Alex had Medi-Cal insurance. He'd had the appointment for at least 2 weeks; why couldn't they have delved into the issue before the day of the appointment? Alameda Alliance had switched him from Kaiser to LifeLong 6 months ago. Dr. Herb wouldn't see him, Robin repeated. She said I should run over to the Ashby Health Center and give them the information they needed.
"No, I'm not running anywhere. I don't have to do the running."
"Well, we'll have to reschedule."
Alberto Flores, the case manager, was still talking to Alex behind the second window. I moved over to speak to him. He didn't want to talk to me. I was probably loud and brusque by then. He kept calling me "Ma'am," and since I didn't remember ever being in charge of a brothel, I reminded him that my name was "Joan," not "Ma'am." He didn't want to talk further and slid the protective window closed. Both windows were now closed tightly. So, I knocked and Robin opened hers.
"Who is it who needs to be updated? LifeLong? Or Alameda Alliance?" I asked. "I'll call them."
She said, "LifeLong." So, I called their number already in my phone and of course, got a recording when I pressed the button identifying myself as a *patient*. So, I called again and identified myself as a *doctor* and a live person answered. I guess they think the doctor is the customer. I was probably speaking a little too loudly, explaining the situation, and when she got a grip on the fact that I was not a doctor, she transferred me to an inside line where someone actually answered. I explained the problem to her: "My son had an appointment and was told when he arrived at 3 o'clock that the doctor couldn't see him because you don't have his insurance information. But, you must have it, because when he had another appointment with another doctor, Dr. Nguyen, at the Ed Robert's Campus building, she was willing and able to see him. So, why now is the doctor not willing to see him? Do you know how difficult it is to get an unwilling, schizophrenic patient to see a doctor?! I've been calculating for years about how to get him to see a medical doctor and now she's cancelling. For *YEARS*!" I went on like that to deaf ears, without hearing a response, thinking she might have hung up, so I handed my phone through the window to Robin, who I imagined would be able to talk with less emotion. She was willing to speak, took the phone and introduced herself as an employee at Berkeley Mental Health, explaining that she doesn't work for LifeLong, but that BMH provides a place for LifeLong to see their BMH clients. I should have put it on speaker phone before I handed it to her, because I could only hear Robin's side of the conversation. By this time I found a pen and grabbed the envelope—the one in which Alex had delivered the four more pages of documents that Tahira had asked me to fill out—to take notes.

"We're told that his insurance information is not updated in the system," Robin said to the LifeLong employee. "What can we do to update the information? He didn't come in so it could be updated" (That meant Robin was using Alex as the excuse for not having the needed information.)…"Can I ask a huge favor? Once you update it, can you call us and let us know? Because you are a representative of Ashby Health, can you let me know that it has been updated?...This is not their office; they just see the client here." Robin said she was speaking with Angelia at LifeLong, who said that I would need to leave a voice mail with the eligibility people at LifeLong, to the effect that Angelia had just updated the information about Alex's eligibility. (It sounded like Angelia was now putting the responsibility to transfer the information on my shoulders. I already did my part in calling Alameda Alliance to change his insurance from Kaiser to LifeLong. No one told me then, that I had to do something else.)

So, why didn't BMH do that before, when they knew Alex's appointment had been made 2 weeks previously? I explained that I had switched him from Kaiser to LifeLong last September. That's half a year ago. Why didn't they do what the LifeLong rep was just able to do in just a minute or two, 6 months before, when Alameda Alliance had made the arrangements to switch Alex? They had enough time to update his information. Wherein lies the blame? I was never informed that I had to do anything more. I had called Alameda Alliance in early September because they're the organization set up to handle Medi-Cal in Alameda County, California. They sent me their papers listing all the provider choices in order for Alex to choose a new health plan. I picked LifeLong because their building was within walking distance and that was what Alex told me he wanted, so he could "walk to the doctor." But, the people in his head who keep him safe, telling him what he can and can't do, wouldn't let him go into the new Ed Robert's building ("because they do crack cocaine over there," he said) or even to the LifeLong urgent care clinic in the Herrick Hospital building. The voices told him he could only go to BMH with whom he was familiar after 10 years in their care. Now, LifeLong's lack of follow-through and customer-service knowledge forces me to pick some other medical care provider and Alex won't like that. And I'll have to call Uncle Jerry for some help in financing a private provider. Everyone should have an Uncle Jerry.

It took me from 4pm when I finally left BMH until 1am this morning, with the help of a round of gym exercises and 3 TV episodes of *When Calls the Heart* to calm down enough to write. I bet they wished they could afford a security guard or two at BMH, like they have at Herrick, so they could have escorted me out, like they did at Herrick. At least the BMH people showed more compassion. Nurse Peggy came out of the office to where I was crying over by the windows, to explain to me that this is a big issue and they're working on how to figure it out. Deepa, Dr. Herb's assistant, also came over to me to say the same thing. She indicated that Tahira, on Friday, shouldn't have called back to say that everything was OK. They did still need information about his insurance, she said. I told Deepa that I didn't have any more information; I gave it all to Alameda Alliance on the phone in September. So, Alameda Alliance, who represents the Medi-Cal program, who, in essence, *IS* Medi-Cal in Alameda County, CA, are the people who have all the information, already had the information, and, indeed, simply didn't put it into their computer until the moment that Robin spoke to the Alameda Alliance worker, Angelia. So, it was

someone in Alameda Alliance, themselves, who just didn't update the insurance in all the computers, even though they've had the information to update the insurance for 6 months.

This is exactly what Henri Montandon, M.D., Ph.D., was talking about, when he wrote about the absurd treatment of patients by the Mental Health System, from his own perspective as a psychiatrist. The lack of understanding about who they are supposed to be serving is rampant and extends from the lowest functioning worker in the system to the highest paid *servant* - the doctor. Their lack of accountability is rampant as well; apparently, they can do what they want, without consequences. They just don't know, don't want to know and don't have to care about serving their customers. They probably don't even know that the patient is the customer of their services.

I experienced this for myself, more than once. The most grievous incident of doctors not realizing that I was the one who she was supposed to be helping, a doctor who was supposed to be serving *me*, not a mental health doctor, but my own doctor at Kaiser Permanente in Hayward in 2009 until 2011, who told the judge when I took her to arbitration, that she couldn't give me a surgical consult even after I had received all of their protocol for the 2 previous years with another Kaiser doctor in Oakland who also had given me no option to see an orthopedic surgeon following my January 2007 car accident. They let me suffer in intolerable pain for at least 3 ½
of the 4 years before I finally got a surgery consult and needed a laminectomy and fusion ASAP. She told the judge that she couldn't let me speak to an orthopedic surgeon, "because my colleagues would think I had poor clinical judgement." So, who was she concerned about? Not her patient, for sure. No, the customer was apparently her colleagues. I can only conclude from this incident that Stanford University, where she went to medical school, didn't provide training in customer service as they do in their business school.

Unless something changes, and changes quickly, I'm out. The End! I've become Rip Van Winkle. The first of next month, Alex's 38th birthday, is the end of 20 years of sleeping through my own life. So, now I'm waking up. I was supposed to be in business as Joan-Of-Art-Centerpieces™, manufacturing Goodie Table Designs© starting when I exhibited my new product at McCormick Place that October in 1995, just as Alex was getting sick. There was interest enough to be able to obtain free magazine and newspaper promotions, receive over 100 phone calls expressing interest, make enough sales to pay for the cost of printing the tablecloths plus profit, and receive an invitation to speak to 600 caterers and event planners. The Manager of Catering, Gail Skelton, at The Ritz-Carlton Hotel in Atlanta called me after seeing the write up in *Special Events Magazine*. She sounded excited to ask me to be the keynote speaker at her organization's national convention in Seattle, the International Society of Event Specialists, so I could tell them how I came up with the idea of dessert centerpieces. And that was August of 1998, before the fruit people. Now that I had finally found my market, I couldn't take them up on it because I, myself, was too overwhelmed by his illness to put the necessary energy into serving the Hospitality Industry. The whole venture had already begun to lose steam when Alex became obviously psychotic that March 1st 1996, his 18th birthday. So, I decided that I couldn't do it because I didn't have the necessary energy two years later. I needed counseling myself.

And I owed the design of my new product to Alex, so he came first. The very idea for the business only came into my head because of a mother's love for her little boy—causing me to make the first table top centerpiece for his 4th birthday party at nursery school. I didn't even have a camera, because I didn't know what I would be doing; I just brought a bunch of goodies to school. My brother Jerry came over later to take pictures of the event. So, I made the decision to take care of Alex instead of taking care of business. It was impossible to do both so emotionally draining was the unpredictability of his behavior.

Now that I see that the state of the mental health system, itself, is going nowhere, I have to return to Goodie Table Designs just to preserve my own sanity. Why? Because there is no "system" in the Mental Health "System." Because there is no help that one would expect from the people who are supposed to be serving him. Because there is no medicine that brings him back to anywhere near normal so the rest of his family or friends would want to be in his life. Because serious mental illness isn't a high priority in Washington. Because psychiatrists like to treat patients based on what they see in front of them, rather than talking to the family about what doctors apparently think is *irrelevant* history, *so the doctor ends up repeating what didn't work before*. Because there is so little attention being paid to the issue of serving the seriously mentally ill, that he is relegated to remaining sick for as long as he shall live. And based on his life style of making poor judgements, it shouldn't be too long. Most of the people employed in the mental health field whom I've encountered, seem either disoriented themselves, disengaged from any work ethic or purpose, and disconnected or overwhelmed because they can't get the necessary cooperation amongst other personnel similarly employed within the system, for the system to function smoothly enough, to cause employees to be motivated do their jobs. They apparently, see no purpose in being focused on patients, when they can get by without caring about doing the job they were hired to do. So, what's the point?

In the end, more people have to want to make the system work better, not just a few mothers. A lot of help is needed to put the necessary pressure on government workers and their supervisors, who handle programs like Medi-Cal, for instance, to exact a better outcome for Medi-Cal recipients. But, why should workers want to do their jobs when they can get their paychecks anyway, even with low-level performance? Perhaps the answer lies in providence: No one knows who will be affected next…maybe someone *they* love. Then, they will be the ones needing a better support system for the future. If they don't change their work habits, and realize who they are supposed to be serving, their children and families will suffer, too. The only thing we *do* know for sure, is that someone's child will soon be struck down with a serious mental illness. Whose family will be the next to suffer? One in four families are already affected by serious mental illnesses. So, why can't families, legislators, government workers, psychiatrists, psychologists and other mental health employees, work together to set up the Mental Health System to do the job it should be doing now? Speaking for myself, I say, "Let's make it happen!"

Wednesday, February 24, 2016

Olanzapine 15mg; Not sure about the Metoprolol 50mg being taken last night-maybe they gave it in the ER; the Benztropine wasn't taken either am or pm yesterday; Not sure about the Amlodipine Besylate 10mg being taken last night-maybe they gave it in the ER; Depacote 1500mg; Asenapine (Saphris brandname) 5mg.

Oh, is there more? Yes, it's never ending. Alex is back in the Alta Bates Emergency Room. He walked there last night because I called the non-emergency police line around 9pm and he didn't want to see another police officer after my neighbor, Wesley, had already called the police earlier in the afternoon around 3pm. "They cuffed me," Alex told me at 9pm, as I was trying to explain that he needed to take the blood pressure medicines, even though his psychiatrist didn't put them on the list he gave to Alex, a list of "only those medicines I'm supposed to take," Alex said. But, *it wasn't the list of all that he was supposed to take*; it was a list of the medicines that Dr. Johns was willing to prescribe. There's a big difference. Alex was supposed to get the prescription for his blood pressure medicines from Dr. Herb, since she's now his medical doctor. But, of course, she cancelled his appointment on the 8th and he refused go on the 22nd. So, he never got a prescription nor did she call it in to CVS.

The officer I spoke to on Tuesday afternoon said they were going to take him to an ER, but for one reason or another, they took him into BMH which was just down the block. Maybe that was the reason. I didn't know this until Alberto called, sounding a little giddy. He apparently wasn't told that Alex had yelled at me at a very high decibel rating, as I was getting into my van, so of course I knew that Alex was in police custody, because I had asked Wesley, my upstairs neighbor, to call them since I couldn't locate my phone at that moment. I wasn't really sure if Wesley called, because he went into his apartment immediately, and I know he doesn't like to get involved in other people's affairs. But, being a compassionate person, he did, because I asked him to. I really felt threatened as Alex loomed too close for comfort while so upset. No, Alex was volatile, not just upset. He realized that he couldn't cajole me into giving him his $20. I was serious about not giving him his money if he didn't go to the doctor. And he didn't go, just the day before.

Nurse Peggy had made the appointment for him two weeks before, to see Dr. Herb on Monday, the 22nd, at BMH. She'd given me the appointment slip on the day that Herb wouldn't see him, Feb. 8th. I was soon to find out that he wouldn't go this time because "She cancelled our appointment last week," he said, talking about Dr. Herb. He probably took it personally. It had taken a lot for him to walk into BMH at the time of the appointment, just to have the door slammed in his face, as it were. So, he didn't want anything to do with them, I imagine. I couldn't get him over there, nor could Peggy, who actually came over to the apartment on Monday, 15 minutes before the 2nd appointment, to coax him to come over. He wouldn't. All I heard was double talk. He's good at that. He sounded pleasant, but it was hard to understand. He wouldn't budge. It was compassionate of her to volunteer to come over, when I went there to talk to her, a half hour before the appointment.

I'd sent an e-mail about an hour before Alex's outburst on Tuesday, to a general number that I'd located on the web, as well as to the BMH Compliance Officer, explaining what's going on in more depth and received this reply in just a few hours.

RE: Changing the patient's medicine delivery
Sent By: MentalHealth
On:Feb 02/24/16 9:01 AM
To: JOAN
Cc: Steven Grolnic-McClurg
Hi Joan
I'm forwarding your email to Steve, Grolnic-McClurg our mental health manager.
Thanks for bringing your concerns to our attention.

Patrina Foote'
Mental Health Division-FYC
Health, Housing & Community Services
3282 Adeline Street
Berkeley, CA 94704
(510) 981-5233 (ofc)
(510) 981-5255 (fax)
email: pfoote@cityofberkeley.info

Please be aware that e-mail communication can be intercepted in transmission or misdirected. The information contained in this message may be privileged and confidential. If you are NOT the intended recipient, please notify the sender immediately with a copy of HIPAAPrivacy@CityofBerkeley.info and destroy this message immediately.

From: JOAN [mailto:JoanOfArt44@comcast.net]
Sent: Tuesday, February 23, 2016 1:18 PM
To: MentalHealth <MentalHealth@ci.berkeley.ca.us>; Katuala, Yvette <YKatuala@ci.berkeley.ca.us>
Subject: Changing the patient's medicine delivery

To whom it may concern in mental health at the City of Berkeley:

I'm trying to make sure my son takes his medicine...on time and accurately. He completely ran out last Friday, of one of the several meds that he takes, because his psychiatrist, Dr. Johns, changed the way Alex's meds are delivered. There should be a conference before any such changes are made that should include the mother, when the mother is and has been the patient's main or only care giver. I'm the mother, the person who has for most of these past 20 years, when he's been living with me, (approximately 18 years considering hospitalizations and board and cares) been picking up

the medicines from CVS (or other) Pharmacy and Alex has been willing and able to take them in my presence up until now. I do not want his willingness to take the medicines to end, because of the way the medicines are now being delivered.

All of a sudden I wasn't able to pick up the Benztropine last Thursday, because there was no prescription renewal from Dr. Johns, the CVS pharmacy assistant said. I heard the pharmacist tell his assistant that Dr. Johns only told him that he would no longer prescribe the Metoprolol, even though I had informed the BMH receptionist, Robin, that we were completely out of the Benztropine. Johns apparently said nothing about the Benztropine to the CVS pharmacist. There was no word of what was going on with the Benztropine, even though we were out. Alex didn't know how it would get into his hands, nor did I. And then, a representative of a different pharmacy delivered half a month of Benztropine to our door. That may sound good to someone who doesn't understand schizophrenia and how it has taken over my son's brain.

This is the issue: Apparently, no one asked Alex what it was that he wanted. They just went ahead and made changes that suited themselves at BMH. So, please allow me to inform those interested parties in the mental health field at BMH, that what he wants is this: to be able to be more independent and take care of himself. I think that is a laudable desire, and one that I have been trying to encourage by making sure his medicines are doing what they should be doing. Yes, I have been monitoring and evaluating how good he is at any point in time, based on the medicine that he is taking and has taken over most of these 20 years, because I want him to get better. And for my own safety, because I live with him, I need to be sure he is stable. And it has been a tremendous challenge to be able to get him to the point where he wants more independence without (his) being a tyrant. He now wants to cook his own meals, pick up his own medicine, take the medicine on his own, etc. The doctor should have asked Alex what it was that he was trying to achieve by changing the way the medicines are delivered. What he wants is to be able to pick them up himself, so that he can have that feeling of independence, but they have to be available before he runs out of the previous batch, and they are not. The Benztropine that was delivered last Friday is still not available to Alex... Alex won't take them *because* they were delivered. He asked to *pick them up*, but they were "delivered" instead. Because of that fact alone, Alex won't take them. He says that they are not his, that they may have been tampered with, that *I ordered them* to be delivered when he wanted to pick them up. What Alex told me just now about the situation is: "You can only take 1 prescription at one time, not two. I can't take your medicine, Joan. That medicine that was delivered wasn't mine; it was yours. I keep all my medicines in my backpack." Granted, he's still confused and delusional, but he wants to be more in charge of his own life, none-the-less. That's a good thing, isn't it? So, he wants to do what he *can* do... to pick up the medicine, whether from CVS or BMH. But, if he goes to BMH to get them, he's not going to be able to take them before BMH closes. He takes half of them at 9pm, not at 4pm. He usually falls asleep an hour after the Zyprexa is taken. I don't want him going to sleep at 5pm.

I did come into BMH this morning and asked to speak to Nurse Peggy, who is not really handling his case like she used to, but has always been a willing BMH employee to stand up to help whenever I needed help to work through the system. Unfortunately, our brief conversation didn't produce the Benztropine that he needs today, before he goes off, for lack of it. Not taking it does make him testy, at best. And not having come to a conclusion that would give Alex the medicine that he needs today, motivated me to sit down to write about the situation. It's all a matter of customer service, or the lack thereof. According to a very successful retail department store owner, you have to find out what the customer thinks they want and give them what they really need.

I'm sending this to the only e-mail addresses that I have been able to find.

Sincerely,
Joan Miro
attachments: a few journals of the last 5 years while Alex was with BMH

I decided to go over to BMH after writing this, to tell Alberto that although the Alta Bates psychologist, Dr. McGuire, said the ER was going to discharge him to home around noon today, he still wasn't home at 3pm. So, I wondered if he had stopped over to see anyone at BMH. Alberto replied negatively. I had another question for Alberto, while I was there: "I don't understand, Alberto. Dr. Johns wrote a list of medications that Alex now keeps in his backpack, that is supposed to state everything that Alex has to take, but the blood pressure meds aren't on that list. Why is that?"
"Yes, the list does have all the medicines that Alex is taking. So, he's not taking Metoprolol anymore if that's not on there."

It was a brief, unplanned conversation and I didn't want to take more of his time. But, I wondered how, after being on blood pressure meds for over 15 years, he all-of-a-sudden doesn't need them. It certainly looked like, when he yelled at me yesterday, his blood pressure was elevated to at least 170/135. I have high blood pressure, too, so I know what it looks like. If under normal conditions his blood pressure is under 120/89, isn't that because he's taking the blood pressure meds? He was still taking the Metoprolol and the Amlodipine until Monday, February 22nd, and only refused to take it on Tuesday evening, because he insisted on following Dr. Johns' list, and the Metoprolol wasn't on that list. And it's not only his blood pressure that is at risk. Last Thursday, when I asked Robin to ask Dr. Johns to reorder the Benztropine, and then went to CVS to pick it up, I found then, that he intentionally didn't reorder it at CVS, but switched it to another pharmacy without saying anything to either Alex or myself. The pharmacist acknowledged that Dr. Johns did call but only to say that he's not prescribing blood pressure medications anymore. He had nothing to say about Benztropine.

Now, that's not the first time he has said he wasn't going to prescribe the blood pressure meds. The first time was several months ago shortly after Alex was discharged from Villa. He wanted Alex's Kaiser doctor to write that prescription since Alex still had Kaiser. But Alex hadn't been to a Kaiser medical appointment for maybe 4 or 5 years, so the doctor in Union City Kaiser wasn't thrilled to write it, but she did, and had been writing it all along, since she was the last medical doctor that Alex had seen, other than in emergency rooms. Around August, 2015, because he wouldn't even go to Oakland Kaiser, but promised he would go to be seen by a medical doctor if he could walk there, I was arranging to switch Alex from Kaiser to LifeLong. That came through in September of last year.

The Kaiser physician, Dr. Yonabayashi, had been reluctantly, but kindly, writing the prescriptions without having recently seen Alex and she didn't want to continue doing that. She had done it for years, since Alex was seeing the BMH psychiatrist before Dr. Tran. That doctor was the one who would call her to ask her to call in the prescription to Oakland Kaiser pharmacy where I would pick it up. But, I had to switch Alex to another provider organization, because he wasn't willing to get into the van to drive to Kaiser appointments. The voices tell him he

can only walk. LifeLong was to provide the next medical doctor starting last September. But, Alex still refused to go, even though he could now walk to the Ed Roberts Campus less than a mile away. Maybe lying is in his genes, not from me, of course. I remember asking Dr. Johns to please continue to write Alex's prescriptions for blood pressure, because I could no longer get them from Kaiser, since he dis-enrolled, and he still hadn't seen Dr. Nguyen at LifeLong, although she had called several times to try to connect with him. She sounded frustrated but relieved when I called her to say that I finally put it together that Dr. Herb was also a LifeLong provider, and available at BMH, so Alex could see her, instead, because he was more familiar with BMH. Dr. Johns had consented to continue the job of writing the medical prescriptions since Alex's discharge on April 14th of 2015, from Villa, until Alex was able to see a medical doctor. But, I can only suppose that he didn't want to do it anymore. And I guess that was last Thursday that he decided he wasn't going to write both the blood pressure and the omega 3 fatty acid medicines. But, Alex's need for blood pressure medicine hasn't changed. If it's good, it's because he's been on the Metoprolol and the Amlodipine Besylate, and if it's too high, it's because he's not getting the Metoprolol. No, it's not the need for the blood pressure medication that has changed, it's the decision of the doctor to not write the prescription for a medical medication because he is only responsible for writing psychiatric medications and he doesn't want to have to write additional prescriptions just because Alex didn't see a medical doctor. Alex's high blood pressure was discovered and treated not too long after he became ill with schizophrenia. I would think his blood pressure became high just dealing with these new delusions and hallucinations…which he still has to deal with on a daily basis. And no matter where he has been treated, he always needed and received blood pressure medication. So, all-of-a-sudden, just because Dr. Johns is tired of writing the extra prescriptions, am I to think that Alex's blood pressure is now normal? I greatly doubt it. But, Alberto said Alex didn't need anything except what was on the paper.

The more psychotropic medicines he takes, the easier it is for him to anger, therefore, the higher the blood pressure goes. Everything is related. As he was feeling a new independence from the administration of the newer psychotropic medications, Latuda and Saphris, a few new results had/have been produced, causing him to run away overnight for up to 24 hours each time, and to have to survive on the streets every 3rd day (on the Latuda), and the smashing of his backpack on the dining room table 5 times in a row, while keeping a steady glare at me (on too much [10mg] Saphris), making me think that he needs both the Metoprolol and the Amlodipine to keep him from having a stroke. And that's what I'm trying to prevent…a stroke. It's in the family history. I don't want him to have a stroke in addition to all this schizophrenia hell. That's where I know more than Dr. Johns knows, because I not only live with him, I've been observing him and documenting, documenting and observing, until the pieces just fall together on their own. Whereas, Dr. Johns hasn't even seen him since Monday, November 23rd, 2015. On Wednesday, December 16th he called in sick, and in January the doctor was a no show, and no one even called to let us know that the appointment wasn't happening, and on Thursday, February 25th, when it was rescheduled, he didn't knock either, because I was typing not 10 feet away from the door all day, and still no one let us know that he wasn't coming to Alex's appointment. Yet, it's a lot of work for me just to make sure Alex remains at home for the appointment. He forgets and is always ready to take off. I have to keep my eye on him. And when he does "see" him, Dr. Johns is really talking to me, while Alex is in his room and may

come out to talk for a few minutes, or may not. Alex will come outside to talk to BMH personnel when he wants to complain about me because I might not have given him all of his money. One might want to know why I do that; let me explain.

I've been incorporating the strategy promoted both by behavior modification practitioners in the educational field, (which included spending 20 working years for both the Philadelphia School District, and the San Leandro Unified School District plus substitute teaching in other Bay Area school districts after retiring) and by a Dr. Ragins from Long Beach, who writes that one has to find out what the patient "wants" so they can be encouraged to do something in order to get what they want. Liz Rebensdorf, NAMI East Bay President, even acknowledged what I was doing a couple of support groups ago, after she'd heard of some other research that rediscovered that same strategy: find out what they want and then make them work to get it. When he brushes his teeth, he earns a dollar. Just this morning, when he asked for his money, I said, "Did you remember to brush your teeth?" and without a problem he went into the bathroom and brushed. And he earns more dollars for:

1. Keeping the apartment door locked always
2. Helping out
3. Being home before dark (or outside in the back yard to smoke)
4. Dressing appropriately when outside, and only 'reasonably' fashionable
5. Cooking only when mom is home and knows you're cooking
6. Eating at least 1 meal at home
7. Going to all scheduled appointments
8. Washing at least 5 dishes after eating or cooking
9. Drying hands after washing them
10. Drying body after shower
11. Keeping your bed room in order, that is, put things where they belong
12. Helping out with your laundry, that is, at least put it away or come to the laundromat
13. Being pleasant
14. Keeping mattress from getting ragged, that is, keep your shoes off the edges, and keep it dry
15. Sleeping quietly after 10pm and before 7am, that is, no loud mantras
16. Keeping your room clean, that is, no food squashed in a napkin and hidden in drawers or closet
17. Using soap when washing body
18. Flossing teeth at least once /day
19. Brushing teeth at least twice/day

20. Either wearing warm pajamas and one blanket or if no pajamas, then 2 blankets
21. Taking all medicines on time, drinking liquid after each one
22. Socializing during the day- Ashby Flee Market, La Chiam, BMH- say hello when appropriate
23. Not going outside to smoke until after 7am

The problem with implementing any kind of behavior-mod approach is that Alex is so ill that he doesn't think he needs to do anything to have money because he's under the delusion that he has a retirement income that he is entitled to, to do with whatever he wants. Of course, he does receive Social Security to the amount of what his father would have been receiving had he lived. And I take almost half of it to go towards the rent, food and utilities. The rest is the $20/day that he gets when he does what he's encouraged to do. But, Alex doesn't want to understand that the amount is a limited amount, just under $1,200/month. He has the delusion that he has enough money to do whatever he wants to do, because, he says, his Uncle Jerry replenishes his bank account with the exact amount that Alex withdraws. Just as soon as he takes that amount of money out of said account, Uncle Jerry puts it back in, leaving in the account at any point in time, a balance of $3,000, Alex believes. So, he has virtually, an endless amount of cash. His delusions put me at a disadvantage. But, making it clear to him that he won't get his money until he brushes his teeth or goes to the doctor's appointment, etc., keeps him in better health.

It's sometimes difficult to enforce, especially when he complains to BMH that "She's not giving me my money." Alberto told me today, Wednesday Feb. 24th, to "Give him all of his money!" no matter what. That was the day after the police incident. I say, Alberto either was never a teacher or doesn't really care about Alex's health, as Villa personnel didn't, when they refused to take him to the oral surgeon to have his 3 abscessed teeth pulled, even though they detained him for 8 months in their facility. I'm just hypothesizing here, but I believe Alberto would simply prefer that Alex not bother him about the money. Yet, I feel that the case manager should be supporting the family in trying to train Alex to do the things that a normal person does without even thinking about it. But, BMH doesn't try to support me in my quest to make Alex healthier and more normal, so Alex fights me that much more. Instead, they go along with Alex's delusions and "support" *him* in his quest to be more ill because, should the truth be known, they are simply hoping to keep him quiet, rather than helping him to recover.

This afternoon I found myself driving to the Berkeley Marina, because I always have to be near water when I'm feeling disoriented. So, that's where I am, sitting and typing, now that I've finished walking around the boat docks and looking out across the bay to San Francisco. It's a relaxing scene. And after some serious reflection, I determined that Alex needs the Benztropine (1 gram-twice a day) prescription, the Metoprolol (50mg) as well as the Omega-3 Ethyl Fatty Acid (1 gram in morning) to be called in to the CVS Pharmacy ASAP. Alex was better with those medicines since he left the hospital. The medicines on Dr. John's list are incorrect. They don't include, not only the Metoprolol, but the reduced dose of Saphris (5mg only taken once/day in the morning). He got his list from Herrick Hospital and since

Johns hasn't asked Alex what he's now taking, nor has he talked to me since the discharge, he doesn't know what has transpired. I would encourage Dr. Johns to read p. 92 in regard to the Saphris, because after only 1 week on the 5 mg Saphris, taken both morning and night, (total 10mg/day) Alex was very agitated, almost like he was on the Latuda, so he's only taking it in the morning now, once a day since a week after discharge, because I don't want him that agitated. He was tyrannical. That was inappropriate behavior and I won't have him acting like that due to a medicine. According to the Hofstra study that was released last October (p. 61 and repeated below), "In the new study, doctors used the medications as part of a package of treatments and worked to ***keep the doses as low as possible*** minimizing their bad effects":

> Doctors praised the study results.
>
> "I'm very favorably impressed they were able to pull this study off so successfully, and it clearly shows the importance of early intervention," said Dr. William T. Carpenter, a professor of psychiatry at the University of Maryland School of Medicine, who was not involved in the study.
>
> Dr. Mary E. Olson, an assistant professor of psychiatry at the University of Massachusetts Medical School, who has worked to promote approaches to psychosis that are less reliant on drugs, said the combined treatment had a lot in common with Open Dialogue, a Finnish program developed in the 1980s. "These are zeitgeist ideas, and I think it's thrilling that this trial got such good results," Dr. Olson said.
>
> In the new study, doctors used the medications as part of a package of treatments and worked to keep the doses as low as possible minimizing their bad effects. The sprawling research team, led by Dr. John M. Kane, chairman of the psychiatry department at Hofstra North Shore-LIJ School of Medicine, randomly assigned 34 community care clinics in 21 states to provide either treatment as usual, or the combined package.
>
> The team trained staff members at the selected clinics to deliver that package, and it included three elements in addition to the medication. First, help with work or school such as assistance in deciding which classes or opportunities are most appropriate, given a person's symptoms. Second, education for family members to increase their understanding of the disorder. And finally, one-on-one talk therapy in which the person with the diagnosis learns tools to build social relationships, reduce substance use and help manage the symptoms, which include mood problems as well as hallucinations and delusions.
>
> For example, some patients can learn to defuse the voices in their head — depending on the severity of the episode — by ignoring them or talking back. The team recruited 404 people with first-episode psychosis, mostly diagnosed in their late teens or 20s. About half got the combined approach and half received treatment as usual. Clinicians monitored both groups using standardized checklists that rate symptom severity and quality of life, like whether a person is working, and how well he or she is getting along with family members.
>
> The group that started on the combined treatment scored, on average, more poorly on both measures at the beginning of the trial. Over two years, both groups showed steady improvement. But by the end, those who had been in the combined program had more symptom relief, and were functioning better as well. The researchers expect to have lowered average doses in the combined program but had not yet finished analyzing that data.

"One way to think about it is, if you look at the people who did the best — those we caught earliest after their first episode — their improvement by the end was easily noticeable by friends and family," Dr. Kane said. The gains for those in typical treatment were apparent to doctors, but much less obvious.

Dr. Kenneth Duckworth, medical director for the National Alliance on Mental Illness, an advocacy group, called the findings "a game-changer for the field" in the way it combines multiple, individualized therapies, suited to the stage of the psychosis.

The study, begun in 2009, almost collapsed under the weight of its ambition. The original proposal called for two parallel trials, each including hundreds of first-episode patients. But that plan was changed due in part to recruiting problems, said people familiar with the project.

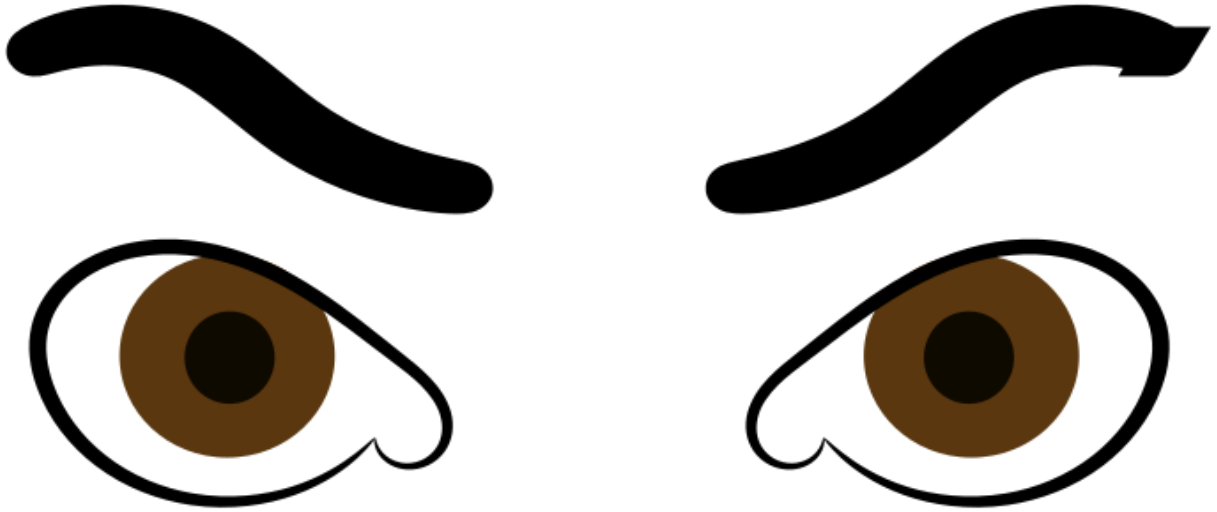
"It's been a long haul," Dr. Heinssen added, "but it's worth noting that it usually takes about 17 years for a new discovery to make it into clinical practice; or that's the number people throw around. But this process only took seven years."

Correction: October 22, 2015
An earlier version of this article referred incorrectly to the conclusions of the study. Though it studied a program intended to reduce medication dosages, the researchers do not yet know for sure if dosages were lowered or by how much. Therefore, the study did not conclude "that schizophrenia patients who received smaller doses of antipsychotic medication and a bigger emphasis on one-on-one talk therapy and family support made greater strides in recovery." (The study did conclude that the alternative treatment program as a whole led to better outcomes.) The article also erroneously attributed a statement to Dr. Robert K. Heinssen, who oversaw the research. It was scientists familiar with the project — not Dr. Heinssen — who said that the study's original proposal, calling for two nearly identical trials, was changed in part because of recruiting problems. (Dr. Heinssen said that one trial was redirected, but did not say why.) And because of an editing error, the article misidentified the institution of which Dr. Heinssen is the director of services and intervention research. It the National Institute of Mental Health, not the Centers for Medicare & Medicaid.

A version of this article appears in print on October 20, 2015, on page A1 of the New York edition with the headline: *New Approach May Alleviate Schizophrenia*.

The psychiatrist at Herrick, Dr. Stanger, M.D., who first prescribed it, agreed to lower the 10mg starting dose, but he never did. He didn't keep it low, that is, as we agreed he would. I meant lowering the usual starting dose, 10mg., by 50%, according to the Hofstra Study, and keeping it low until discharge. He started it at 5mg., at 5pm, according to insider information, but added another 5mg. for the morning administration, *the very next day*, which is the regular starting dose, so sly was he in telling me one thing and doing another.

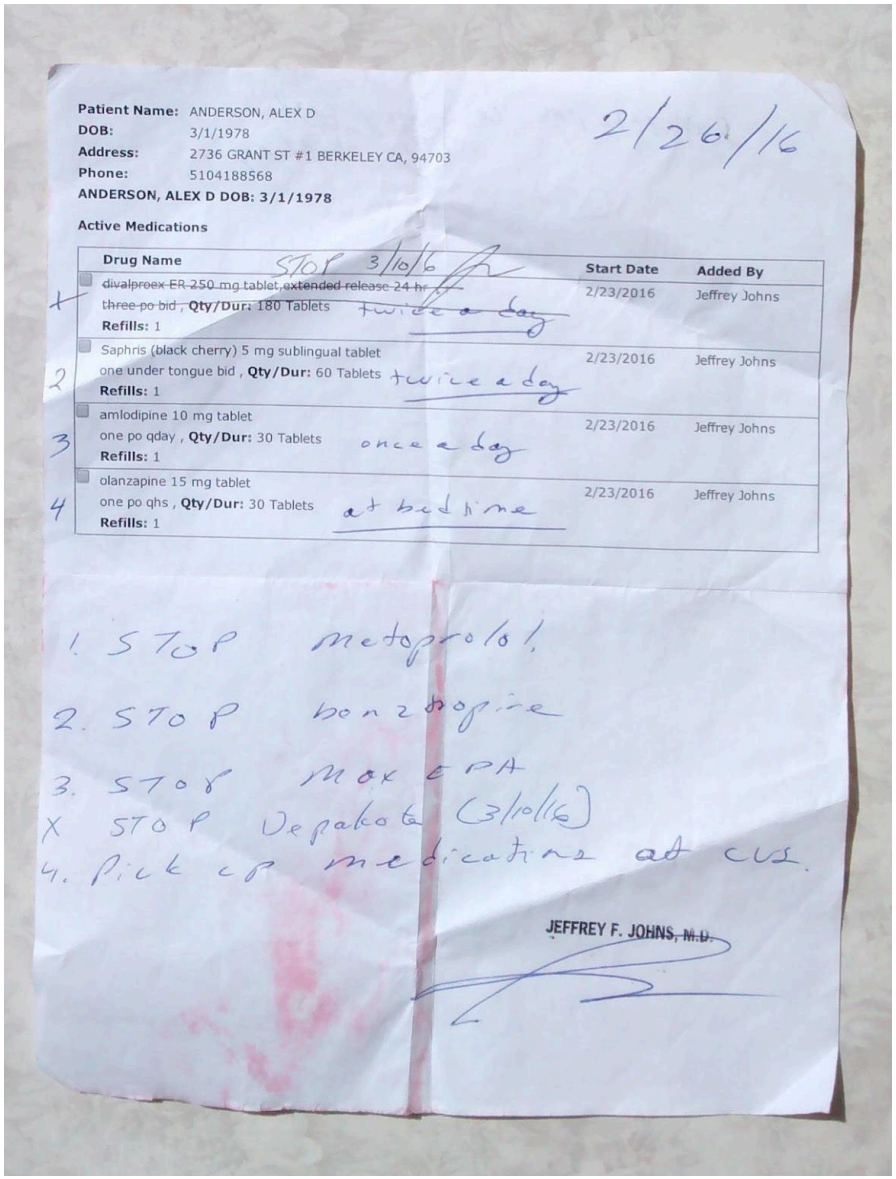
Remember boys, *I'm the MOTHER and I'm watching!!!!!* Save your tricks for Halloween.



Friday, February 26, 2016
NO Omega 3 Fatty Acid; Olanzapine 15mg in pm; NO Metoprolol; Benztropine 1mg in am only; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg in am 0mg in pm.

At pm medicine time, Alex showed me a new list of meds that Dr. Johns gave him today, discontinuing the Metoprolol, the Benztropine and the Omega 3 Fatty Acid as of tonight. What is his motivation, I wonder, to make those kinds of changes all at once? He told Alex to *take the Saphris 2 times/day*, according to the paper, as Dr. Stanger had prescribed, and to make those changes immediately. I, very sincerely, told Alex: "No Saphris in the night time, only in the morning. You are only taking 5mg/day." He said he won't take it, (the nighttime Saphris) but I don't really know. He didn't take it at the table tonight, but who knows that he won't take it later in his room. He keeps everything in his backpack and keeps it with him wherever he is. He wants to follow doctor's orders, and that's usually a good thing.

I guess Dr. Johns didn't like what I had to say about him, or maybe he didn't like that the journal got into the hands of his boss. Maybe Johns wants Alex to kill me and then have a stroke with that high dose of Saphris plus the 15mg of Zyprexa and no Metoprolol. Raising the Saphris would be a good strategy to accomplish that. Or maybe he thinks the doctors at Herrick, who prescribed the meds, at least one of whom went to Harvard Medical School, (Robert Dolgoff, M.D., I believe, the only one who called me on day 1 to get the mother's take on his patient). Did Johns think the Herrick doctors are stupid, for prescribing two blood pressure meds and a Cogentin generic. And then, Alex said, Dr. Johns took the vials of Metoprolol and Benztropine from him, *so he wouldn't be able* to take them. I don't think Johns makes the co-payments, so I can't imagine that they're his to take. No, I've been making the co-payments all these years, because I've been the one until now, picking up the medicines. I'm going to e-mail the president of NAMI to get a recommendation for a private psychiatrist. What happened to "Do no harm?"



Patient Name: ANDERSON, ALEX D
DOB: 3/1/1978
Address: 2736 GRANT ST #1 BERKELEY CA, 94703
Phone: 5104188568
ANDERSON, ALEX D DOB: 3/1/1978

2/26/16

Active Medications

	Drug Name	Start Date	Added By
X	~~divalproex ER 250 mg tablet,extended release 24 hr~~ STOP 3/10/16 ~~three po bid~~ twice a day , **Qty/Dur:** 180 Tablets **Refills:** 1	2/23/2016	Jeffrey Johns
2	Saphris (black cherry) 5 mg sublingual tablet one under tongue bid twice a day , **Qty/Dur:** 60 Tablets **Refills:** 1	2/23/2016	Jeffrey Johns
3	amlodipine 10 mg tablet one po qday , **Qty/Dur:** 30 Tablets once a day **Refills:** 1	2/23/2016	Jeffrey Johns
4	olanzapine 15 mg tablet one po qhs , **Qty/Dur:** 30 Tablets at bedtime **Refills:** 1	2/23/2016	Jeffrey Johns

1. STOP metoprolol
2. STOP benzodiazepine
3. STOP Max EPA
X STOP Depakote (3/10/16)
4. Pick up medications at CVS.

JEFFREY F. JOHNS, M.D.

Let's look at Benztropine to see what that's about. The first time he received it in recent times was last December, when Dr. Dolgoff took care of him at Herrick, (p. 76) but Dolgoff left after a few days for the holiday, and Dr. Fisher took over, then, after a few more days, Dr Troutner took over. Somewhere along the line, he was getting Benztropine that week because Alex hadn't taken Benztropine (Cogentin) before that admission since May 7th of 1997, when Villa Fairmont made him catatonic for 10 days on Cogentin, Haldol, Zyprexa and Resperdol administered all at once while the psychiatrist, Dr. Economy tried to change him from the Zyprexa back to Haldol. From that perspective, it looks like it may not be what Alex needs. Plus, Alex doesn't have Parkinson's disease, and he's not taking Haldol. And whenever he stops taking the Benztropine, there is always a bad reaction of anxiety. But, why didn't Johns *reduce it* instead of just stopping it abruptly and not putting it on the list, so Alex has to go from 2grams/day to 0grams/day…in one day. That's why he's reacting like this again tonight…from the cold turkey discharge of the Benztropine. It's not like Alex is in a hospital setting, to be ridding himself of 3 medications overnight. So, my objection is with Johns' method of stopping the medicine. He's making Alex anxious while leaving him in my care.

Drugs.com

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Benztropine Dosage

Overview
Side Effects
Dosage
Interactions
Professional
More
Applies to the following strength(s): 0.5 mg ; 2 mg ; 1 mg ; 1 mg/mL

The information at Drugs.com is not a substitute for medical advice. ALWAYS consult your doctor or pharmacist.
Usual Adult Dose for:
Extrapyramidal Reaction
Parkinson's Disease
Usual Pediatric Dose for:
Extrapyramidal Reaction
Additional dosage information:
Dose Adjustments
Precautions

Other Comments
Usual Adult Dose for Extrapyramidal Reaction
Acute dystonic reaction:
Initial: 1 to 2 mg administered IM or IV one time usually relieves the acute condition.

Maintenance: 1 to 2 mg orally administered once or twice a day as needed until the source of the dystonia (e.g., phenothiazine or other drug) has been removed. Once the offending agent has been discontinued, benztropine therapy should be continued for 24 to 72 hours, then ceased.
Usual Adult Dose for Parkinson's Disease
Initial: 0.5 to 2 mg administered orally, IM, or IV, once a day.

Idiopathic parkinsonism: start with a dose of 0.5 to 1 mg orally once daily at bedtime.

postencephalitic parkinsonism: most patients require larger doses. It may be appropriate to initiate therapy at 1 to 2 mg orally once daily at bedtime.

Maintenance: titration up from the initial dose should occur gradually by raising the dose in 0.5 mg increments every 5 to 6 days, up to 6 mg/day, until optimal relief is obtained.

Usual Pediatric Dose for Extrapyramidal Reaction
0 to 3 years: use of benztropine in this patient population should be restricted to life-threatening emergencies.

> 3 years: 0.02 to 0.05 mg/kg administered orally, IM, or IV 1 to 2 times a day.

Dose Adjustments
A single 4 mg IM dose of benztropine has been used in adults treated in the emergency room setting.

The dosage should be individualized based on severity of symptoms and patient characteristics. Elderly patients and those who are thin or underweight generally do no tolerate higher dosages and should be dosed and titrated cautiously. If possible, anticholinergic drugs, such as benztropine, should be avoided in the elderly.

Benztropine is indicated as adjunctive therapy in the management of Parkinson's disease and is not usually prescribed as monotherapy. If given concomitantly with levodopa/carbidopa agents, periodic adjustments in dosage may be required to obtain maximal therapeutic benefit.

Because the onset of drug action associated with both routes of parenteral administration is essentially the same, intravenous administration should be reserved for situations that preclude intramuscular injection.

Precautions

Because of atropine-like side effects benztropine should be used with caution in pediatric patients over 3 years of age.

Other Comments
Benztropine is ineffective in the treatment of tardive dyskinesia, and should therefore not be used for that indication.

Saturday, February 27, 2016
Just Saphris 5mg and 750 Depacote in the am; nothing Saturday night because he was not admitted into the ER until after midnight on Sunday am after walking around the grounds of Alta Bates from 7 pm Saturday night.

Again, it was one of the Herrick doctors who put Alex on the Omega 3 fatty acid back in September of 2015. I have no comment except to say that it did no harm and sounded good. Web Dr. research says: "Not all fats are unhealthy. Omega-3 fatty acids are one of the "good" types of fat. They may help lower the risk of heart disease, depression, dementia, and arthritis. Your body can't make them. You have to eat them or take supplements." So what reason would Johns have to take him off of it? I can't read his mind and he doesn't talk much, so I don't know. I do know that Alex is looking and sounding more depressed.

A little reluctant to leave Alex, I was away most of today, being treated to the ballet by my older son Brenden and his partner, Monica. I knew all would not loom well for Alex being by himself. Although I was happy to see that he was home upon my return at 7 pm, that was just the beginning of Saturday Night Lively. Immediately upon seeing me he ran past me at the door, like he used to do on the Latuda. Maybe he took the Saphris last night and was overmedicated. He certainly didn't acknowledge that I was his mom; I was just that lady he lives with, he later told the police. And that's what he thinks when he's overmedicated. He was definitely on an uneven keel from not taking the Metoprolol last night, the Benztropine both morning and evening and the Omega in the morning. All he took on Saturday was half the day's Depacote and 5mg of Saphris. I'm sure they're not going to give him anything in the ER at 1am on Sunday. Saturday's over so by tomorrow morning, he'll definitely be admit-able, because that's all he's had: Depacote and Saphris in the morning. That won't do it. He's already decompensating. He ran out saying that he's going to hang with the doctors in the ER. I hope they'd feel the same way, that they want to hang with him, but somehow I doubt they will be happy to see him so soon again. One of them from his last ER admission just 4 days ago, did call yesterday to see how he was, a Dr. Mondavi or something like that. I knew he wouldn't be right, after having stopped all three meds at once.

Instead of staying home, I decided to get back into the van and beat him to the ER. I wanted to make sure to give the doctor the most recent information and I'd printed one copy of this journal on Friday just to edit, so I brought it with, but it only had information up to Friday. The receptionist at the ER was a bit short with me. She didn't want any books, because, she said, he hadn't yet arrived at the

ER. I would have to return with the information after he was admitted. I really didn't get why she couldn't put it under her desk, since I knew he was coming soon, but I didn't argue. As I was returning to my car, I saw him walking down the street toward the ER. I left quickly to get home to write up Friday's information, so I could return in an hour or so after he would have been admitted. But, when I returned around 9pm to learn from the short-tempered one at the desk, that he did fill out the registration form but left shortly thereafter, I looked around and located him in the garden just down the ramp from the ER. He didn't want me around, I deduced from his facial expression. So, I left again, but not before calling the non-emergency number to the police. Three cars came, but Alex had already taken a hike, so they disappeared, too, telling me to call again if I find him. That was 9:30ish. I guess I was pissed off, because I stuck my head in the ER door and loud enough for everyone to hear, telling the receptionist: "Thanks for no help! It wouldn't hurt if you could have reached out and talked to him yourself to bring him back in. He was just down the ramp in the garden. Some of the more compassionate people who work here do that." By 11:30pm, after having driven all around the nearby Berkeley streets, I did see him again, walking back to the flower garden behind the ER. But, I wanted to double check first and placing a blanket on my head so he wouldn't recognize me; I peaked into the garden area. It *was* him. I called the same non-emergency number and they came, just not as quickly as the first time. Thank goodness he was still there when they arrived. The male officer walked over to my van, appearing a little confused, and asked me again what I wanted them to do. I said I wanted them to bring him in to the ER because that's what Alex had said he wanted to do, go to the emergency room. The female officer seemed to understand what to say to him, and before long there they were, walking him up the plank to the door. I could hear her voice engaging him in pleasant sounding conversation.

I hid in the ER's bathroom motioning to anyone who would look, to tell the desk clerk to come over. I asked him if they could get Alex admitted quickly, since he'd already signed in and had already been called a few hours before. So, that's it. The police officer came over to the bathroom, too, after the clerk and advised me to leave, following me to the van because he first wanted to make sure I was the mother since Alex told him I was not. I showed him Alex's high school graduation picture on the front page of last year's journal because I didn't have the birth certificate that he asked me for. That seemed to convince him. So, that's it. He's admitted to the ER. I stayed 'till the job was done because I was a Girl Scout. We're always prepared and do what we have to do. It's 2am and I'm going to bed. It's been a long day, what with Swan Lake and Alex decompensating all in the same day. This is the last chapter. I'm just going to bring a book or 2 to the Herrick office if he gets admitted to the hospital, which I hope happens because it will take a little time to find a new psychiatrist.

Sunday, February 28, 2016

I'm not sure yet that Alex is heading in a better direction. I know I had a good night's sleep because I didn't get up 'till 10am since he was in the ER. I wouldn't have heard the phone if it did ring, because I didn't realize I left it in the van last night. So, I don't know if the emergency room called to let me know anything. I called them in the morning, but the person who answered simply said he wasn't there, so I just waited. After a while, I called Brenden to let him know he should go there to see if he could get more information that they weren't giving me because I'm a woman...an old woman after 20 years of this sxxx. But as soon as I hung up, the lock was being turned by Alex's key. So, I e-mailed Brenden to un-invite him to the hospital:

> Brenden,
>
> That was really a fantastic ballet yesterday. I really enjoyed it. I was happy, too, that I could sit still so long. Thanks to you and Monica a lot for thinking about doing it and arranging it all. Gloria was good company, too.
>
> Just letting you know that Alex seems a bit better at the moment than he appeared last night. They didn't give him any medicine in the ER, he said, but he took his own, he said, that he had in his backpack, soon after midnight when he came into the ER: the Zyprexa, Amlodipine—but no Saphris—he said. So, he is following what I said, to keep the Saphris just for the morning. Maybe it was the Benztropine that was too much for him and it's a hard one to get off of, too. He sounded like he knew what he was talking about, as far as what he took. I'm glad he had everything with him because the ER never gives meds unless you press them to. So, it sounds like he took enough of what he needed. After I called you that he'd come home, he just went to sleep and as he was leaving, after a 2 hour nap, he took my hand and said "thanks for all your help." I gave him his money so he can get some food. Ok, thanks for being there to talk to. Hope you're enjoying your weekend. I'm going to get out, too.
>
> Love,
> Mom, or Joan, or whoever I am

I stayed home for the most part, just to observe him and noted that he was being more obedient, less independent, than he was on the discontinued medicines. It may sound good, but it's not. There was definitely a difference. For one, he took a shower. That part was good. I usually suggest it, but he did it on his own. He hadn't done that, take a shower, for more than a week because of not taking his regular meds on 2 different days in the one week. He normally makes a change when medicines are changed. But, although he hadn't been clean for the week, he had been dressing nicely in some handsome shirts that he'd purchased recently, on his own, under the influence of his independence-producing medicines, Saphris and Beztropine. Unfortunately, after his shower, he found other clothes that

were not as appropriate: a girls', pale blue, knitted pants with a flounce just below the knee where the pants ended…pedal pushers, as it were. The other problem with the pants was the stretched-out elastic at the waistband.

But, he found a solution by wearing a pair of dark plaid boxer shorts (underwear, I believe they are used for) that he wore on top of the knit pants so the pants would stay up. Then he pulled the pants up even higher so the elastic of the underwear would hold them up better or longer, but the light blue on top of the waist band hung over the shorts for a few inches, as if it were another curvy flounce. He topped the outfit off with a bright red/orange, tightly fitting knitted long johns top, that ended just short of his belly button, so that 3 or 4 inches of his stomach hung over the pants. It was definitely a unique look that will certainly draw attention to him out there in the street, and say to people: "Look at me, I'm out there." Or, "Watch out!" Or at worst, "I *may* be as crazy as I look. So, call 911." Yes, it's an attention-getting look, and I'm certain it will get the wrong attention. He doesn't need that kind of attention.

Maybe I shouldn't have insisted that he take off the dress that he'd first put on, but he doesn't need to wear dresses; he's not gay. And besides that, it was a very expensive gold lame dress that was my mother's, so exquisite that I wanted to frame it. And after insisting he take off the dress; I couldn't keep insisting that he take the next outfit off.

It looks like it was the Benztropine after all that had helped him to make better judgments about how to dress. Maybe it helps the antipsychotics work better. He was definitely dressing better with it than he is now. And how he presents to the public is very important. He needs to fit in so he doesn't get hurt by people who are not compassionate.

Tuesday, March 1, 2016
AM: Saphris, 5mg; Depacote 750mg; and last night he had Amlodipine Besylate 10mg; Zyprexa 15mg; Depacote 750mg.

Happy Birthday, Alex!

He's still pleasant but less talkative, keeping more to himself. I gave him some big bucks because he said he wanted to buy new clothes. He couldn't take off the underwear outfit before leaving for the store, he said, because he has "nothing else to wear."
I said, "What's all the clothing in your closet?" to deaf ears. He came home from Walgreens in a better pair of slacks and a top that almost matched. It's just that it's more of a girls' knit top. But, at least the other outfit is history. It's going to find a new home. I'm grateful he wasn't arrested or hurt. Brenden and Monica are coming over to join us for dinner out for his birthday; he says he's not going.

20 years ago today, he became stiff limbed…like a just-risen dead body, walking across the cornfield in a Halloween movie. I guess he's a little better, just not much, certainly not better enough considering he's had 20 years of psychiatric treatment. I do know that he was better on the Benztropine because he was more active, ate better, dressed more appropriately, and took better care of himself. It was on the Benztropine a couple of weeks ago, that he wanted to go to see a movie down town, and walked there with me, sitting through a long viewing of the new *Star Wars*. He hasn't been inside a movie theatre for at least a decade. Yet, even though tonight was his birthday, he couldn't walk to a restaurant to have dinner with his family (without the Benztropine). Since he won't eat my cooked food, I didn't cook, so we had no choice but to go without him and bring home his requested fried chicken. Yet, he would and did go to a restaurant on Brenden's birthday, July 7th, of last year. Let me see. Then, he was on just 50mg Metoprolol, 10mg Amlodipine and 15mg of Zyprexa—which is what he came out of Villa on—but it was before the Latuda, Saphris or Depacote or even the Benztropine. Maybe he just wanted that $35 crab legs dinner.

Now that I think of it, on the Benztropine he was eating home cooked food out of the refrigerator and freezer, as long as he was sure that it was made by and put there by his mother, Cest. And Cest, I've come to learn, is just me when I'm sweet, cuddly and forgiving—the ideal mother. He was even cooking food safely on his own under the influence of the Benztropine. Now he "can't eat" that same food, so he has to eat out, and that seems to involve buying a lot of junk food easily available on a shelf, like potato chips and additive-rich cake and cookies. No, he hasn't been eating well since Dr. Johns dropped those 3 medicines.

What could have been Johns' motivation? He hadn't even seen or spoken to Alex for the 3 months before he decided to do it. He wouldn't have known that **Alex was progressively improving since the addition of lower doses of Saphris (5mg) and Depacote (1500mg) and the prescribed dose of Benztropine (2mg)**, all medicines that were authorized by hospital psychiatrists. And why didn't Johns do any prescribing? He doesn't see Alex enough to know. Could he have been reacting to the letter I sent him the first time Alex ran out of Benztropine, because his dictum about stopping the medicines came shortly thereafter. At the time I wrote the letter and gave it to Robin's teammate, Tahira, I didn't know if it was still being prescribed, nor did the pharmacist at CVS. Everything was clandestine. I understand from Alex that the case manager came right over after Johns received this communication, but I wasn't home.

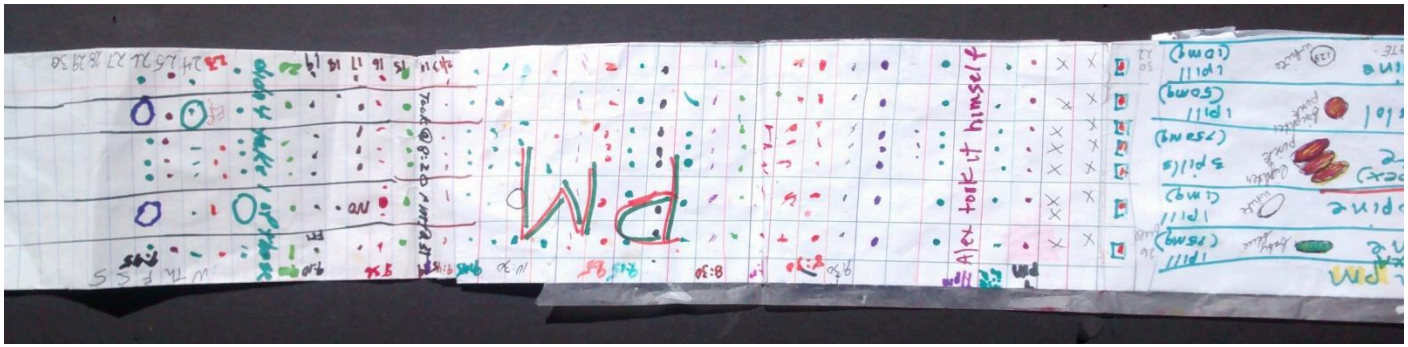
Dr. Johns Feb., 19, 2016

Alex is confused and he is completely out of Benztropine. He said that he doesn't have to take it anymore if it can't be picked up at CVS. But, that isn't so, is it? He was prescribed it at the hospital and when he stops taking it even once, he gets really off kilter. So, are you no longer prescribing it? He's completely out.

Are you going to let him know the way he is going to get his medicines? Because he only knows that they are in his back pack and when he runs out of them he will go to BMH to get more. He thinks BMH will then give him all of them, he said. Does that mean he will be getting them all? Peggy told me that they ordered 14. Does that mean he will get a vial of one week's worth to take at home? Or will he be coming there at 9am and 4pm to get his meds on a daily schedule. He doesn't know and he needs to know and I need to know what's going on. Because I'm involved very much and in fact, I am the one who sees and feels the effect of his not taking the right medicine. He gets upset sometimes, to the point of him being really scary…for me. On too much of the Saphris, for instance, he banged his heavy backpack on the dining room table 5 times in succession without taking his eyes off of me. That was after 10mg of Saphris for a week. On the Latuda, he ran away twice a week for 6 weeks …overnight…for 20 to 24 hours each time. That was very debilitating for me. So, I'm involved, yet you ignored that fact, and just made new arrangements with Alex who doesn't exactly understand what's going on. He only has 1 Benztropine in his vial in his backpack at this time. So, are you expecting him to pick up the new ones today? Tomorrow? He has no clue.

Based on this new arrangement that you have secretly made with Alex, I will no longer be able to provide a place for him to live. I cannot put myself in the jeopardy that you are placing me in. I am not well enough to defend myself against a 38 year old man who isn't always sure who I am to him. I am not willing to be at risk based on whether you will or will not be administering his meds to him in a timely fashion. I have a system that insures that he is taking his medicine, even if he does keep it in his backpack. He takes it out in front of me and takes it one at a time as I check it off on my list. I don't really see or understand how you can do it better. In any case, if this is what you are doing, then you need to let him know that it is not acceptable to me and you need to find him another place to live. The only way he can stay with me is if I know that he is, indeed, taking what he is supposed to be taking.

Sincerely,
Joan Miro, Alex's mother



It turns out that Dr. Johns, on his own, decided to have the Benztropine *delivered*. He wasn't thinking of *discontinuing* it at that time. Did he a few days later simply decide to discontinue the medicine because I criticized the fact that he had had it delivered without informing either Alex or myself? **Why, all of a sudden, would Johns discontinue the medicine if he had just spent his own time to arrange to have it delivered by another pharmacy?** He was aware that the Benztropine was originally prescribed by one of the Herrick psychiatrists and he kept ordering the prescription after Alex's discharge from the hospital. Then, all of a sudden, he stops the medicine, only after I complained about the method Johns chose to get it into Alex's hands: delivering it. And the new pharmacy did deliver it...20 pills, but Alex wouldn't take them because he was "sure" they weren't for him. It certainly sounds likely that Johns wouldn't have appreciated my sending the next letter through the City of Berkeley mental health website which was then forwarded to the Mental Health Manager at BMH, Steve Grolnic McClurg, because it was right after that, that he simply decided to *discontinue* the Benztropine, instead of revising the delivery of it. So, if he couldn't have it delivered his way, he chose to discontinue it altogether? What about, "Do No Harm!" Did that ever get put into the equation? And I was under the impression that psychiatry was supposed to be about helping the *patient/client/customer* get better.

When it comes down to it, he did not help Alex by discontinuing his medicines. Alex is worse— not better—since he can't get those 3 medicines. I don't know what Johns was concerned about, but it wasn't his patient. I can only imagine that he was ruminating over the fact that I said I needed to be consulted. How dare I tell him that I need to be in the discussion about how the Benztropine will be disbursed! As I recall, Alex wouldn't take it because Alex insisted it wasn't for him because he simply wasn't expecting it to be delivered. It's well known that schizophrenia doesn't like surprises. It sounds like the Benztropine was stopped, not because it wasn't good for Alex, but because Johns didn't like the sound of being told how it should or should not be delivered; so instead of having Alex pick it up at CVS—which is what Alex wanted to do—he just disabled Alex from taking it altogether, not because it wasn't helping Alex—it was—but because, if we didn't have it delivered *his* (Johns') way, he wasn't going to let Alex have it at all. What

kind of medical school did he graduate from? the University of Retribution! He was so affronted by my saying that we, neither Alex nor I, wanted the Benztropine *delivered*, that he got retribution by discontinuing the Benztropine prescription altogether? I have to admit, sometimes it takes me a while, but I eventually figure it out. That may also be why he never showed up for the February appointment after missing the January appointment, and didn't call to let us know he wasn't coming on either occasion. And the Benztropine is definitely a loss, but why would Johns care? He wouldn't, because, I submit, he dropped the 3 medicines deliberately and in revenge for my letter writing. After my handing the office receptionist, Tahira, a typed, sealed letter on February 19th, to deliver to Dr. Johns in front of a witness, her co-worker, Robin (p. 126), in regard to the confusion in the delivery of the Benztropine, there was no response to the letter. It appeared that Alberto may have been sent over to say something to me, since he came over to our apartment coincidentally and immediately after the letter was given to Tahira. Maybe Johns didn't like that I finally sent that e-mail (p. 111 and below) to the mental health department at the City of Berkeley as well as to the Compliance Officer, Yvette Katuala:

From: JOAN [mailto:JoanOfArt44@comcast.net]
Sent: Tuesday, February 23, 2016 1:18 PM
To: MentalHealth <MentalHealth@ci.berkeley.ca.us>; Katuala, Yvette <YKatuala@ci.berkeley.ca.us>
Subject: Changing the patient's medicine delivery

To whom it may concern in mental health at the City of Berkeley:

I'm trying to make that sure my son takes his medicine...on time and accurately. He completely ran out last Friday, of one of the several meds that he takes, because his psychiatrist, Dr. Johns, changed the way Alex's meds are delivered. There should be a conference before any such changes are made that should include the mother, when the mother is and has been the patient's main or only care giver. I'm the mother, the person who has for most of these past 20 years, when he's been living with me, (approximately 18 years considering hospitalizations and board and cares) been picking up the medicines from CVS (or other) Pharmacy and Alex has been willing and able to take them in my presence up until now. I do not want his willingness to take the medicines to end, because of the way the medicines are now being delivered.

All of a sudden I wasn't able to pick up the Benztropine last Thursday, because there was no prescription renewal from Dr. Johns, the CVS pharmacy assistant said. I heard the pharmacist tell his assistant that Dr. Johns only told him that he would no longer prescribe the Metoprolol, even though I had informed the BMH receptionist, Robin, that we were completely out of the Benztropine. Johns apparently said nothing about the Benztropine to the CVS pharmacist. There was no word of what was going on with the Benztropine, even though we were out. Alex didn't know how it would get into his hands, nor did I. And then, a representative of a different pharmacy delivered half a month of Benztropine to our door. That may sound good to someone who doesn't understand schizophrenia and how it has taken over my son's brain.

This is the issue: Apparently, no one asked Alex what it was that he wanted. They just went ahead and made changes that suited themselves at BMH. So, please allow me to inform those interested parties in the mental health field at BMH, that what he wants is this: to be able to be more independent and take care of himself. I think that is a laudable desire, and one that I have been trying to encourage by making sure his medicines are doing what they should be doing. Yes, I have been monitoring and evaluating how good he is at any point in time, based on the medicine that he is taking and has taken over most of these 20 years, because I want him to get better. And for my own safety, because I live with him, I need to be sure he is stable. And it has been a tremendous challenge to be able to get him to the point where he wants more independence without being a tyrant. He now wants to cook his own meals, pick up his own medicine, take the medicine on his own, etc. The doctor should have asked Alex what it was that he was trying to achieve by changing the way the medicines are delivered. What he wants is to be able to pick them up himself, so that he can have that feeling of independence, but they have to be available before he runs out of the previous batch, and they are not. The Benztropine that was delivered last Friday is still not available to Alex...Alex won't take them because they were delivered. He asked to pick them up, but they were "delivered" instead. Because of that fact alone, Alex won't take them. He says that they are not his, that they may have been tampered with, that I ordered them to be delivered when he wanted to pick them up. What Alex told me just now about the situation is: "You can only take 1 prescription at one time, not two. I can't take your medicine, Joan. That medicine that was delivered wasn't mine; it was yours. I keep all my medicines in my backpack." Granted, he's still confused and delusional, but he wants to be more in charge of his own life, none-the-less. That's a good thing, isn't it? So, he wants to do what he can do... to pick up the medicine, whether from CVS or BMH. But, if he goes to BMH to get them, he's not going to be able to take them before BMH closes. He takes half of them at 9pm, not at 4pm. He usually falls asleep an hour after the Zyprexa is taken. I don't want him going to sleep at 5pm.

I did come into BMH this morning and asked to speak to Nurse Peggy, who is not really handling his case like she used to, but has always been a willing BMH employee to stand up to help whenever I needed help to work through the system. Unfortunately, our brief conversation didn't produce the Benztropine that he needs today, before he goes off, for lack of it. Not taking it does make him testy, at best. And not having come to a conclusion that would give Alex the medicine that he needs today, motivated me to sit down to write about the situation. It's all a matter of customer service, or the lack thereof. According to a very successful retail department store owner, you have to find out what the customer thinks they want and give them what they really need.

I'm sending this to the only e-mail addresses that I have been able to find.

Sincerely,
Joan Miro

attachments: a few journals of the last 5 years while Alex was with BMH

To summarize, on February 19, 2016, my letter (p. 126) was delivered to Dr. Johns in regard to the confusion in the delivery of the Benztropine, because Dr. Johns on his own, consulting with neither Alex nor myself, rearranged how it was to be placed into Alex's hands. That gesture, itself, indicates that Dr. Johns intentions at that time were to continue the Benztropine as usual, but just to have it get to Alex in a different manner. Immediately after Johns received my letter, the Case Manager, Alberto Flores, came to the

apartment but I was not home. He apparently had something to say to me, but saw only Alex who didn't say anything particular about Alberto's visit. Then on February 23rd, 2016, four days later, out of the frustration that comes when nothing happens and not knowing what is supposed to happen, I wrote the above e-mail to the web-site and to the compliance officer. But, instead of the situation being taken care of, and Alex either being advised to pick up the Benztropene prescription from BMH or to pick up the Benztropene, itself, from the CVS pharmacy, the doctor decided to punish Alex and myself by discontinuing the Benztropene altogether, along with 2 other medications that had been prescribed for him by other psychiatrists and medical doctors at Herrick Hospital.

Besides eating poorly since the discontinuance of the medicine, Alex can no longer sit at the table to eat. He does a lot more sitting and smoking in the back of the building, however, or sitting on his bed saying mantras out loud: "on heal many; on heal many; on heal many," ad infinitum. Or, other times he laughs out loud from whatever he finds funny that no one else is privy to. That's all he does, because there is nothing left for him to do, since the medicine was taken away: no more watching television, no more conversations, no more writing, no more listening to music, no more sitting down to eat, no more taking showers. He did do all of those activities on the 1500mg or more of Depacote, 15mg Zyprexa, 50mg Metoprolol, 10mg Amlodipine, and half the normal starting dose of Saphris, (5mg) as long as the 1mg of Benztropine 2x/day was taken. Yes, it was right after the administration of Depacote that he was able to sit on a chair after not sitting for a few years since he last had Depacote in 2013. But, it was also at that time (last December) that Benztropine was started. So, it was not just the Depacote that enabled him to sit down to eat and have conversations, it was the Benztropine. It was not just the lower dose of Saphris that enabled him to go to the movie theater last month, it was the Benztropine. His eating habits and judgement are so bad now that on Wednesday, March 2nd, he had salsa and chips, for example, for breakfast, lunch and dinner, even though he was offered good food. His judgement, without the benefit of the Benztropine, is very impaired, even though issues, like food and dressing appropriately, are very important. If Johns intensions were malicious, he certainly succeeded.

And judging from the fact that Dr. Johns did willingly write the prescriptions for Metoprolol, Omega 3, and Benztropine for the entire year that Alex has been his client; and judging from the fact that Dr. Johns thought it important enough to make time to change the delivery of the Benztropene to a different pharmacy, making it easier for Alex to receive it, before he received any letter from me or notice from the Mental Health Manager at BMH, Steve Grolnic Mc Clurg, of the e-mail that I wrote to the City of Berkeley; and judging from the fact that Dr. Johns decided at that time—after being advised of the letter and e-mail—to eliminate altogether Alex's Benztropene, Metoprolol and Omega-3, **cold turkey**, after he was informed about my complaint, one can only draw the conclusion that the discharging of the medications was a vindictive move and one that was not in the best interest of his patient, Alex Anderson.

Housing

Another meeting involving *Housing for the mentally ill* took place last night. It's a relatively new group, started last year by an Oakland business woman, Laverda Allen, and now being further developed by additional parents who have the hope to gain access to monies, property and professionals who will work with them to get the mentally ill into suitable living conditions when families are no longer capable of taking on the job of caring for their children at home. That's what we're discussing…what kind(s) of housing they will need and how we will go about obtaining it. Most of the dozen moms present—plus Steve Bischoff, Executive Director, Mental Health Association of Alameda County, who hosted the meeting—weren't surprised that it would be at least a 4-year project to work the details out. We're in the research stage now. There have already been several meetings, but this is only the second one that I've attended. While listening to the discussion, I made a quick sketch on a napkin of what housing for the mentally ill might look like and passed it around. "Project Container" I'm calling it, because it may be less expensive to use premanufactured shipping containers. Of course, it's not the only option.

There were more smiles than blank stares as they passed the napkin around. And there is hope as long as we continue to work on the project. Housing is important. The mentally ill shouldn't be on the street. No one should, of course. But, their judgement is too far off. Neither should they have to reside in Board and (Don't) Care situations, where regulations are sparse and peanut butter and jelly sandwiches are standard lunch fare, as it was at Fulton House. No, no one should be on the street, but the severely mentally ill more often than not, don't have that choice to make. They couldn't take care of themselves even if they did receive enough money to obtain housing. The housing they need would need to include services like dispensing medicine, cooking and serving food, cleaning, psychological and medical, supervisory and transportation to and from activities. Envision it more as an overnight camp than just a house.

My Own Conclusions

Over the past 20 years, my son has gotten sucked down into a system of repetitious band aid fixes without attention to his needs, much less his wants. What he wants most is to be able to interact with friends and family, but even when they're around, he can't. He avoids them when they do come over and goes into his room, saying they're not real and doing what he does best: talk to the people in his head. So, in order to have relationships, he has to be well enough to engage with them, and well enough that family and friends want to be with him. **Therefore, he needs medicine that works.** Were he not so ill, it would be clear what wants to do…things like going to the gym, the theater, the restaurant…all those things that he liked to do before. In order to do them again, he needs to be able to make better judgements, be more motivated and independent enough to feel valued. Decisions about appropriate clothing, food, safety, etc., that tend to keep people in good shape, all are a part of the picture and **can only be addressed by better medicines that can bring back what brain functions were lost due to the schizophrenic break.** He wants to be independent enough to make his own meals, live in his own room, take his own medicine and buy his own food. He needs to relearn how to do those things safely and effectively. He needs to be able to realize the importance of getting into basic health habits—like brushing his teeth, seeing the doctor and going to the dentist—as a result of knowing that taking better care of himself will bring him better health. Therefore, he can't be so preoccupied with his delusional thoughts that he's not able to focus on and understand the salience of those things. **He needs better medicines**, ones that can help him to do those things that he can only now think about doing: saving all the children. That's all he thinks and hallucinates and talks about. And maybe he would have saved someone's child as a social worker or physician himself. He was always getting rave notices from his science teachers. But, that was before.

And how can these hopes become reality? For one, more research into the etiology of schizophrenia would have to take place. Only then can medicines begin to be developed to eradicate the cause. In order for anything to happen, I would reiterate Dr. Henri Montandon's hope for working to achieve recovery: ***"***…people have not realized that we have this opportunity to ***come together and help one another." Are we going to take this opportunity now***, before it eludes us, or continue along this dead-end path holding the severely mentally ill hostage forever? Are we going to make up our minds to ***stop abusing the mentally ill*** by ignoring their ***need for medicines that work*** well enough so they can have decent lives in normal communities? Are we going to ***stop blaming and ignoring the mentally ill*** for being mentally ill? Are we going to ***discover the causes*** of mental illness in order to research intelligent, appropriate cures? Are we going to ***end isolation*** by creating clean, well designed, activity-focused housing and other community groups that are age appropriate? Are we going to ***share information*** within counties or states so that bad outcomes at hospitals don't have to be incessantly repeated? Are we going to ***fund research*** on a national level that can accomplish all of the above? I hope so, because only then is recovery possible.

Synopsis of Alex's medications for the 20th year

Tuesday, March 1, 2016
AM: Saphris, 5mg; Depacote 750mg; and last night he had Amlodipine Besylate 10mg; Zyprexa 15mg; Depacote 750mg.

Saturday, February 27, 2016
Just Saphris 5mg and 750 Depacote in the am; nothing Saturday night because he was not admitted into the ER until after midnight on Sunday am after walking around the grounds of Alta Bates from 7 pm Saturday night.

Friday, February 26, 2016
NO Omega 3 Fatty Acid; Olanzapine 15mg in pm; NO Metoprolol; Benztropine 1mg in am only; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg. in am. 0 in pm.

Wednesday, February 24, 2016
Olanzapine 15mg; Not sure about the Metoprolol 50mg being taken last night-maybe they gave it in the ER; the Benztropine wasn't taken either am or pm yesterday; Not sure about the Amlodipine Besylate 10mg being taken last night-maybe they gave it in the ER; Depacote 1500mg; Asenapine (Saphris brandname) 5mg am.

Monday, February 8th, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 2mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg am.

Super Bowl Sunday, February 07, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 2mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg am.

Monday, February 01, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 2mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg am.

Sunday, January 31, 2016

Olanzapine 15mg; Metoprolol **50mg**; Benztropine 2mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg.

Friday, January 29th, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 2mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg.

Thursday, January 28th, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 2mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 5mg.

Thursday, January 21, 2016
Olanzapine 15mg; Metoprolol 50mg; Benztropine 1mg; Amlodipine Besylate 10mg; Depacote 1500mg; Asenapine (Saphris brandname) 10mg.

Monday, January 5th, 2016
Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg; Benztropine MES 2mg.

Wednesday, December 30th, 2015
Omega-3 Ethyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg, Benztropine 1mg am, 1mg pm.

Tuesday, December 29th, 2015
Zyprexa 15mg, Depacote 1500, Amlodipine ?, Metropolol 50mg

Friday, October 30, 2015
Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg

Thursday, October 29, 2015
Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg, Latuda 40mg
Tuesday, October 27th, 2015
Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg, Latuda 40mg

Wednesday, October 21st, 2015
Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg

Monday, October 12, 2015
Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg, Latuda 20mg

Friday, October 9th, 2015
Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg

Thursday, October 08, 2015
10am: I know not about what he took yesterday or so far today
3pm: Omega-3 Etyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg (NO Latuda)

Monday, October 5th, 2015
At 3pm: Latuda 40mg (cut the 80 in half); Omega-3 Ethyl Esters 1 grm cap; Olanzapine 15mg; Amlodipine Besylate 10mg; Metropolol 50mg

Sunday, October 2nd, 2015
No meds taken

Friday, October 2nd, 2015
I don't know exactly what he took last night.

Wednesday, September 30, 2015
no meds last night - the Zyprexa, Amlodipine Besolate, Metoprolol were not taken last night, just the Latuda and Fish Oil were probably taken at 2pm yesterday
Tuesday, September 29, 2015
Zyprexa 15mg; Metoprolol 50mg; Amlodipine 10mg; Omega-3 Ethyl Esters 1gm cap (fish oil); Latuda 80mg.

Monday, September 21st, 2015
Zyprexa 15mg; Metoprolol 50mg; Amlodipine 10mg; Omega-3 Ethyl Esters 1gm cap (fish oil); Latuda 80mg.

Friday, September 18th, 2015
Zyprexa 15mg; Metoprolol 50mg; Amlodipine 10mg; Omega-3 Ethyl Esters 1gm cap (fish oil).

Thursday, September 17th, 2015
Zyprexa 20mg; Metoprolol 50mg; Amlodipine 10mg; Omega-3 Ethyl Esters 1gm cap (fish oil).

Sunday, September 13, 2015
Zyprexa 15mg (taken at 2pm); Citalopram HBR 20mg; Metoprolol 50mg; Amlodipine 5mg.

Thursday, September 10th, 2015
Zyprexa 15mg (taken at 2pm); Citalopram HBR 20mg; Metoprolol 50mg; Amlodipine 5mg.

Sunday, September 6th, 2015
Zyprexa 15mg (taken at 2pm); Citalopram HBR 20mg; Metoprolol 50mg; Amlodipine 5mg.

Friday, August 28th, 2015
Zyprexa 15mg; Citalopram HBR 20mg; Metoprolol 50mg; Amlodipine 5mg.

Friday, April 3, 2015
Zyprexa 15mg; Fish oil

ADMISSIONS &. DISCHARGES HOSPITAL

To ER	from ER	to inpatient	from inpatient	
Sept. 12, ’15		Sept. 12, ‘15	Sept 23, ‘15	A B/Herrick
Dec. 21, ‘15		Dec. 21, ’15	Dec. 30, ‘15	A B/Herrick
Jan. 18, ‘16		Jan. 19, ‘16	Jan. 22, ‘16	A B/Herrick
Feb. 24, ‘16	Feb 24, ‘16			AltaBatesER
Mar. 14, ’16	Mar 14, ‘16			AltaBatesER
Mar. 22, ‘16		Mar. 22, ‘16	Apr. 12, ‘16	John George

LATUDA per the Sunovion Website

How to Take LATUDA

LATUDA is Taken Once a Day

…Be sure to take LATUDA exactly as prescribed by your doctor. If you have any questions about your dosage or how to take LATUDA, don't hesitate to ask. You can also take a look at this Doctor Discussion Guide for some other questions to bring up at your appointment.

What to Remember When Taking LATUDA

1. Stick with it.
Everyone responds to medication differently. LATUDA may work gradually, so it may take some time to notice improvements. Click for some helpful tips.

2. Keep cool and drink plenty of water.
Your body may not be able to control your temperature as effectively when taking LATUDA.

3. Stay away from alcohol.
It may make side effects worse.

4. Skip the grapefruit and grapefruit juice.
They can affect the amount of LATUDA in your blood.

5. Take LATUDA with food—at least 350 calories.
Food can help your body absorb LATUDA.

6. Watch out for drowsiness.
Until you get used to LATUDA, don't get behind the wheel or take part in any dangerous activities.

7. Reach out for help if your symptoms get worse.
Be sure to tell your doctor if your symptoms get worse after starting LATUDA.

8. Remember to take LATUDA once a day.
Once-daily LATUDA should always be taken exactly as it is prescribed for you by your doctor. Talk to your doctor before stopping LATUDA or changing your dose. Click for some helpful tips.

Important Safety Information and Indications for LATUDA
INCREASED MORTALITY IN ELDERLY PATIENTS WITH DEMENTIA-RELATED PSYCHOSIS; AND SUICIDAL THOUGHTS AND BEHAVIORS
Elderly patients with dementia-related psychosis (having lost touch with reality due to confusion and memory loss) treated with this type of medicine are at an increased risk of death compared to patients receiving placebo (sugar pill). LATUDA is not approved for treating elderly patients with dementia-related psychosis.
Antidepressants have increased the risk of suicidal thoughts and actions in some children, teenagers, and young adults. Patients of all ages starting treatment should be watched closely for worsening of depression, suicidal thoughts or actions, unusual changes in behavior, agitation, and irritability. Patients, families, and caregivers should pay close attention to any changes, especially sudden changes in mood, behaviors, thoughts, or feelings. This is very important when an antidepressant medicine is started or when the dose is changed. Report any change in these symptoms immediately to the doctor. LATUDA is not approved for patients under the age of 18 years.

LATUDA can cause serious side effects, including stroke that can lead to death, which can happen in elderly people with dementia who take medicines like LATUDA.

Neuroleptic malignant syndrome (NMS) is a rare but very serious condition that can happen in people who take antipsychotic medicines, including LATUDA. NMS can cause death and must be treated in a hospital. Call your healthcare provider right away if you become severely ill and have some or all of these symptoms: high fever, excessive sweating, rigid muscles, confusion, or changes in your breathing, heartbeat, or blood pressure.

Tardive dyskinesia (TD) is a serious and sometimes permanent side effect reported with LATUDA and similar medicines. Tell your doctor about any movements you cannot control in your face, tongue, or other body parts, as they may be signs of TD. TD may not go away, even if you stop taking LATUDA. TD may also start after you stop taking LATUDA.

Increases in blood sugar can happen in some people who take LATUDA. Extremely high blood sugar can lead to coma or death. If you have diabetes or risk factors for diabetes (such as being overweight or a family history of diabetes), your healthcare provider should check your blood sugar before you start LATUDA and during therapy. Call your healthcare provider if you have any of these symptoms of high blood sugar (hyperglycemia) while taking LATUDA: feel very thirsty, need to urinate more than usual, feel very hungry, feel weak or tired, feel sick to your stomach, feel confused, or your breath smells fruity.

Increases in triglycerides and LDL (bad) cholesterol and decreases in HDL (good) cholesterol have been reported with LATUDA. You may not have any symptoms, so your healthcare provider may decide to check your cholesterol and triglycerides during your treatment with LATUDA. Some patients may gain weight while taking LATUDA. Your doctor should check your weight regularly.

Tell your doctor if you experience any of these:
feeling dizzy or light-headed upon standing,
decreases in white blood cells (which can be fatal),
trouble swallowing.

LATUDA and medicines like it may raise the level of prolactin. Tell your healthcare provider if you experience a lack of menstrual periods, leaking or enlarged breasts, or impotence.

Tell your healthcare provider if you have a seizure disorder, have had seizures in the past, or have conditions that increase your risk for seizures.

Tell your healthcare provider if you experience prolonged, abnormal muscle spasms or contractions, which may be a sign of a condition called dystonia.

LATUDA can affect your judgment, thinking, and motor skills. You should not drive or operate hazardous machinery until you know how LATUDA affects you.
LATUDA may make you more sensitive to heat. You may have trouble cooling off. Be careful when exercising or when doing things likely to cause dehydration or make you warm.

Avoid eating grapefruit or drinking grapefruit juice while you take LATUDA since these can affect the amount of LATUDA in the blood.

Tell your healthcare provider about all prescription and over-the-counter medicines you are taking or plan to take, since there are some risks for drug interactions with LATUDA.

Tell your healthcare provider if you are allergic to any of the ingredients of LATUDA or take certain medications called CYP3A4 inhibitors or inducers. Ask your healthcare provider if you are not sure if you are taking any of these medications.

Avoid drinking alcohol while taking LATUDA.

Tell your healthcare provider if you are pregnant or if you are planning to get pregnant. Avoid breastfeeding while taking LATUDA.

The most common side effects of LATUDA include sleepiness or drowsiness; restlessness or feeling like you need to move around (akathisia); difficulty moving, slow movements, muscle stiffness, or tremor; and nausea.

These are not all the possible side effects of LATUDA. For more information, ask your healthcare provider or pharmacist.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.
Call 866-300-4374 to Office of Emergency Regulations to notify the FDA of an emergency.

INDICATIONS
LATUDA is used to treat adult patients with:
Depressive episodes in bipolar I disorder (bipolar depression) when used alone or with lithium or valproate
Schizophrenia

Oct 28, ’16	Oct 29, ’16	Oct 29, ’16		A B/Herrick
Nov				
Nov 27, ’16	Nov 28, ’16	Nov 28, ’16	Dec 13, ’16	A B /Herrick
Dec 13			Dec 13 ‘16	Villa Fairmont