‘Hell’p!

Alex’s Story

of

Mental Illness

within

The Mental Health “System”

A Parent’s Perspective of

His Descent

Into

Schizophrenia...

The 18th Year

2014-2015

by Joan Miro, Mo.M., and Henri Montandon, M.D., Ph.D.

Letter to SAMHSA

Re: Villa Fairmont Mental Health Center
and the treatment of a patient there-my son, Alex Anderson

The 'Recovery' Meeting

As early as September 11th, 2014, the second day of my son's stay at Villa Fairmont Mental Health Rehabilitation Center, (Villa) I was invited by Paul Nicholas, M.D., Alex's first psychiatrist at the facility, to a 'Recovery' Meeting for the following Tuesday. I had been impressed with being invited. But, after waiting an hour in the hall outside the meeting room, a staff member came out to tell me that I could *not* come into the meeting. Later that day, Danielle, the social worker, explained that the reason I was uninvited was because my son, himself, hadn't come in; he had to be there in order for me to be invited in. I, therefore, didn't attend subsequent meetings until weeks later, after Alex told me that he finally went into a meeting in the beginning of October, so I talked to him about going again and said if he would go, I would go, too. Although I'm not a student of the bible, I do live by, "Whither thou goest, I will go," for my Alex.

Finally, on October 21st, we both walked into a full house of employees: nurses, psych techs, social worker all on the "team," at least a dozen individuals. My intention was to let Villa's new doctor know what Alex is like on higher doses of Zyprexa, so Villa wouldn't overdose him again. I said "hello" to the lady in the white coat, Dr. Freeman, who, I was told, had replaced Nicholas, MD, temporarily. And I introduced myself as Alex's mother, telling her she could call me "Joan" because I don't use my married name anymore.

I sat quietly next to Alex while the doctor interviewed him first, asking him why he thought he's at Villa and what he thought he needed to do to get out of Villa. She wanted the team to see what state of mind he was in, his degree of illness. But, I felt incriminated by her questions to him. Her face had a smirk, implying to everyone present that this patient really had a problem and the mother was the cause. Alex referred to the lady caretaker, Marissa, in answer to the 'why' question as if she were the reason he was detained at Villa.

The Caretaker

I had arranged for Marissa to replace me as his caretaker when I would have to be in the hospital for a couple of weeks, starting last July, 22nd, 2014, for another major surgery. And she may have been the main reason for his stopping the meds, because if she had cooked for him as she'd agreed to, and made sure he took his medicine, he wouldn't have been so out of his mind to yell and fling himself at me in order to grab the cell phone after I said I was going to have to call 911, knocking my back into the bookcase only a few days after I'd returned home from my second spine surgery and rehabilitation hospitalizations. But, she was only partially the answer, because after all, it was I, myself, who did the calling, when I noticed that he was so out of it, and secondly,

because I'm not willing to be abused especially not in such a frail state.

I had called a number of other people starting in June, to inquire if they could watch him, beginning with the several brochures I'd collected at a Sacramento rehab hospital after my first spine surgery in March of 2011, but could only find a caretaker for me, Comfort Keepers, but the spokesperson said they don't work with the mentally ill. I hired them for me and kept looking for another mental health caretaker. A social worker from Kaiser Permanente, Alex's and my own health care organization, who returned my call, said she could offer no advice about who would care for the mentally ill either. The day before surgery, I found myself in desperation and thought of the helpful police officers I've been blessed to know in Berkeley, so I stopped at the Police Department for advice, but the office window had already closed at 3:30pm, so I was out of luck. I sat down and randomly called 981 numbers, and one compassionate city employee connected me to Berkeley Mental Health. Of course, I'd already spoken to Alex's new doctor there, Jeffrey Johns, MD, PhD, who had not yet seen Alex, and had no caretaker lists, he said. My family was all on vacations scheduled months, if not a year in advance and I didn't dare ask them to change their plans, ('though I guess they could have if they wanted to,) especially since my granddaughter was busy getting ready to go off to college on the East Coast and planned to be in Peru with her cousin at the time of my last-minute surgery.

Phone numbers on my cell had disappeared after I made a change in service. But, I could still see some dialog boxes in the text messages and recognized them as Marissa's, with whom I'd communicated several times since she'd left Berkeley two years before, at which time I helped her move out of her 52 ft. boat that I was dreaming of buying. Marissa, now in LA and still unemployed, was willing to jump on a plane and let herself in the next day, which was the day of my surgery. I gave her the information she would need over the phone, 'though she'd only met Alex once at his birthday party the previous year, so he probably wouldn't remember her. Combining the fact that Alex wasn't happy that I needed to leave him, to the fact that Marissa was willing but unprepared for the venture and after accepting the $100/evening to feed, medicate and sleep over to keep him safe, she decided—although she wasn't a CNA—that she wanted more money than she had originally agreed to. That attitude may have produced the problem. She had me over a barrel. I think he did take the medicine the first week, but the rest of it was kept in my van, so he would only be able to have access to what he needed for a week in the apartment. Maybe she just didn't bring it back into the apartment and fill up the vials for the second week, because she went home in between week 1 and week 2 and when she returned, she decided she needed to be paid more than twice as much, $250/day. That, she claimed, was what it was worth. I tried to explain that I was already paying that total amount but more than half was going to the other caretaker from Comfort Keepers. She didn't seem to get it, and decided she wasn't getting enough money, even though she'd already agreed on the $100/day for making dinner, being sociable, making sure he took the meds and sleeping over. She could use my van to do whatever she wanted to do for herself during the day.

While in LA after the first week, and unbeknown to me until my brother Jerry told me, she'd arranged to meet Jerry to have a conversation about money, since he was now

paying for her services. She didn't think that I was talking to Jerry, since I'd informed her earlier that I didn't talk to him for years, but I finally did speak with him when he returned a call that Alex had made to him.

Alex hadn't seen him for most of the years he's been ill and always asked if I would connect him to his Uncle Jerry. But, Jerry was mad at me, accusing me of making Alex get schizophrenia, so I was keeping my distance. Finally, Alex was well enough (on only 10mg of Zyprexa) to figure out how to call my other brother, Jay, to get Jerry's number and left a message on Uncle Jerry's phone. A week later when he returned Alex's call, I told Jerry the situation, and Jerry called back the next day to offer to pay for Alex's caretaker. When I told Marissa that he would be paying her, she took it upon herself speak with him to renegotiate for another $50 from him to add to the $100 she had originally accepted from me, and insisted that I should also give her $150. In my mind, since Jerry had offered to pay for Alex's services, I was no longer paying Marissa. That was the arrangement I had with Jerry, but Marissa wanted money from both of us. Before she would return from LA to work week #2, she told me that the reimbursement check that Jerry was sending me to repay me for the first $800 check that I'd already given her, belonged to her. And unless I paid her for the second week, too, I imagined that she wasn't committed to work. I couldn't argue, because I was too ill and still in a Castro Valley Rehabilitation Hospital, so I had to give her what she wanted. Finally discovering what she was really like made me realize that she intentionally didn't give Alex what he needed…food, medicine and care. She was being abusive, but I couldn't let on that I knew; I just cancelled the check after she finally went home.

But, she was only part of the problem. Other issues factored into it. His decision to not take the medicine was another part of the problem. I found more than a day's worth of Depacote and Zydis hidden in his dresser drawer ex-post-facto. Why that happened, I don't know. Maybe he was angry because there was no freshly cooked food like he's used to. She admitted that she doesn't cook, but only after the first week was over. I was dismayed to find that the caretaker from Comfort Keepers wasn't available all of a sudden when I called them at discharge time after spending my first 5 days in Kaiser Sacramento. That's when Marissa informed me that she could come up to Sacramento to bring me home. Somehow Comfort Keepers, who had agreed to pick me up that weekend after my Tuesday surgery, when I had predicted being discharged, was "reassigned." They wouldn't/couldn't tell me why they weren't following through with our agreement, only that the caretaker was no longer available. I wondered if Marissa had called them to cancel so she could get extra hours. The Comfort Keeper person did show up the next day to take care of me, but I was so out of it, having turned down the longer-term rehab in Sacramento, so I could be home with Alex, that I collapsed the next morning and they both took me to the Kaiser Oakland ER to begin a rehab hospitalization anyway.

Back To The Recovery Meeting At Villa

Alex answered that he was required to go to groups in order to get out. The doctor suggested that he might want to change his clothes, too, indicating that that could help him get out. He mumbled something about his grandmother but thank goodness she

didn't inquire further. I was grateful because the more he would tell them what nonsense was in his mind, the longer he'd be cooped up. I knew that he was deluded into thinking that the approval of his grandmother, great grandmother and mother was needed in order for him to change his clothes. That would be me, Ethel and Sima or Anna, may they rest in peace, and the grandmother group seemed to be more lenient about what clothes were wearable when he was on less medicine, that is, they allowed him to change clothes daily on 10mg, but I didn't say anything by way of explanation, because she was talking to *him,* and everyone was looking at him and it wasn't my turn. It must have been very intimidating for him to be stared at by so many people. It couldn't help coming to mind that when Dr. Novis would have a meeting back in 2009, it was just the appropriate social worker, nurse and doctor with Alex and me. When they got what they needed from him, I imagine that proved he was in need of Villa's services. Then, she asked if he were staying in the meeting while they would speak to me. I knew he was uncomfortable being in a group where people were talking about him, but I, too, tried to encourage him to stay. He didn't want to and left. It was my turn up at bat; I should have been prepared for the curves but I actually thought she might listen since I had been invited to share this information. I had to imagine that she'd already read my three letters from 2 weeks before. My letters were accusatory, so, maybe she was going to let me know who was boss. But, there was no way I could have prepared for the verbal fisticuffs.

She indicated her level of knowledge of customer service when she said something about it being "my license on the line!" That was in reference to my telling her how much better he was on a lower dose of Zyprexa. She wasn't going to discuss medicine with me. She only asked me what type of person Alex was. I didn't mind revealing how nice Alex was and still is—and toward that end I took out a page of childhood photos from the 2010 journal and passed them to her.

She looked for a few seconds and passed them back—but I wanted to get my two bits worth of information heard, about how you can't go too high on the Zyprexa, for sure not past the 20mg that he's already on. At home he was on only 10mg. and able to function as best he could on Zyprexa alone. After all, Eli Lilly didn't even do research on doses higher than 20mg so why would practitioners want to go higher? Are they researchers now, too? At 25 to 30mg, he's "very angry, agitated, aggravated" and all the other "a" words.

She didn't want to hear it and kept interrupting me every 5 seconds with a high pitched screech, Cxxxssshhhhhh!—like a cat. She indicated that "it could have been for other reasons" than medicine that he seemed aggravated. No, it was definitely the high doses of Zyprexa that changed his personality and his brain functioning.

I found it very curious to be invited into a meeting, asked to speak for 5 minutes, and then

to be verbally assaulted. After all these 18 years of Alex's illness, I didn't realize that the hospitals allowed doctors to intimidate the parent. I thought it was only the patients that were assaulted, by the medicines that doctors prescribed, because doctors really didn't know what reaction the patient would have to a medicine. No, parents, too, were their targets. And yet they had the audacity to call it a "recovery" meeting. They didn't want recovery to take place. That would put them out of a job if their mentally ill clients recovered.

A Little History

I wish I could have showed them the video I shot at 27.5mg when he was yelling all over the apartment after getting out of Herrick on 30mg of Zyprexa due to High-Dosser Charles Connor, M.D. in January of

And at 40mg of Zyprexa, I said, he was in a coma. OK, catatonic. It looks like a sitting-up coma. Of course that was due to the research that David R. Tomasini, M.D., performed at John George, AKA Frankenstein Labs, not because of Villa, I could have said, so the Villa employees wouldn't feel I was picking on them. In fact, Villa's Lawrence Novis, M.D., started to lower it in December, 2008, as soon as he saw the catatonia. He had been transferred to Villa from Tomasini at the end of November 2008, and it took Novis until April 30th of 2009 to lower it enough to be able to discharge him from Villa, I would have said if she didn't keep interrupting me with the screeching. At least Novis was willing to talk to me on several occasions during those months, when he was lowering the extremely, high dose of 40mg of Zyprexa to get Alex from practically catatonic to be able to walk to the cafeteria. It had been a nurse who admitted to me that Alex couldn't move, and didn't go to meals on his own for over a week. I can picture him so still, even now, 5 years later, sitting hunched over on his bed. They don't have to do lobotomies with *surgery* anymore; the medicines do it just as well!

Novis was even willing to start him on Clozapine at my request because it had worked so well in 2007 after only 10 days under the care of another doctor, Richard Slawsky, M.D., at John George. Novis actually didn't like Clozapine because of the weekly blood test requirement, and because "patients died in Europe from Clozapine," Novis told me, thus the mandated blood tests to check for white blood cells, and tried to discourage me, but I brought it up enough until he acquiesced. He willingly worked with me. Clozaril was billed as "the one that worked when the others didn't." Who wouldn't want that for their beloved son? And Alex was better on it at 100mg, along with 10mg. of Abilify and 17.5mg Zyprexa, but when it came time for discharge the following April 30th, Alex still didn't want blood tests, so I took the tough-love road which was difficult for me: "You have to take the Clozaril if you want to come home. Alex, after 6 months, the blood tests are only every other week, then after a year, only once a month!" I was really selling…desperate to get him on what was supposed to work. "No," he said at the Villa discharge table in 2009, "I'll go to a Board and Care." I threatened that I wouldn't visit. No, he didn't want anyone poking holes in his arm.

So, from May until November of 2009, you could find him at Fulton Place, not your

regular Board-and-Don't-Care, as I normally call them, and not a mile from my apartment, so I did visit, but only twice a day. By November, I was taken aback to hear Alex say to me, "Can I come home?" Apparently tough love works, but it's tough on the parent. At first, I thought he meant come home that night for dinner. But, no, he was willing to get the blood tests now. He preferred living at home in his own room. You have to know what children want and find a way that they can work towards getting it. I can understand that Tough Love is for the parent what Behavior Modification is to the teacher. But, behavior Mod is a more positive approach.

Back To The Recovery Meeting

Dr. Freeman was twisting everything I said. Instead of a meeting where people could speak for a certain amount of time, it was a court of lawlessness where the witness could be interrupted and shut down. She was the attorney, trying to discredit me on the stand. I didn't even know I would be on the stand; I hadn't prepared for this. I had silly hopes that we could work together for the benefit of my son. Before starting to speak, I had asked her how much time I had to speak and she said, "5 minutes." But, after only 5 seconds, she would interrupt with the screech, repeatedly, because I would keep talking after she stopped screeching. It was obvious that she didn't want me to talk about medicine and its effect on Alex. None-the less, I felt I had to caution her about overdosing him. I didn't want him having to be put through another overdose. Doctors had already done the damage and put his brain through too much, too many changes. Maybe she already had done some research about what happened that day in May in 1997, right there at Villa Fairmont. Something told me that it probably wasn't still in the chart, if it ever was, and if it were, she wouldn't go back that far because it wouldn't be pertinent to her. But, it is pertinent, because the then, Dr. Economy and then, Director Segalove, M.D., were responsible for putting him in a coma. OK, they insisted it was only catatonia. Whatever you want to call it, the only thing that could move were his eyeballs for more than 10 days.

THE FIRST CATATONIA CAUSED BY VILLA FAIRMONT IN 1997

The first two years of schizophrenia in my journaling were still only handwritten until now, because after the overdose, when he stopped moving, I was in no condition to write, but as it was happening, I did make a few brief, handwritten notes that follow:

> **5/3/97**
>
> Mrs. Long, the psych tech looked in his chart. I told her the problem that I saw: "He looks totally different." She read, "He went to three groups last week...He's getting liquid Haldol plus Zyprexa." Surprised, I told her that Dr. Segalove said he wasn't going to get Haldol. This information was conflicting. Dr. Segalove had said that over the phone to me just the day before when I advised him that Alex had been on Haldol at Herrick on a few occasions when they needed to use injection and they found that it caused EPS at normal doses.
>
> So, I called the Kaiser psych nurse who told me to have the doctor call to discuss release of information. And "ask to speak to the supervisor. I don't know whether you're

documenting to see if he's getting nourishment. Tell the social worker: 'I understand there is a treatment team meeting...I want to be involved. And ask, 'What can I do to help?' Don't forget to talk to the patient's rights advocate." She was informative.

So, I called Debra, the supervisor at Villa, on the phone, who assured me, "They are carefully monitoring what he eats." Then she mentioned that there is a "do not give out information to anyone" in the chart that has been in there since the date of admission." This one wasn't trying to be very helpful. I wonder if there really is a note in the chart regarding not giving info to anyone. How do I check on that?

5/4/97 2:30pm

Alex was still in bed, the bed disheveled. Somewhat more alert looking, but non-communicative and more antagonistic. He didn't want to get up. Eyes were open, but wanted to sleep. He didn't answer my question about what he had eaten today. The clerk said he didn't go to breakfast but ate 80% of lunch according to the record. I opened his windows; they were breathing stale air. Then, as I gathered up his dirty underwear to take home, he told me not to sit on his bed, that I "make him shake." He said this twice. the second to me when I tried to straighten the sheet because he was partially lying on the plastic mattress.

5/5/97

I copied the following information from a note the nurse pulled out of the chart at 12:40pm which was stuck to the first page of the chart:
'Alex Anderson- hold meds until further notice except PRN, Cogentin/Benadryl
30th to change Zyprexa from 10 to 20 night
Depacote to suppress on May 3
2 x Sat 1 x Sun Haldol
10mg 2 x day for 4 days
Discont'

I'm just seeing a note from Alex on the same note paper I'm reading from to transcribe this. It says:

> Moms your color is of the center
> that shines like a diamond from the heavens up above.
> Your smell is like rose pedals that blend
> as a sweet Bouquet in an array of potpourris.
> Happy Birthday, love Alex.

He must have written that just before being admitted because my birthday was 5 days earlier.

I called the pharmacist at Eli Lilly, manufacturer of Zyprexa. Phillip told me a few consoling things: "It appears very unlikely that changing the dosage would cause a change in behavior...The medicine has a half-life to last once a day...Typically you would not expect him to deteriorate after 3 weeks. I don't have any experience with Haldol, but have no concern with the drug interaction.

5/7/97 5:00 am

The nurse stated that Zyprexa looks like a white pill with 4117 and LILLY 10 mg written on it. It only comes in 10mg, 5mg and 7 1/2 mg. Not 20, yet they talked about taking a larger pill once a day. It says LILLY in blue writing.

1:50 pm

They asked to have me wait in the lobby but the desk clerk let me go back...unusual. I should have known something was amiss.

When I saw Veronica, who opened the inner door, she stated: "I thought you were going to be here from 1 to 2:00? I said I am here between 1:00 and 2:00. I feel he doesn't want me to stay, so I came late.

Went into his room. He was immobile, staring straight up, barely breathing. I spoke to him, but he didn't move or look at me. I grabbed him and hugged him and told him everything was OK. He moved his eyes toward me and tears came out. I asked him a few questions [like], "Shall I rub your neck?" and told him to look toward the door if the answer were 'no' and toward the window if 'yes.'

I ran out to the living room; I guess I was loud: "What's going on!" I demanded. "Where's the doctor?" She had been in his room when I first came in, but I never met her, and only suspected that it was she. I went to the nurses' station and said, "Please have Dr. Economy and Dr. Segalove come into Alex's room. I'll be in there."

I called [my brother] Jay from the patient phone and after a minute or two, the fire alarm went off so I couldn't hear him. [So, I hung up.] Dr. Segalove [came over and] escorted me into his office and we waited for Dr. Economy to come in. They pulled up chairs and told me what they suspect happened. "Someone gave him Haldol and he is very sensitive to it, thus, the reaction." I stated that on the previous Friday, 5/2/97, the day before this was given, Dr. Segalove had said they were not giving him Haldol. But, "someone" did it "over the weekend," because he appeared "agitated." He received three doses of it…Saturday, Sunday and Monday. (Later another nurse said he got 20mg/day x 4 days.)

What all of them neglected to tell me was that he had fallen down at 10am and had to be carried to his bed in this same state. He fell on the hard floor coming out of his room, almost, but not quite, hitting his head. Instead, he had banged his left shoulder and elbow. I got this info later from Cassandra, another patient. (Alex complained of the shoulder pain several times in the next days-Monday and Tuesday.)

5/5/97 3:00 pm

Anyway, they suspected that he was "cheeking" his medicine (Zyprexa) for a while because they found 3 or 4 Depacote in his shirt pocket. So, they began giving him liquid Depacote on May 2nd, but there is no liquid Zyprexa being made by Eli Lily. So, "Someone" gave him Haldol. How much, I forgot to ask. After the meeting, I left since I was upset and went to Kaiser to see how I could get him into the ER. (I forgot to state that Dr. Segalove was so 'compassionate' that he gave me a long body hug when I left the facility after this meeting…guilt? Sucking up?

5/5/97 3:30 pm

From Kaiser I called Jay back, [and] Susan Smith, MD, PhD, who told me what to ask: "My concern is making sure he had enough fluid. Is there a consulting internist that can look at him?" I had called Dr. Smith re how he was supposed to get water if he was laying there in a stupor. He might need IV's Also, [I] called Vivian, President of the National Alliance for the Mentally Ill (NAMI).

5//5/97 4:00 pm

I called and left a message with Dr. Abramson [the neurologist at Kaiser Hayward] to see if [Alex] should come to the ER. While I was talking to Vivian Jackson, Abramson called back and volunteered to talk to Dr. Segalove. He called back stating that Dr. Segalove said that Alex looked better and was moving around at 4:40pm. [Dr. Abramson told me to] call him when I see Alex tonight if Alex isn't up like Dr. Segalove said.

5/5/97 7:00 pm

When I arrived back at Villa, Alex was still in bed but awake and aware. I slowly got him up to walk around sliding him off the foot of the bed since the guard rails were still in place. He was then weak, and in pain in his elbow and left shoulder. He walked haltingly leaning on me. I asked at the nurse's station for him to go to ER [at Kaiser]. The nurse said she had been an ICU nurse and he didn't appear that ill. Do you have to be intensive-care-level ill, now, to go to an ER? She said she'd ask Dr. Rosenberg to look at him. His blood pressure had been 90/60 earlier and they took it again as I spoke to Dr. Abramson. It was 150/90. Instead, Dr. May, who used to work in an ER before he became a psychiatrist, he said, took him to a cubicle and examined him. [He] felt his stomach and looked at his eyes and mouth to see what the bleeding had been about. He ordered some blood tests. Used a stethoscope. Alex spent the rest of visiting hour walking around with me and sitting in the living room with me and Cassandra. No talking. All he said was he'd had 2 tacos for dinner tonight and he thinks he's dying.

No meds for Alex tonight while I was there. They stated they are discontinuing the Haldol and going back to Zyprexa. I went food shopping as I always do when I'm stressed; somehow relief is hooked up with spending money.

5/6/97

John Mogey, [social worker at Herrick Hospital where Alex was transferred from] called me back. [He] stated, "We made it clear that he's fairly sensitive to neuroleptics: Haldol, Prolyxen, Navane. He gets EPS from standard medical doses." They can easily request the info from last year.
Casey Economy, MD, is the name of his doctor at Villa [Fairmont.] Dr. Segalove answered the phone. I was just going to leave a brief message telling him of Alex's super sensitivity to neuroleptics. He stated he hadn't seen Alex yet this AM but he was much improved by late afternoon yesterday. I asked about getting the release of information signed again since Alex 'supposedly' already signed that no one gets information.

He stated that Alex is very adamant against the Zyprexa and says he did not stop taking it, so Dr. Economy is thinking seriously about Risperdal. So far they haven't started anything yet. I stated that he hadn't had the ultimate trial--6 weeks—[for the Zyprexa]. He stated that Alex should be sure to tell any hospital in the future about his super sensitivity to neuroleptics.

He stated that he understands that I'm interested and that's why he's talking to me even though Alex signed that no one gets information. I thanked him for being very empathetic. I think he was explaining away the hug that he gave me when I left yesterday.

He wondered how Dr. Abramson got involved because he didn't think Alex had a neurological problem. I told him the school counselor thought I should check out whether Alex had had a stroke and that I had brought him to several Kaiser doctors in the three weeks before he went to Highland originally.

5/6/97 9:00 pm

Janice, nurse or psych tech, (I don't know) seemed very willing to tell me how much of what meds he'd been getting. I wrote it down on the poem Alex gave me for my birthday, but Alex was so agitated when both she and I were trying to get him to eat something, that I must have left it in his room.

Janice had some difficulty stating what it said; it must be hard to decipher. I believe it was:
5/2 Zyprexa changed to 20 mg pill x1. The order for this was written on 4/30.
5/3 Haldol was initially administered on Sat 5/3 x 2 and Sunday x1 (This agreed with what Dr. Segalove had stated). Janice then corrected herself and said 4 doses.
Cogentin
Respiridol?
Alex was not doing well after the shower that Brenden gave him. Brenden was there when I arrived on Tuesday, 5/6, last evening. (This writing is 5am on 5/7.) I didn't realize he would be there and I was anxious to tell him all that had transpired. I spoke with both of them about it, probably shouldn't'[t have. I seemed to upset Alex, but I'm definitely hyper at this point. In pain with my hip, etc. Thank G-d, at least, I'm on vacation this week.

5/7/97 4:00 am

Blood Pressure: 130/92
Discrepancy: Dr. Segalove stated yesterday on the phone that Alex should tell any hospital in the future of his super sensitivity to neuroleptics. The problem with this statement is that it puts the onus of responsibility on Alex to tell. And yet, Dr. Segalove appears to be saying that his hospital "didn't know." Yet John Mogey, MSW [at Herrick] stated very clearly to me yesterday that Villa was informed that Alex "is fairly sensitive to neuroleptics." Why did "someone" as Segalove stated , it was the weekend "on-call" who decided to give Alex Haldol because "he was agitated" and "he asked for Haldol." These were two reasons that were stated to me by Dr. Segalove and Dr. Economy, (I believe at the 5/5 meeting in Segalove's office) Did no one look in the chart to see that he was sensitive to neuroleptics? Alex wanted Haldol [Segalove said.] I think the reasoning behind this conclusion is even more critical. An x-patient, Sherida was promoting to Alex how good Haldol was for her. She talks to Alex a lot on the phone and she stayed with me for a few days. So, Alex got this idea about Haldol being better for him in this manner.

What Alex wants should certainly be taken into consideration but more importantly or, at

least, just as importantly, what information that was clearly written in discharge summaries and in the chart from Herrick (which is easily available to Dr. Economy) should be taken into consideration. Yet, Villa did not have this information before this Haldol situation/decision was made. Indeed, they asked me at the 5/5 meeting what dosage was given at Herrick. This Haldol decision was made by "someone…on the weekend" without consulting the history of the Haldol reaction from Herrick [and] apparently, without consulting Dr. Economy or Dr. Segalove who had just the day before on Friday, May 2 assured me that they were not planning to give him Haldol (in answer to my question about what they plan to give him). I had stated that he had had Haldol in the beginning and Navane all year and he didn't do well on them.

Questions to ask at the meeting:
Did Dr. Rosenberg see him?
*no
How were the results of blood tests?
*normal
Does he need blood pressure meds?
Has Alex been put on a vegetarian diet?
*N/A

Page 18 [in my handwritten notes]

5/7/97 6 am

I don't like several things at Villa:
He hugged me and stated that I was a caring mother—the emotional ploy.
They never told me he fell.
There's so many discrepancies
Why the Haldol when they knew?
Can't get information /then can get it.
Everyone has a different story.
The money issue-
He's saving somebody money.
He (Segalove) stated he likes to try all the neuroleptics first (first Tues meeting).
He's trying to ingratiate himself with me. He doesn't have to give me info—but he is because I'm so interested, such a good mother, etc. He's kissing up. Why? What's his motive?

I think they never gave Alex the Zyprexa at all…too expensive. The nurse on April 30th talked about one large pill x 1 a day instead of the 2- 10mg pills. There is no one large pill!!!!! She was very surreptitious about it.

The situation of their taking him off of it [the Zyprexa]on February 12, [when he had been admitted] the first time, after which he jumped the fence [right before I took him to Florida for mom's funeral on March 16th .]

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Whenever I stated that he was to be put on one large 20mg pill, no one ever corrected me. And there is no one large Zyprexa. There may be one large whatever they've been giving him, but it's not Zyprexa!

He (Dr. Segalove) laughs too much. Always chuckling to himself. Is he getting something over on me? Everyone?
Alex says he always took whatever they gave him. Maybe they planted the 4 Depacote in his pocket-or just said they found it. Because when I asked: Why do they think he's cheeking the Zyprexa, if it was Depacote that they found in the pocket? So, they started giving him liquid Depacote. Maybe they are trying to kill him. Maybe it was just a ploy in order to give him liquid Haldol??
When I saw the medicine one evening, it was an orange pill-elliptical and one small white pill.

5/7/97 8:10 am

Jan in pharmacy at Eli Lilly. Called Lilly about whether they use a three letter shortening of the word…like PCP, PTC because the note on the chart said:

5/5
Stop immediately the
Use of all meds except
PRN Haldol, Cogentin
PTC

Did not refer to Zyprexa.
Jan said, 'no', she has never seen it in the literature or advertisements.

8:30 am

I got dressed and drove the old car to Villa Fairmont intent on finding that note that I dropped saying what the meds to stop were. I planned to tell them that I needed to go into his room to "find my keys that I left there". The keys to my other car. I need it today." Anyway, they said someone would come out to the front and walk me around. On the way in Mary, the cook , stopped us to tell me

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that she understands Alex is kosher and she's more than willing to make him something special. She knows about kosher food. Anyway I found the paper I was looking for and snuck it into my pocket as I pretended to look for the keys. I noticed that Alex was very still and I asked the clerk and Mary if he ate breakfast-negative-I sensed that I needed to stay there and asked who I would need to talk to get permission to help out-maybe feed him. They stated "the administrator" so I hung around the nurse's station while they made communications about my intent. I asked one of the nurses to show me what he was taking. The pills were Zyprexa and said LILLI 4117. So, that neurosis was cleared up. But, I never saw him take that pill only the elliptical and a small one. He took two pills only the night I looked and the small white one was probably Cogentin. The Zyprexa was much larger. I'm still not convinced that they were giving it to him. I should have watched him each night I was there instead of only once. But the once was definitely not Zyprexa. It should have been, shouldn't it? If he's supposed to be getting either one at night or 2 at night, It's still suspicious. The one night would have been the same as all other nights.

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1/8/98

The previous entre made on 5/7/97 was never completed so I'm writing about it now-eight months later.
I was too upset to put this nightmare into writing. I kept ostensibly cool as there was no one to help me.

5/7/97 9:30 am

After Alex was found to be virtually in a coma (that's what I call it; they called it catatonia). And I'd insisted on staying with him to "feed" him, . They didn't throw me out. What they did do was ask me to wait in the locked room next to the nurses' station and someone put Alex into a wheel chair and after some time- ½ hour- wheeled him into 'my' room. They gave me cereal and milk, juice and a straw. Alex sat up in the chair as they placed him, but other than breathing, he could do no more. I remember putting the straw into the juice and then in his mouth, talking quietly to him telling him to "sip". But, there was nothing going up the straw. He must have heard me because he tried to sip and the juice moved perhaps a quarter of an inch. His eyes were open, staring sometimes at me

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but mostly just in front of himself. He was able to open or close his eyes but there was not much blinking.
I told the male nurse at the desk outside my door that [Alex] couldn't eat and I wanted him to go to Kaiser for rehydration. He saw and said he'd ask Dr. Whoever.

When I asked him a ½ hour or so later what was happening and if he needed help calling the ambulance, he said, "No, they've been called." I never did see the faces of Segalove or Economy or an administrator that morning. Were they afraid to show them?

It was 10:30 am when we arrived into room 8 in the Kaiser Hayward ER. We remained in room 8 in the trauma area until 6:30 pm when Alex was taken to John George Psychiatric ER. It was strange how he happened to be taken right back to Telecare. One of the psychologists who had met Alex once in the first part of his illness - March of '96 - was on call.

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Dr. Mann.
There was nothing for [Dr. Mann] to say to Alex because Alex was unresponsive the entire day. He just breathed, opened and closed his eyes and sometimes seemed to be focusing his eyes on something. I was lucky that (my friend) Sabrina's husband, Dr. Wesley, decided to care for him in the ER because that other doctor who was originally assigned to Alex had said, "Oh well, he's a 5150," not knowing that I was his mother. Like catatonia was par for the course and acceptable [and Alex doesn't need care]. Paul got the tests done and they showed he was medically passing them. The psychologist on call, Dr. Mann, called Martinez Kaiser to arrange for a bed but Martinez told him Alex wasn't a member. I told him he was and the business office, Linda, reiterated that he was, and could go to Herrick. But, Dr. Mann asked for an IV- administering bed and the one that Herrick had was being used, so the doctor called John George to arrange for a bed [there]. They refused, said they couldn't take him either. He went over the doctor's head

to the supervisor in the ER who accepted him. Was that Dr. Weinstein? I'm not sure which one was in charge. Meanwhile John George didn't even have one IV-administering bed. Dr. Mann didn't even ask for an IV bed. Meanwhile Herrick did have a regular bed also, and I wanted him to go to Herrick where they knew him. But, Mann didn't ask Herrick for a regular bed only an IV- administering bed. Anyway, I didn't find all this out until after he got to John George and I spoke to John Mogey several times in the next day or two.

Dr. Weinstein, the one in the fencing outfit, did take good care of him in the ER, and just gave him a little dose of Ativan that relaxed him enough to be able to sip.

5/7/97 5:15 am

I called Eli Lilly's customer service again and a young woman answered. She told me the pills only come in 5, 7.5 and 10mg. on which is written in blue: Lilli and the number 4117 [or 4116.] The problem here is that the nurse on April 30th, said he'd been taking one larger pill once a day instead of two 10 mg. pills 2 x a day. Problem that needs to be checked is: the pill only comes in a 10mg. not "one large [20mg.] pill."

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5/7/97 08:10 am

Called Lilly

Why The Parent Has A Right To Be Heard

I have a right to be listened to by my son's physician because what dose he takes of the medicine that the doctor prescribes, affects me, too. For that alone, I should be consulted. Because I'm living with a disoriented person, I'm the one who has to wipe up the bathroom 4 or 5 times a day because Alex thinks he can't use a towel and has to air dry on the higher doses. I'm the one who has to smell the odor in the apartment each day when he doesn't take showers for two years on the 22.5 mg doses or higher. I'm the one who has to pay for someone to wash the carpet after he's been peeing on it in retribution, because he's angry on such a high dose, 27.5 or more, of Zyprexa—or when he stops taking medicine altogether—that it makes him agitated and argumentative. I'm the one who has to pick 36 "pee flees" off of the ceiling when they nap after they've finished their lunch on his carpet. I'm the one who gets depressed, looking at him when he's unable to even move a muscle from the 40mg of Zyprexa forced into him, and just sits on his bed like a statue because of their doing medicinal lobotomies. All of the Doctor High-Dosers need to think about what it does not only to the patient but to the family who cares for

him, and include the parent in the conversation about what can/should/could be used to get the best outcome. It's the parent who lives with their temporary client, who sees the results of what the doctor experiments on him. I have to use the "experiment" word rather than any other, because they don't know the outcome. It's just trial and error. They, personally, haven't done the research. Therefore, I should think the doctor would want more information about the cause and effect that is not in their own chart. After 18 years of illness, where the patient is in the hospital maybe a total of one to two years out of those 18, there is a lot of pertinent information that the hospital doctor doesn't have. The parent can give them access to it. Why would they turn up their nose to it?
"It's my license!" Dr. Freeman said. "He's my son," I replied, "and you should want to know what I've witnessed." No, she hissed, like a cat at the presumed enemy, me, the mouse, in front of the dozen or so nurses and other caregivers, discounting what I said about his being angry and agitated because of the 30mg dose. And she hissed again, several times, in between the few words I was able to interject between the hisses. I'd asked her how much time I had to speak. "Five minutes," she said. But, she gave me five seconds between hisses, until she finally yelled, "Get out!" another 10 times. Admittedly, I ignored her repeated put downs and demands, because I needed her to know what my son does because of /due to/as a result of each dose of Zyprexa that I'd been journaling about almost daily for the past 17 years. As far as Freeman, MD, was concerned, I was inept at my observations. It "could have been something else he was angry about," she said, discounting my record of his behavior. Do I really look that dumb? Maybe I should let my hair go gray like the men talking on C-Span so I can look more intelligent.

Admittedly, I only went to college for the basic degree of Bachelor of Science but who writes "BS" after their name; it hardly has that "higher than thou" effect. But, on my own behalf, I do have teaching credentials and have continued taking post baccalaureate coursework that totals over 200 semester hours so that the number of years that I've been taking 1 to 10 classes/year since starting 1st grade in 1949 is 60. That means, as of 2014, I've neglected school for only 10 years of my life. I've taken more than a half-dozen college classes in psychology alone, in preparation for hopefully going back to do research on the etiology of schizophrenia. I'm awaiting an e-mail from William Beardslee, MD, George P. Gardner and Olga E. Monks Distinguished Professor of Child Psychiatry in the Department of Psychiatry, to let me know who may be doing that sort of research. Harvard's research is on the effects of war on veterans, he said, when he signed his book, Out of the Darkened Room: When a Parent Is Depressed: Protecting the Children and Strengthening the Family for me, at a National Association on Mental Illness (NAMI) conference in 2013, where he was the keynote speaker. I must have looked stupefied, until he asked if I were the Joan Miro who e-mailed him. I've never thought of myself as stupid, 'though for sure, I wasn't number 1 at Northeast High School in January, 1962. That was my friend Karen Rappaport. No, in fact, there were forty some students ahead of me in the smart line, out of not quite 700 in the class. So, I'm just normal. But, for some reason, I've never really left school, making sure to show up for every kind of class from economics to scriptwriting these last 50 years since high school graduation. Actually, going to school is almost an obsession with me. Even after I had my first spine surgery in March, 2011, in the middle of my screenwriting class, I

returned for the last few classes before the three month recovery period was even over. I didn't want to miss hearing everyone's scenes read to an audience of all of Instructor Joey Xander's classes and guests, including my own granddaughter who commented to me, "It was better than the other ones, Bubby."
"It's not a competition, Alanah." I replied. "Well, maybe between you and yourself," I should have said.

Schizophrenia Research

And a few years later, when Alanah drove over to see me—right after getting accepted to Harvard with a full-paid gift from the University—to tell me, "You were my inspiration," I asked her to please walk over to Dr. Beardslee's office when she gets to Boston, to ask if he was able to remember a school that's doing research on the etiology of schizophrenia. Because I haven't yet found a college, except the one in Japan, that is doing that research. It seems they don't care about the cause. A clinician at UCSF, Kevin Scotnicki, who came to the lobby to talk to me, when I went there to inquire if they were researching etiology earlier this year, told me that. He said, I should "Google 'UCSF Psychiatry,' then 'research,' and click on 'Join a clinical trial or research project,'" he notated, if I want to do anything with UCSF. No thanks. That's not what I had in mind. I only want to see if being an undiagnosed, untreated bili-baby has anything to do with etiology. A College in Japan that I Googled, did research and already connected hyperbilirubinemia with schizophrenia a dozen years ago. And I agree that they are connected, because of what happened in my own family. I'm hoping someone else will want to do more research because I haven't found a school thus far that is.

In brief, my idea on the etiology of schizophrenia has to do with undiagnosed and therefore, untreated hyperbilirubinemia. My oldest son, Brenden had to have 3 complete blood transfusions and was under the lights for over a month, after he was diagnosed with it at birth. Yet, even though Alex, 7 years younger, had the same two parents, he was not diagnosed or treated. My contention is that Alex was a bili-baby, too, and after incubating for 18 years, the bilirubin caused the schizophrenic hallucinations and delusions. Catherine Schaefer, Ph.D., Director of Kaiser Permanente Division of Research, spoke to our NAMI-East Bay group one evening, around 15 years ago, and planted the idea in my mind that it was an in-utero issue, as she explained five in-utero factors her group was studying as a possible cause. I only remember 2. One factor was folic acid deficiency and another, a pharmaceutical that the mother may have ingested, that may have had the effect to cause schizophrenia, like thalidomide had its effect on the fetus. I don't remember the other 3, but it was the first time I started thinking that the cause might be associated with the unborn and the incompatible blood types of the parents.

But, UCSF isn't interested in cause, or anyone I've spoken to so far whether an ER doc, a psychiatrist or social worker. They just deal with what's in front of them. That makes me think that clinicians are happy to be able to make money with all these hospitalizations time and time again without ever contemplating a cure. With no cure, the mentally ill just remain sick, which keeps the hospitals full. Let's face it, the mental health system in

America is a mess, a farce, a sham. In my opinion, there is no “system.” And Villa is just the ugly, uncaring face of it.

Here's Act II, Scene III which actually happened several years ago:

Alex’s Story Act II Long Journey Of Losing Son

This is the story of a son who becomes mentally ill at 18 years old, and his mother, who is seeking recovery for him, and how they are forced to work within a system of public mental health that is satisfied with the revolving door status for patients, a system that doesn’t even include the concept of ‘recovery.'

[scene: Visiting Alex at John George Psychiatric Pavilion once he's admitted

value: plus to minus happy to frustrated]
INT. JOHN GEORGE PSYCHIATRIC HOSPITAL MAIN ENTRANCE AFTERNOON

Mom is running late for whatever reason, and parks in the hospital lot, happy that there is still a half hour left of the hour-long visiting time. Upon jogging up the 20 steps to the building, she rings the bell, then waits a few minutes for security to let her in, the first of many such hold ups. After entering the hospital foyer she darts to the reception desk and is informed that Alex was already admitted to a room, so she wants to hurry through the doorway and down the atrium to his unit but her hopes are again dashed by both the receptionist & the nurse who apparently can get away with giving poor customer service while maintaining a facade that it’s good enough.

Looking at receptionist, she makes an effort to smile pleasantly after the inordinate wait at the door.

MOM
Hi. Alex Anderson? He was still in the emergency room when I left last night.
SECURITY GUARD
Please step over here when you’re through so I can check your belongings.

MOM
Turning to look at where the voice is coming from.
Oh, sure.
RECEPTIONIST
Mom turns back to receptionist, who is taking her time looking through their antiquated paper lists of each unit.

Beat
Receptionist looks for, then hands Mom a locker key.

He was admitted this morning to Unit D. Please put your belongings in a locker by the door, when security is finished, and I'll buzz you in.

SECURITY GUARD

Turning around, Mom stops at the Security Desk on the way to the lockers. Security guard, sitting on desk, stands and frisks her, then looks inside her pocketbook for potential weapons, then at his watch.

Hands straight out to your sides, please. There's only 23 minutes left of visiting hour y' know.

Beat

Thank you.

MOM

Mom follows receptionist's instruction fumbling hurriedly to stuff her pocketbook into the locker, then taking it out again, she removes a file folder, and stuffs the pocketbook back in. She then moves over to wait by the door to the Unit, turning a few times toward the receptionist who walks out, returns, and is now gabbing with a coworker, so Mom bides her time reading a sign next to the door entitled "Patients' Rights."

RECEPTIONIST

Did you ever see anything so funny in your life?

Receptionist giggles.

RECEPTIONIST #2

No, that man cracked me up!

Receptionist #2 giggles

When you go back in, see if he's still wearing... Y' know.

RECEPTIONIST

Turning toward Mom, her tone changes from convivial to serious. The receptionist finally beeps the door which opens to clear a path through the atrium toward Unit D. Mom walks quickly, allowing herself to be only slightly perturbed at the lost time.

EXT. HOSPITAL ENTRANCE TO UNIT D AFTERNOON

[value: plus to minus hopeful to disenchanted]

Passing 3 buildings she comes to Unit D. As she starts to ring the bell a tall male nurse with an authoritative gait, passes by on the way in to Unit D and stops to address her.

NURSE

Oh, are you ready now? And you're visiting whom?

MOM

Hi.

Beat

Alex Anderson; he's a new admit.

NURSE

Well, I would recommend that you come back later tonight. Visiting hours are over in 10 minutes.

MOM

So, that means that right now, it's still visiting hour?

Beat

To herself

You mean it took 20 minutes just to get through the main door?

Addressing the nurse

Thanks, but I really need to see him now, while there's still time. You understand. Just to assure him he's loved, give him a hug. Like that.

NURSE

Well, I'm Alex's nurse. And, actually, he's been a problem since he came to the unit, and has been moved to the quiet room. I would encourage you to come back when things calm down.

MOM

Really! What did he do?

NURSE

I can't tell you. You don't have power of attorney, so it's private information.

MOM

Beat

How do you know that?

NURSE

There's nothing in our records, so I can't talk to you about him.

MOM

You've looked? That's odd. Those forms should already be in his chart.

Beat

She digs into her file folder and hands him a paper Alex signed giving her power of attorney.

Here's another copy. Would you be sure it gets into the right place in the chart this time? And if you're having a problem, maybe I can help you calm him down.

NURSE

Well, actually, I already had to give him something to quiet him. I'm sorry, but I don't think you ought to come in now.

MOM

Beat.

She collects her thoughts, takes a breath to calm down.

Is that right?!

Beat

Well, you're certainly entitled to your opinion. And I just have one question before I leave: Are you familiar with Patients' Rights? I noticed a sign in your vestibule that says patients have the right to see visitors during visiting hours.

Beat.

Nurse seems confused, so Mom repeats.

Patient's Rights? It's still visiting hour.

NURSE

Let me check.

Beat.

He unlocks the door of Unit D and goes in while Mom waits anxiously to see if she's going to get inside at all. Nurse comes out shortly.

MOM

Mom stares at him.

NURSE

OK, you can come in for a few minutes. There's only a few minutes left of visiting hour anyway. We'll see if he can handle it.

MOM

Mom walks past the nurse, who then turns to show her into a room right in the front next to where they'd been talking, and he unlocks the door.

INT. JOHN GEORGE PSYCHIATRIC HOSPITAL QUIET ROOM DAY

[value: minus to plus anxious to relaxed]

Alex is lying in bed. Quiet, but teary eyed. Mom walks in and Alex looks at her. The nurse looks in and then leaves them alone with the door open.

MOM

Hi honey. Are you OK? They said you were upset. What's up with that?

Beat.

Were you? I thought you liked this place. The food and new-looking building and all that.

ALEX

Too much medicine, Mom.

MOM

I'll find out about it, Alex, but in the meantime, don't get upset, OK? That doesn't help. Remember, we all love you.

ALEX

Annoyed

Who's 'we all'?

MOM

Defensively, she starts counting on one hand the family members who are still interested in continuing a relationship with both she and Alex.

Well, let's see. You have Brenden for one. He stuck around, didn't he? And now we have Alanah, too. Right?

Beat

Unfortunately, Bubba and Zadda are gone, may they rest in peace. Remember? They took care of you that summer in Florida when I went to New York to look for a job? No, you weren't even 2; I guess you wouldn't remember.

ALEX

I remember

MOM

So, who more do you need? Uncle Jay? Uncle Jerry? Don't look for them. They're only 'good time uncles.' Mom should have named them both Charlie. When you're better, they'll be friendly.

Beat

Look, Alex, this is about you. Think about what you want, what you want to do, where you want to go.

ALEX

She kisses him on the forehead.

Why would I want to frustrate myself by thinking about what I don't have, what I can't do?

MOM

That's not what I'm saying. I'm saying just to think about what you want...what you want to do. And don't say you can't! You don't know if you can or you can't. But you do have to want something... so you have a reason to get better.

Beat.

Alex, remember your song? Think about the words and maybe it'll calm you down when you're upset, and we'll get through this. And remember...
it's for sure that I love you.

She sings to him [the first two sentences are recited] while he lies there listening quietly and smiling as he's touched by the words she wrote just for him at an earlier time when she thought "recovery" was certain.

MY LOVE FOR YOU IS EVERYTHING. YOU'RE MY LIGHT! MY DARLING.

MY LOVE FOR YOU IS EVERYWHERE, IN THE SEA, IN THE AIR.

WILL YOU WALK INTO THE LIGHT,

FEEL THE FREEDOM OF THE NIGHT?

NOW THAT YOU'RE THE VICTOR OF THE PAST.

WILL YOU RECOGNIZE YOUR STRENGTH,

THEN GO TO ANY LENGTH

THAT IT TAKES TO MAKE THAT FREEDOM LAST.

WILL YOU DO WHAT YOU MUST DO

TO BE THE CAPTAIN OF THE SHIP CALLED, “YOU,”

SO THAT YOU CAN HAVE THE FUTURE OF YOUR CHOICE?

WILL YOU LISTEN TO THE WISEST WORD

THEN GIVE SOME THOUGHT TO WHAT YOU HEARD

BEFORE PUTTING THOSE THOUGHTS TO A VOICE.

MY LOVE FOR YOU IS EVERYTHING. YOU’RE MY LIGHT! MY DARLING.

MY LOVE FOR YOU IS EVERYWHERE, IN THE SEA, IN THE AIR.

DO YOU KNOW HOW PROUD I FEEL,

‘THOUGH THESE TIMES HAVE BEEN UNREAL.

YOU NEVER GAVE UP, WHEN HELL WAS ALL AROUND.

AND I KNOW YOU’LL DO WELL SON

BECAUSE YOU’RE THE ONLY ONE

WHO MAKES GEMS FROM THE ROCKS THAT YOU FOUND.

AND YOU KNOW I LOVE YOU SON;

I’M SORRY FOR THE THINGS I’VE DONE.

PLEASE FORGIVE ME THOSE MISTAKES THAT I MADE.

AND I KNOW YOU LOVE ME, TOO.

IT SHOWS IN EVERYTHING YOU DO.

LET’S NOT TAKE ANY HATE TO THE GRAVE.

MY LOVE FOR YOU IS EVERYTHING.

Captain of the Ship- Song (vocal mix), by Joan Miro @ www.joanmiro.bandcamp.com

ALEX

Thanks Mom. I love you, too.

He gets out of bed, they hug, and then both exit the quiet room.

MOM

Listen to these people. OK? Tomorrow then.

She blows a kiss.

They are seen by his nurse at the station, who looks up at them, but doesn't do or say anything, perhaps because Alex seems to be acting appropriately.

Characters-Actors

Narrator

Mom- Joan Baez

Security Guard

Receptionist

Alex

Receptionist#2

Nurse

Friday, November 7th, 2014

The Oral Surgery Appointment That Never Happened.

I returned home from Villa today, Friday November 7th, 2014, just before 5am, the time all of us should have been at Highland getting Alex the care he needs—kind of expecting that the Villa organization would do the right thing and get Alex ready to go to Highland Hospital's Maxillary Oral Surgery Department, after Brenden and I tried to keep the surgery in their view since the dental appointment by meeting separately and intermittently with Danielle, (Oct. 30th) the social worker, and Brian, the clinical administrator. But, there wasn't the same energy emanating from Villa that there was at the dental appointment exactly a month earlier, on October 7th.

His nurse wouldn't even let me inside to speak to Alex or to her. I was made to wait outside in the dark at the entrance talking through the intercom. Having called before I left at 4:10am, Nurse Amy didn't appear to know anything about a transfer to Highland. I would have thought everyone on Unit C should know that a patient would be leaving so early in the morning. It should have been important to get him over to the dental visit,

but, it wasn't. Not to them anyway. His nurse, Amy said, was on break, and I should have left Berkeley at 4 to get there by 4:30am, the time Danielle had said the transport would be leaving, so I couldn't wait, and I'd given up my cell phone so I could afford to buy the pizzas for C Wing a few times a month.

His nurse said through the intercom that Alex said he didn't want to go. Who the hell would want to get up in the middle of the night to go to surgery? "He went back to sleep," she said. And she said that when she told him that his mother was on her way, he replied that he didn't know who that woman was. I said that a dentist already informed me that this could be a very dangerous situation; he could lose his eye. Minimizing my comment, she replied that he still has his eye, and they're closed because he's sleeping soundly. Somehow, I didn't appreciate the humor. It showed her disregard for Alex's health and safety. I inquired whether the doctor had prepared him for this dental visit as they had last time when he did go to the dentist for x-rays on October 7th—of course, that was at a reasonable hour during the day—and she avoided answering. I was in no state to pursue the conversation further, standing out in the early morning cold, so I left.

There could have been a meeting about it in advance—to include both Alex and myself—to explain the importance to him of having his abscess fixed. They could have lowered his medicine dose to at least 15mg from the 20mg he's been on since October 2nd, so he would have been able to be more reasonable and to be willing to listen to the explanation. After all, at 20mg, he doesn't even realize I'm his mother, but he does at 15mg. Dr. Fitzpatrick at Herrick, told me he expected the Villa doctor to do any adjusting downward, and according to his phone message to me, he was intending to keep the Zyprexa high at 20mg, but agreed not to go higher because of any potential acathesia:

> 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.

When Dr. Nicholas lowered the Zyprexa on only his second day at Villa, Alex was no worse. He was better. True, he wasn't ready for Harvard. But, the doctor, for some reason, was expecting him to be much improved, but he was only a little improved. Alex was able to recognize me as his mother, and was able to give me a hug after only 24

hours on 15mg., whereas on 20mg he didn't know I was Mom and wouldn't hug me. I thought that alone was an improvement. He was on 15mg. for only a week when he was taken to Eden hospital's ER on September 17th, without any protesting, where they left him on his own until I arrived a few hours later. He had been put back on the higher dose, 20mg, for about five days, when he was still able to be talked into going to see Dr. Sharma, DDS. But, now that he's been on 20mg. since October 2nd, he's recalcitrant. That's 5 weeks on the high dose, so it's taken effect. For sure, he was no worse on the 15mg; he was a little better. If they would have lowered it to what he was getting for the four months (10mg.) before being hospitalized—that is, before he stopped taking the medicine altogether—he would have been much more reasonable and may have on his own volition, been willing to go to the dentist again. "It could be a very dangerous situation if it's not taken care of. The antibiotics will wear off in one to two months," Steven Gurzoff, DDS, my inside track to dental health, told me from his home in New Jersey just after the abscess appeared almost two months ago. Alex's own dentist, Dr. Sharma, filled out several papers after taking x-rays and giving all of them to Villa's psych tech, Uday. So, they knew all about the tooth abscess at Villa because they had it in writing from the dentist. Sharma didn't say much, just that he needs to go to oral surgery and gave me the form with her oral surgeon's address on it in Alameda. I gave it to Danielle, at the social worker's request, without first making a copy. I should have received copies of everything that Uday got, but I didn't think about all that because I was over anxious about trying to maintain a comfortable atmosphere for everyone at the dental office.

Alex's social worker, Danielle, called back yesterday to say that I should probably meet the transport team at Villa rather than just going to Highland by myself to meet them there. Apparently, she was predicting what she thought would be the outcome. I could have given the writ hearing a better chance by putting some pressure on Alex to tell the public defender that he wants to leave Villa and go home. Because he has said many times that he wants to come home especially when he was on the lower 15 mg dose. But, 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. The three memos, that I had put into their mailboxes, follow:

Memo To All Interested In Mental Illness And How The Mentally Ill Are Still Treated

> My son--who is now at Villa Fairmont Mental Health Rehabilitation Center in San Leandro, CA, who has had schizophrenia for now half his life of 36 years, who has had high blood pressure since a couple of years after he'd been taking the great variety of medicine that he's been given (from the neuroleptics of the 1950s to the 'new' ones of the 1990s) for those18 years, who thinks that he has

to wait until his "spaceship lands," before allowing the nurse to take his blood pressure--is being denied his 50mg of Atenolol by the nurse, who said last night while giving out the meds: "He's not allowing me to take his blood pressure." I asked, "How long has this been going on?" She said, "For the past 6 days." So, they did not even wean him off the 50mg; just stopped it abruptly? She couldn't have informed me sooner so that I might help?
I informed her that it's his mental illness—that is not allowing her to take his blood pressure and it's the way she's asking him if she can take his blood pressure—that's not allowing her to take his blood pressure. For example, I explained to her: "One very understanding-of-mental-illness-Berkeley Police Officer—whom I had called, because I needed Alex to get into my van, and he wouldn't get into the van in-order to go to his Kaiser doctor's appointment— said to Alex: "Alex, would you do me a favor? Would you get into the van? That would really be helpful for me." Alex immediately got into the van and, short of breath, I sped off without even taking the time to thank the astute officer, because I was afraid Alex would change his mind. But he didn't. He was smiling, so happy was he to be able to do a favor for the man in uniform. He actually told me that he was happy to do him that favor.

Since then, I've been telling the various nurses at the various mental hospitals that story, when I hear one of them say, "He wouldn't take his medicine," or "He wouldn't let me get the blood test." They should already be trained in how to work with patients rather than standing behind signs that say "HIPPA." HIPPA doesn't mean that practitioners don't have to work. I have to explain that Alex is in another world most of the time. And in his world, he is saving the universe, saving "all the children," taking off and landing in his spaceship. He often insists on leaving his bedroom window open wide— too wide—so that his ship can take off when it needs to. But, I confront him about that, explaining that I live here too and I can't let him put both of us in jeopardy. Sometimes, he gets me mixed up in his world and tells me I just "killed his twins," because I might have just turned on the blender, or the sewing machine, or because I was cooking and "making smoke." And this is ON medicine.

I have not yet found a doctor who wants to take the time to zero in on which medicine actually works for Alex. G-d knows, they've used what medicine is out there: Haldol, Prolyxin, Zyprexa, Seroquel, Risperdal, Cogentin, etc. It's just that there's not much out there. The research that gets done apparently has to be similar to the research that's already been done so that it will be able to pass the FDA qualifications more easily, like Risperdal which is similar to but not exactly the same as another medicine that's already on the shelf. So, where is the money for "real research?" something that's different? something that works? Is my son and everyone else's sons and daughters just to be kept in this state of dis-equilibrium the rest of their lives? Are nurses and other mental health workers trained in how to talk to the mentally ill? I don't want to add "stroke" to my son's already diminished life style.

From: Joan Miro, Alex's Mother HYPERLINK "mailto:joan.miro@att.net"joan.miro@att.net Date: Thursday, October 2, 2014

MEMO #2:

To: Dr.Nicholas Re: Alex Anderson

From: JoanMiro Date: October 6, 2014

It just came to my realization that you changed the Zyprexa upwards to 20mg on the same day that you received the memo I wrote about Alex's blood pressure medicine. It would be retributive to change his medicine just because you didn't like what I wrote about his not getting the blood pressure medicine. I saw at our first meeting on his second day there that you took an immediate dislike to me. My voice was too loud, you indicated. You let me know that you don't like my writing, and my reporting it to higher authorities, but that's what I do...write. I have to write. It's the way that I can keep everything that's going on with my son—what's being done and what's not being done for him, and how he reacts on different medicines, in perspective and in memory, as it were, because I can't remember everything. Enclosed is the letter I spoke to you about, from his very first doctor in 1996, who didn't seem to mind my writing down what Alex was taking and what he was doing because of it. As I recall, he would actually read what I wrote each week for a few minutes before visiting with Alex. Then Telecare took Henri Montandon, MD, PhD, away from Alex and placed him with STRIDES without even asking Alex or me. Talk about immoral. And that was when my journals started to include more about the mental health system in addition to Alex's reaction to the various medicines.

I certainly hope you weren't offended that I wrote about Alex not getting his blood pressure medicine for 6 days before I finally was able to get that information myself, from the evening nurse. Someone should have been checking that out before I learned that he was only getting the 25mg in the morning when he would allow the blood pressure cuff to be used. And I appreciate that you did something about it. Had I been told that he wasn't allowing the nurse to take his pressure the first time it happened, I might have been able to help by not giving him some of what he wants—food, freedom and friendship, in that order. Doesn't using what patients want, as per Mark Ragins, MD, help you get them to do what you want? At other times when I had asked about his medicines, the nurse might have been on a break, or at a meeting or was just too busy, or appeared to not want to tell me so she would just presume he didn't sign a release, and therefore, wouldn't tell me and would look busy with other things. Toward that end, I wondered why I was never given a copy of that release that both Alex and I signed. It would take me a lot less time to produce my copy than it takes some of the nurses who have to look through a lot of papers to find that one that makes sure the mother has permission to know, especially those of the nurses who already have an attitude and find it annoying to be bothered to look, to see if I am entitled to information.

If you think that I have a lot of nerve to write about what I think and what I see and what I know is happening, just remember what I told you about what happened here at Villa on May 7th, 1997, when Dr. Economy with the permission of Dr. Segalove, put my son in a catatonic state for well over a week. I wonder if it ever got into the chart. It's in Kaiser's chart. I wonder, too, what you would have done if that were your son. And how close would you then monitor what other doctors are doing if they didn't even make an effort to sit down and talk about it with you? My mistake, Drs. Economy and Segalove, did talk to me, but

only after he was comatose where only his eyeballs could move. Doctors should sit down and talk about the plan before anything else happens that could have been prevented. According to the website: “Telecare works in concert with our customers to deliver recovery-centered services that enable people to live their lives in a more hopeful, healthful, fulfilling way that is in line with their hopes and dreams." I would think that statement implies that you would need to work with the family to find out what the patient’s hopes and dreams are, when the patient is too ill to say what they want. The family, then, is also the customer because the family knows what they want.

I was made aware that you went back up to 20mg. Why would you not have the courtesy to tell me you intended to. And you did it on the same day that I gave those memos to you, the social worker and director. That speaks for itself. Yet, you told me at our first meeting on September 11th that you would be willing to lower the Zyprexa to 15mg. I don’t know what compelled you to say you would, but I appreciated your doing it, and it was nice of you to talk to me on only the second day after his arrival, because it was the higher doses that caused him to wear the same clothes all these weeks. It’s not the first time that he’s done that. At Herrick he wore the gown only, so he did the same thing there on 20mg. Other times on high doses would find him unable to wear normal clothes or to change clothes or to eat or bathe. It’s more because of his reaction to the higher doses of medicines that make him do inappropriate, and self-harmful things. He was on 20mg for almost the entire month at Herrick which is what he was still on when he arrived at Villa Fairmont on September 10. Dr. Fitzpatrick got him quickly up to the 20mg because he was on no medicines when I called 911. Isn’t it so, that behaviors just don’t stop or start overnight; the medicine dose is still in the system for a while.

For the three months before my July 22 surgery, he was on only 10mg of Zyprexa and dressing in a different, appropriate outfit every day. But, I told you 15mg was OK, because Dr. Beck at Gladman liked 15mg. At least he isn’t as aggravated on 15 as he is on 20. Going up more, he's really angry, and then 40mg, he's back to catatonic. That's how he was when he came to Villa from John George in December, 2009 and it took until April 30th, 2010 for him to be discharged. Dr. Novis was reluctantly willing to start the Clozapine but Alex wasn't willing to continue the blood tests until November of 2010, several months after discharge, when he asked me if he could come home from Fulton Place. That's what he wanted, then to come home, and I let him if he would put up with the blood tests. And he's been home since November, 2009, but only was on Clozapine for about 3 years until his last short stay at John George. After that, he didn't want any more blood tests and neither did I. At home, he was taking showers at 10mg. of Zydis, and going on a few long walks each day and to the local stores on 10mg. But, I thought he needed something else to get him more motivated, maybe Abilify at 10mg. I thought when we talked about Abilify after the Tuesday meeting I was invited (and then un-invited) to, that you would be adding more Abilify incrementally. Because we haven't talked since Tuesday Sept 23rd, I presumed you may have gone past 10mg of Abilify, the highest amount that was ok, because he started to look overdosed, but now I see it was because the Zyprexa went back up. I didn't tell you anything about Abilify working at 10mg, but not at higher doses, because you were in the nurses station being bombarded with questions and conversations. I would hope and want to

have a short meeting with you every couple of weeks. I need to know in advance for my other son to be able to attend.

I was really hoping there might be something new to try, to go along with the 10mg of Zydis, because after he would take a morning walk, come home for breakfast, then go out again, he'd just stay home for the duration of the afternoon lying in bed, either meditating or talking to his friends in his head. It was way too isolating. Although he dressed, ate, showered and walked, that was all he did. He wouldn't go to the Creative Living Center program although it moved within walking distance to us, or to any place where there were people like him, like Le Chiam. If there is nothing new to try, then I'll be happy to take him home on the 20mg of Zydis. He wants to be home.

MEMO #3:

To: Dr.NicholasDirector,MedicalDirector,SocialWorker
From: JoanMiro
Re: Alex Anderson
Date: Fri. Oct10, 2014

Dr. Yonabayashi, Alex's regular Kaiser medical physician, is going to message Kaiser Oakland's "Maxillo Facial Surgery Department," she said, because they do have oral surgery at Oakland. He's been a Kaiser member since 1991 when I first received benefits there. Although my best friend's husband, Steve Gurzoff, DDS, in New Jersey, said to "take him to the ER at a major hospital that has oral surgeons on staff, like UCSF." He said, "It could get very dangerous if it starts to swell" [again]. (I didn't have my notes with me when I wrote the card yesterday, so I may have written something a little different, but I'm looking at the scribbles now so this is actually what he said.) They will "have to put him to sleep," he said, after I told him what Alex told me: "I'm not doing surgery. My great grandmother and my grandmother and my mother all said I don't have to."

I wasn't aware that Kaiser had oral surgeons on staff either. But, in the 15 years I worked in admitting in Hayward, I could personally recall one patient who had dental surgery while admitted. So, when I received the first message back as a memo from Dr. Yonabayashi on Wednesday saying, "Kaiser doesn't do dental surgery," but I replied to the person reading the memo, "maybe not in Union City"- using the hospital at San Leandro or Fremont, "but I know they did it in Hayward." She said she'd connect with Yonabayashi again to set up a telephone appointment with me this morning.

So, Dr. Yonabayashi said she'll "contact Oakland Maxillo Facial Surgery and someone would call you," and then Villa Fairmont, so he can have it sooner than later while he's still in the hospital and able to get to Oakland ER. The 10th day of antibiotics should have been September 26, two Friday's ago. So the puffiness could return in two more weeks. I was told by the Eden ER doctor that they wouldn't want to do surgery while the infection was active, so waiting for the infection to return doesn't sound like a realistic or humane thing to do. The other possibility would be to discharge him now and let me worry about how to get him to the ER. It's a possibility, given I could call 911. But, I haven't been able to get him into my van on my own unless a willing police officer is called to

undertake the task and not all of them are. I was just lucky a couple of times. In the past 18 years I could count on one hand how many times he's been in my car/van to go anywhere. That's why he's only been to see a dentist maybe twice since he's been ill, once in New Jersey, and the second time right after he first became ill. After that my dentist in San Leandro ,didn't want to see him anymore. Thus, the abscess. Dr. Yonabayashi suggested that it would be more realistic if he could go while he's still a patient at Villa Fairmont.

I have the $1,125 that I said I would be sending to your business office on the 3rd, when he received his SSA, but I didn't still have the name of the person to give it to and I've been coming too late and have been too upset and disorganized to remember to do it, and too focused on Alex's tooth, so I'm going to put the check in Danielle's copy of this memo today to ask her to give it to whomever is supposed to get it.

Thank you all again for making the dentist's visit last Tuesday go so smoothly. Maybe there was a little help from Carma, too, because my other son, Brenden, was 7 years old on 7/7/77.

But What About His Abscessed Tooth?

Getting back to the present situation, Sept 26, 2014 was day 10 on the antibiotic that was initially given to him by EDEN's ER doctor on Sept. 17th, because his face was blown up due to the abscess. So, when was the follow-up care coming? His dentist says that the infection will return if it's not taken care of within a month or two. The antibiotic will wear off. I was made to wait a week or so just to get a regular dental appointment for him, because Delta Dental didn't have him in all of their computers, the main office of Delta said. But now they do, and now my dentist knows that he's her patient, too. So, I'm forced to be the one to insist that he needs to see a dentist before the antibiotic wears off. Is he my patient? I, by myself, haven't been able to get him to a dentist in many years. But, that's because I can't do it alone. He used to go regularly before he became ill and even once or twice afterwards until our dentist didn't want him as a patient. His present dentist, Dr. Indu Sharma, DDS, at Berkeley Family Dental, has never even seen him in the year and a half we've had Berkeley Family Dental, because Alex won't go to a dentist, unless there's lights and sirens like on September 17th at Eden or when Villa's transport team, two body-guard types, took him to Sharma on Oct. 7th where the dentist explained that he had to have oral surgery and referred him to her colleague in Alameda.

I had picked Sharma after asking her if she would see mentally ill patients. That was the question that I asked all of the dental assistants when I was deciding on one. Apparently she didn't remember, because she'd rather he go elsewhere. I, myself, have been to see Dr. Sharma only once, but I couldn't get the help I needed to get Alex over there. He's too mentally ill to see the need to go to a dentist and unless a man in uniform is telling him to get into my van, he won't. I was told that two teeth just fell out the last time he was in Villa in 2008/2009. So, now, if he does consent to getting into the Villa van, he's going to a dentist, who is, as her assistant implied, only going to look at the problem, but then would recommend a specialist to fix it. She'd rather not have to work on the mouth

of a mentally ill person. She's nervous. I've already been to the Berkeley police station tonight to ask if they could help get him into the van, but she said to go to the San Leandro Police since Villa was there. So, that's about the story. Everyone has their limits. And mental illness is one of them.

If Alex's situation doesn't sound grave to anyone except me and other mothers, just continue reading to see the gravity of the mental health system's problems from the perspective of a psychiatrist. I am including herewith a few correspondences from Henri Montandon, M.D., PhD., which address various issues in mental health that should be available to everyone. He calls it, "The Letter In A Bottle." And who is Dr. Montandon to me? He was Alex's first psychiatrist, highly recommended by the group of family members when I sat on the NAMI - East Bay Executive Board. At that time, Alex and I lived very near to the Shuman Lyles Clinic where he worked, so I opted to bring my son there. Montandon always made himself available to talk to me either before or after he'd seen Alex. He even would take a few minutes to read my journaling before each appointment, and that was before I'd even bought a computer, so it was in long hand. And he didn't get offended whenever I asked to speak to him. Here are some of his and my most recent e-mails (in reverse chronological order) which is followed by his own screed:

Henri Montandon
To me
Aug 23, 2011
Hi Joan,
Thank you for your kind words. I wonder if you would mind if I don't bill you? We are comrades in arms.
Henri

me
To
Henri Montandon
Aug 23, 2011
Dear. Dr. Montandon,

Thank you for helping me. I don't know how to say this. I was very anxious and your reply greatly reduced my anxiety. I am so comforted in knowing better how to administer the new changes and in knowing that you were there and willing to answer my question.

I'm sorry to bother you, but I didn't know where to turn. Alex's doctor sounded upset with me last week because I told him, "Why does everyone [at Berkeley Mental Health] not want my son to recover?" And he replied: "That is an insult. Of course I want all of my patients to recover." I was aghast at his tone. But, it was only after hearing my indictment of BMH, that he did finally say he would be willing to change the medicines to what I said worked 4 years ago. His original stance was to insist on only allowing Alex 2 anti-psychotics at a time, and especially not Zyprexa. Until I told him that I personally knew psychiatrists on the East Coast who used concoctions of more than 2 anti-psychotics, he wouldn't budge. Afterwards, he admitted that he knew doctors who used up to 8.
So far, since I went to 5mg on Sunday night, Alex seems better, is motivated to get out more, is thinking better, doesn't have as many "can't do's, and hasn't freaked out, which is what I was so anxious about. I'm watching closely and he seems to be responding better, not worse. Thank you.
I so very much appreciate your caring ways. You are a very unusual person.
And, don't forget, I am very willing to be and insist on being billed for a second opinion or for professional services or whatever you would call it. I know it was an odd request and it takes your time whether it's in person or in e-mail. Please send it to:
Joan Miro
Berkeley, CA 94703

Or just e-mail me an e-bill with your official address on it, so I can send you a check.

Sincerely,
Joan

Date: Sunday, August 21, 2011, 10:38 PM
Hi Joan first thing I would do is get blood levels of Alex's current doses of Abilify and Chloral. A steady-state plasma clozapine concentration of 0.35 to 0.6 mg/L (NB. - quoted values may vary slightly) should produce a clinical response in most patients. The point of the range of blood concentrations is this: 95% of people who respond will be within the range. If the range is too low, it means that the Clozaril dose should be raised to insure that the maximum benefit is likely. If the range is too high, it means that the dose can safely be lowered with probably no loss of effectiveness. The blood sample should be drawn 12 hours after the last dose of Clozaril. So if Alex takes his Clozaril at 10 PM, the blood should be drawn around 10 AM the next morning, but before he has any Clozaril for that day.

I would not lower the Clozaril immediately.

Instead, I would first add Zyprexa 5 mg and see how Alex does.

If it seems like lowering the Clozaril dose is still the optimal way to proceed, I would lower it slowly, by 25 mg at a time.

I don't know of any data that supports slow downward titration, but I feel it works better as it gives the mind/brain time to adjust.
It's hard to lay out a strict protocol because a lot depends on Alex's response.

All best,

Doc

-----Original Message-----
From: Joan Miro
Sent: Aug 19, 2011 6:11 PM
To: Henri Montandon
Subject: from Joan Miro --a request for a second opinion

Dear Dr. Montandon,

I hope you're well. Could I get a second opinion from you? Is that done in psychiatry? I have a question that I would like to put to you. It's about Alex and I am prepared to compensate you for a second opinion.

As I think I told you, he has a new psychiatrist at Berkeley Mental Health, but he's only available 2 days each week. I've been trying to convince both Alex's previous doctor, and now Dr. Moorehead to put Alex on a mix of meds that I saw him on for 2 weeks in 2007 and on which he was the best that I'd ever seen him: 10mg Abilify, 125mg Clozapine, and 17.5mg Zyprexa. Until this week, no one was willing to put him back on that combination that a doctor at John George, Richard Slawsky, M.D., had prescribed in March of 2007. (At that time Alex was anti-blood tests so he wouldn't continue getting tests after discharge from JG.)

Now Dr. Moorehead has consented to try that regimen, but he didn't tell me how to do it. The nurse says I should just go from what he's on now---10Abilify and 225 Clozapine, right to 10Abilify, 150mg Clozapine and 17.5mg Zyprexa. And I'm supposed to do that in one day? she said. It doesn't sound right to me. I want a second opinion. And that's why I'm writing. Alex won't get into the car still, so he can't leave the neighborhood to come to see you. Would you tell me if that's ok to drop 75mg Clozapine in one day and add 17.5mg Zyprexa in the same day? I don't want to be around when he comes out of the ether. I don't think that's the way they do it in the hospital. And I want it to be administered in a way that will increase the likelihood that he will do well.

I would like a second opinion of how you usually start Zyprexa? Should I start with 2.5mg. The nurse said he ordered 15mg and 2.5mg tablets only, but I may have some other doses around. I'm thinking that going down on the Clozapine is better at 25mg/ day or over the course of a few days. I'll look in the literature on line. And I'm certainly not going to make changes on the weekend when no one is available except the emergency room, if or when he goes off. No, I'm not going to do it this weekend and that's what Peggy the nurse is saying I'm supposed to do.

I look forward to hearing from you. Thank you.

Sincerely,
Joan
PS: I've included an excerpt from last month's journal just to keep you updated.

Henri Montandon
To me
Feb 10, 2011

Hi Joan,

I have finished your remarkable account. I do not recall ever reading anything like it. For me, it conveys better than anything what it's like, what it's really like, at this time. My only concern is that parts of it seem so incredible that the reader will think you are making it up. Or maybe not. Maybe things have gotten so generally bad that it will ignite a fire storm of recognition and anger. This time is so bad only because people have not realized that we have this opportunity to come together and help one another. Your book terrifies me because it is such a powerful account of a kind of aloneness enforced by joylessness and lack of imagination - not on your part - but from those who act out their bureaucratic roles in constant low-level fear and meanness of spirit inflicted on others.

Concerning your question: I think the usual format is JM and HM.... The other way is used when a "ghostwriter" is used.

Onward,
Henri

-----Original Message-----
From: Joan Miro
Sent: Feb 10, 2011 2:24 PM
To: print@copygrafic.com
Cc: Henri Montandon
Subject: Letter in a Bottle

Hi Dr. Montandon,

I'm printing 20 copies of your letter in a bottle to send to whom I've already sent my journal. I'll send you a list of these people once I plug them into the computer. They are mostly ones I've picked out from the previous letters listed in the journal, starting with Obama, then Health and Human Services in DC, the Senate, etc., and down the line with a few in Sacramento and local government. If you know anyone else, do let me know.

I'm going to attach a follow-up letter to it and ask them to e-mail me if they wish to receive a copy of the journal which now includes your letter in the middle of it, so they can distribute it around as an attachment to whomever is interested.

Question: Do you want your name as it appears on the first title page to read:
by Joan Miro **with** Henri Montandon **or** by Joan Miro **and** Henri Montandon.
I'm starting another class in scriptwriting tonight so I may rearrange the story from the chronological as it now is, to a more interesting story format. Then I will find a publisher. Right now I'm just interested in getting it into the hands of political people so it can "...inform the development of mental health policy and services..." as Chris Marshall of the Center for Mental Health Services nicely said. He's the one in the Dept. of Health and Human Services who was forwarded my letter to Kathleen Seibelius and whose response is in front of yours in the journal.
I submitted my journal just before receiving your last letter, to Temple University, although it was a few days late for their submission for papers deadline. I'll copy you when and if I hear from them. You can see what they're doing in **TU** HYPERLINK "http://collaborative.org/" \n _blankCollaborative.org

Later,
Joan

Henri Montandon
To me
Feb 1, 2011
Ms. Miro,

I have been out of town, but still I apologize for not reaching you sooner. You have my permission to use the material you describe in the ways you feel will help promote better mental health care. I have received Alex's Story which I hope to read over the next few days. Thank you for sharing it.

My best to you,
Henri

-----Original Message-----
From: Joan Miro
Sent: Jan 13, 2011 2:58 PM
To: brainmap@earthlink.net
Subject: Another question about permission.

Hi, Dr. Montandon,

I wish you a healthy New Year.

Thank you for your correspondence over the years. You have given me hope. While I'm thinking about the blog idea, I have printed up the goings-on of this past year since Alex went on Clozapine. I'm attaching it to ask if you have any problem with my printing your e-mails and letters in the journal that I am presenting as a "book." Please see page 112, where you name Dr. Thomas: "I have never found Dr. Thomas to be a friend." I noticed that you didn't use her name, specifically, in your Letter in a Bottle, if I remember correctly. I printed up just 10 of these journals in order to get it into the hands of the heads of the mental health establishments that Alex frequents, plus anyone who responded to my letters, plus some politicians. Also, I am wondering if you would like your Letter in a Bottle to be included in, associated with, or somehow attached to my journal as a cooperative effort, doctor and parent, as it were, as was done in the book, The Quiet Room by Lori Schiller and Amanda Bennett, where, if I remember correctly, the psychiatrist wrote one chapter.

I will put a hard copy in the mail to you before I send out any more books to anyone. I did leave one for Alex's chart when he was shoved out of Herrick two days ago. And I did mail one already to Greg Adams, the new president of Kaiser before I remembered that you had cut her name out of your Letter. If you don't want Dr. Thomas' name, or her helper, Barbara Majack's name mentioned, please let me know ASAP. I for one, vote to mention names, as I have mentioned anyone and everyone's name in my journaling, because it's a journal of what actually took place. I feel that we all need to work together on the system and be up-front about and acknowledge what is actually going on so we know what needs changing. And putting the name with the action keeps everyone accountable, making them think twice about what they do.

I'm hurrying to get this journal out since I've switched him to Kaiser and they don't seem to be aware that he's "straight" medi-medi Kaiser since November 1st, and he hasn't been able to get any services from them so I may be forced to put him back into BMH.

Thank you so much.

Sincerely,
Joan Miro
510-857-7937 home
joan.miro@att.net

Unfortunately, upon discharge early in the new century, from Telecare Gladman, Dr. Beck also discharged Alex from Dr. Montandon's care when out in the community, and into the arms of Telecare STRIDES. No one asked him to do that and it shouldn't have been allowed. What does that say? Telecare must think they are the customer, not Alex. It's simply done to build up their own business. None-the-less, Henri and I have still been communicating over the years. Dr. Montandon always cared and knew how to treat the

family with the respect that it is due so that we could work together for the benefit of his patient who was my family member.

The Letter in a Bottle: a work in progress about a system in regress

Being a timid account of public mental health services in Alameda County, California during the twilight of empire.

This is a long letter, because the feeling I have is of being marooned on a deserted island where some quirk of nature visits suffering on the innocent out of all proportion to their lives and choices. This is a letter cast forth in a bottle. Most of all, it is a letter of witness.

I am a psychiatrist who has had the good fortune of working in the same office, in the same neighborhood in east Oakland, California for 23 years. This simple fact has meant a great deal to me. One of the things it has meant is that I am now seeing the second, and sometimes the third generation of some families who come to me for treatment of mental illness. Strange to think of this as a boon, but it means I have gotten to learn some things about families, about mental illness, that most people do not get to learn.

In this letter, I plan to review and highlight my findings. I plan to do this in a narrative fashion, but I will not shun drawing out the implications of what I have seen.

The central law at work in what I am witnessing is the Law of Cruelty. The United States is a cruel country. The well-off don't know this. But the poor know it. The old people know it. The children know it, but they cannot speak it except through the tortured behavior of what they cannot say. And the mentally ill know it, for it is whispered among them that the wheel has come round again, we are in another age of exile and confinement. But unlike other such epochs, exile and confinement are synonyms for neglect. Instead of exile to a long stay in an asylum, we exile our mentally ill citizens to board and care homes and to the street. Instead of confinement behind walls, we confine them in programs of financial "aid" which keep them on the very edge of survival.

In what follows, I have organized my observations in terms of the most basic categories of life: Housing, Food, Medical Care. Scattered throughout are anecdotes, although I do not claim that the anecdote represents an "average case", a "modal value" or a "prototypical category". Mostly they are stories of people I have worked with, particular people who struck me in a particular way. As The Psychiatrist said, "My patients are much more human than otherwise."

Housing

Robert Wilson is an African-American man in his forties. He grew up in Oakland, in a working class home with a father whose ambition and mental toughness led him to a management position at the University of California. While still in high school, Robert became a civilian employee at the Alameda Naval Air Station. He worked in the print shop and soon achieved a Secret clearance. After 21 years there, the base closed, and he decided he did not want to move his family out of Oakland to pursue jobs at other military bases. Soon after, trouble found him. As he puts it, "Imagine leaving your home one morning and never making it back…" He had a number of run-ins with the Oakland police. During one encounter, he was shot in the head from close range with a "non-lethal" projectile. After that, he changed.

Robert is brash and arrogant. When he would not back down in his confrontations with authority, he was arrested, charged with a variety of crimes, and although he had no prior criminal record, spent nearly two years in San Quentin. While he was there, his wife left him, taking their three children. After his release, he tried living for a time in one of the SRO hotels which lay scattered through Oakland like roach traps. Robert complained. He complained about the numerous unauthorized visitors to the hotel. He complained about the used needles he found in the hallway and outside on the sidewalk. He complained about the thefts inside the hotel. He complained to most anyone who would listen, but mostly he complained to the hotel administrators. Robert had declared war on a system he saw as terribly corrupt and cruel. He left that place and moved into another, which costs him $600 a month from his disability income of $800 a month. He remains angry. At times, he is certainly paranoid, but often his observations of neglect and intrusions on his privacy are all too accurate. He wants a small apartment in Berkeley, a town he describes as "close to utopia
as it gets", but he refuses, or is too frightened, to seek help from any programs. He feels very unsafe in Oakland, after his experiences at the hands of the Oakland police. There is little likelihood that he will ever leave the kind of living arrangement he has now, a single room in an SRO hotel, with $200 a month for food and all other necessities of life. In addition, Robert has schizophrenia.

How bad is the housing situation for mental patients in Alameda County? Several years ago, an organization that monitors housing needs in the state of California, announced that there was a shortage of around 900,000 housing units for poor people in the state. In the county now, a one bed room apartment rents for around $1500, even in the poorer sections (read "war zones"). Many if not most patients with chronic mental illness find their way onto Social Security disability. At one time, they were eligible for Section 8 grants which insured that they would not pay more than 30% of their income for rent. That program is effectively ended. There are various subsidized apartments around, where the "30% of income" rule is preserved, but these tend to fill up with so-called dual diagnosis patients, people whose drugs problems often make them troubling neighbors.

Many mentally ill patients live in board and care homes. At one time I made house calls to board and care homes, so I have seen two dozen or so first hand. The quality of life they provide is from fair to third-world. Even the fair homes have living conditions that most so-called normal people could not tolerate: two or more to a room; meals of cornflakes, peanut butter and jelly sandwiches and Kool-Aid, fried anything and Kool-Aid; smoke filled rooms; fights; drug use. The third world "homes", most of which are not-licensed, are nightmares. They are filthy. In one, before I could sit in a chair to interview patients, I had to wipe the mouse droppings off the chair and table. In another, I arrived one morning to find a patient lying dead in the living room. According to the residents, he was asleep. In addition to their obvious deficiencies, such places are not cheap. A patient pays $600 to $700 a month to live there, giving them around $150 a month for everything else. That means they must pay for transportation, clothes, all supplies, all grooming materials, anything that might be recreation. From the board and care owner's perspective, what they are paid is barely sufficient for their survival. Homes are often run by recent immigrants to California. Historically, these have been middle aged, religiously oriented African-American women from the South. More recently, immigrants from various third world countries. The common denominator is that we entrust our mentally ill people to others who are perhaps even more disenfranchised then our patients are; people who are so economically marginalized that they take on a nearly impossible job, relying on employees paid less than minimum wage and family members to do the day to day work of running the place.

Every year, a half-dozen or so of my homeless patients end up in jail. At Santa Rita, it is common to hear that they do not receive medication when they arrive, and sometimes not for weeks. One patient reported he did not get any medication until he returned to court and told the judge. She ordered the jail to supply his medication, but even then it was ten days before they complied. Without the medication he could not sleep, he heard frightening auditory hallucinations, and he scratched and picked at himself compulsively because of Obsessive-Compulsive Disorder.

A few of the patients I see live in homes their families bought years ago. In some of them, the conditions of life are much worse than anything in the third world. Think I am exaggerating? I know three people who live in

dwellings that house garbage dumps. The people live on noisome piles of festering paper, garbage, old clothes, live on top of the heaps, just as if they had roofed over a section of the Oakland dump and then taken up residency there. This is what the psychiatric literature refers to as "extreme squalor". At one of these houses, I helped out on a day when friends showed up to clear some of the rooms. We removed over 200 32-gallon plastic bags of trash from three rooms. There were still four rooms which remained as filled as the three we had cleared. The gentleman who lives there is articulate, a Berkeley grad, and totally disabled. Because the house is in probate, and two of his siblings refuse to sign quit claims, he cannot get any of
the grants or loans for which he is eligible. He does not drink, smoke or use illegal drugs, but his disability income does not allow for repairs to the house. It is much worse a situation then when his family was alive. He lives a few feet above what they started, beneath him the layers of his family's past.

Even the people who are housed "in the system" do not escape peril and sometimes death.

Esther was a woman in her sixties who suffered from depression. She came from a wealthy East Coast family which was recently down on its luck. So she was on her own. I met her just after she moved to Alameda County. She was living in a subsidized apartment but she feared for her life as the neighborhood was the battleground of rival drug gangs. Her sleep was interrupted nightly by the sound of gunshots. She was disabled because of severe medical problems, including asthma and congestive heart failure. There were days when breathing was all she could manage, but she was trying to complete an advanced degree. With some effort, she was able to convince the Housing Authority to move her off the battlefield. They moved her to a mildewed apartment across town. She begged me to help, feeling she would not survive in a place so antagonistic to her health. I contacted the Housing Authority and told them it was an emergency and that she needed to be moved immediately. Two weeks went by and I heard nothing. Phone calls went unanswered. Then I learned that Esther had died from a pulmonary arrest in her apartment.

I wonder if the fact that Esther was so helpless, that she was old and ailing and had no family backing her figured in the Housing Authority's decision to ignore my frantic communications. Or was it spite, or incompetence, or were they just too busy?

The list of afflictions plaguing the lives of those who are exiled to such dwellings is endless; in fact recapitulates torments thought to be absent from Western societies since the middle ages. I name but a few of the more prominent fauna: 1. rats; 2. mice; 3. chiggers; 4. rat mites; 5. fleas; 6. bed bugs; 7. ants; 8. cockroaches, 9. blister beetles and flora: 1. mold; 2. mildew. And do not forget the flaws of the infrastructure itself: 1. stoves that leak gas; 2. heaters that leak carbon monoxide; 3. roofs that leak water; 4. toilets that overflow; 5. no hot water; 6. no water; 7. no

electric lights; 8 rotting floors; 9. collapsing ceilings 10. cold in winter; 11. hot in summer.

In those selfsame middle ages, mentally ill people were kept outside in all seasons; sometimes naked; fed the slops that were given to pigs; because, it was thought, these people had no reason and so they were truly not human, but animals, and could endure being treated like animals (and what would justify the expense of treating them any other way?). In our more enlightened age, we do not have the advantages that such analogies provide. How guilty we must feel, then, when we see mentally ill people still treated like animals.

Nutrition

I am calling this section “Nutrition” rather than “Food”. People can have ready access to food, without having access to nutrition. In the United States, the major cost of an abundance of food and a paucity of nutrition is obesity. When 60% of a people are obese, should we call it a disease or a social pathology? Psychiatric medications are often blamed for the high incidence of obesity among people with mental illnesses, but this is only a small part of the real reason.
Simply stated, many mentally ill people are not skilled at living; it is the burden of their disease. Unless you, yourself, have suffered from a serious chronic disease, or have had major surgery, or have had to recover from a bad accident, there is no way that you can know how hard it can be just to survive. When survival itself is nearly impossible, skill goes out the window. Many mentally ill people subsist on a diet that would sustain them if they were living in Northern Canada, above the arctic circle, and if their ancestors had lived there thousands of years. Their bodies would then be adapted to a diet high in fats. And if the weather turned bitterly cold in winter, they would burn thousands of calories a day just staying warm, but in California these calories are not burned, and they turn into a thick coat of blubber.

Obesity seems more like a disease and less like a social pathology when you meet an individual who is obese. Medical care of the obese is frustrating and not very rewarding. Almost none of the people who are clinically obese ever lose the extra weight which is killing them. They suffer, or will suffer, from the diseases of obesity: diabetes, high blood pressure, heart disease, congestive heart failure, liver disease, back pain, knee pain. Over time, an obese person turns into a kind of living textbook of common medical ailments, which kill people sometimes, and rob them of vitality and joy always.

The only, repeat ONLY, resolution for the problem of obesity is to become a culinary artist, and an active, a very active, participant in the dance of life. And since most people certified normal in mind do not practice these skills, who among the mentally ill do we suppose will be able to?

Number of morbidly obese patients counseled for weight loss: 14.

Number of morbidly obese patients who lost weight successfully: 0.
Number of morbidly obese patients referred for weight-loss surgery: 4.
Number approved by their insurance companies: 1.

Just to be fair, I must admit that not every person living under the auspices of "the system" suffers from being massively overweight.

Kay is a vibrant woman in her fifties. Her family is haunted by the ghost of Huntington's chorea, a progressive, inherited, neurological ailment which begins with twitchy muscles and over the years bends people to the ceaseless labor of a grotesque dance where all their limbs fling them around, uncontrollably and incurably. Kay's sister had been so stricken, and so potent is the power of this disease to terrify, that Kay was the only family member to stand by her. To say that Kay shows strength of character is a laughable understatement. She has more strength of character than any person I know.

Item: When her sister's public insurance would not approve an expensive wheelchair for her, one with ample padding which would protect her as she flailed, Kay battled the insurance company, through two law suits until she won. Elapsed time of the battle: five years.

Item: When her sister developed pressure sores which did not get better, it was Kay who led the fight to bring the staff of the skilled nursing facility where her sister is living into compliance with codes for proper treatment.
Item: When Kay herself was diagnosed with the disease, first by genetic screening, and then by the appearance of the first harbingers of the disease, it was she who brought to me piles of information on Huntington's chorea, and continued to do so.

If her own diagnosis did not break her, it certainly rocked her, and she came to me for treatment of depression and anxiety. Fair enough. She also had numerous medical problems in addition to her neurological illness, and she was able to arrange the best medical care she could to deal with these problems. Fair enough. The disease ground on, and Kay grew unable to do all the work of scheduling appointments, traveling to appointments, traveling to pharmacies, traveling to various therapies, for herself, and, of course, for her sister. Fair enough. For herself, she requested a case manager to assist her. Now, a case manager is a person who is meant to function like your best friend, to coordinate all aspects of your life if you need them to, to make sure you get to your appointments, if you need them to help, to make sure you get the medication you need, in fact, to make sure that you stay alive and reasonably healthy.
To get her a case manager, Kay fought, and I fought, for nearly two years. All this time her disease was progressing. Not fair, not bloody fair at all. After this time, the case manager who "took her on" was as indifferent as "the system" had been in denying Kay the help she needed for so long.

The last year she lived in Alameda County, all of her doctors noted that she was losing weight. She was, before her illness, a hefty, healthy woman, not obese, not that, but like a big farm girl, the kind of hefty that

is strength. She swore she had no problems with her appetite. She swore she was eating just fine. The neurological disease by itself could not account for so drastic a loss of weight. Her doctors did all the tests, but just as she had always been, with the exception of The Disease, she was very healthy. So why was she losing all this weight?

The answer came to me by way of a frantic late Friday afternoon phone call from Kay. She was hysterical on the other end of the line. She had had no food for ten days! She could not face another weekend of no food. Yes, this had been going on for months! Yes, it was the reason she had lost all that weight.

Strong Kay had been too proud, too determined to tell anyone that she ran out of money in the middle of every month. From there she starved.

I called the case manager and miraculously she answered the phone. Of course, she would go immediately and get food for Kay. Of course.

But she never did. She did arrange for Meals on Wheels which did begin to deliver a meal a day to Kay, but two weeks after that frantic phone call.

Time dragged on, and Kay's disease progressed. The case manager did only what was absolutely necessary. When Kay needed some in-home help, she had the misfortune of contracting with a couple of people who stole from her, or who said they would show up and then did not.

Kay found that another county in California had a pretty good program for people with progressive neurological ailments, and she moved to that county. Never mind that she was born and raised here. She wanted to live independently as long as she could.

Kay's story brings to mind a motto, a motto which the organization who had provided her with the case manager from hell might consider adopting (and with apologies to the famous movie):

"If you don't offer the services, they will leave."

Farms in Berkeley? Yes. Starvation in Alameda County? Yes, that too.

Medical Care

Alameda County Supervisor: What do you think of public health care in

Alameda County?
Doctor: I think it would be a good idea.

It is rumored that the public health medical clinics in San Francisco have been deluged by medical refugees from Alameda County . Apparently they flock to San Francisco to try to get medical care they cannot find in this county.
Why do I believe this might be true? Because in Alameda County, it is easier for a Republican to fit through the eye of a needle then for a MediCal patient to find a primary care physician. Some organizations, when they are able to take on new patients, do a good job. I think here of North Oakland Family Practice, Berkeley Primary Care and the Life-Long Clinics. Physicians there are skilled in medical practice, and skilled at interacting with people with mental illness. Many physicians shun these patients.
Primary care doctors are loathe to take public insurance patients because they lose money on these patients. Being poor, these patients are usually sicker than people with something approaching an adequate income. Poverty means bad or insufficient food, unhealthy living conditions and endless other factors that lead to illness. As Robert Sapolsky noted recently, “When you examine socio-economic status, a composite measure that includes income, occupation, education and housing conditions, it becomes clear that, starting with the wealthiest stratum of society, every step downward in socio-economic status correlates with poorer health.”

Jessica Palmer is a 43 year old woman who was injured playing soccer 9 years ago. Multiple surgeries on her shattered ankle followed, and chronic pain, ending her career as an insurance executive. As orthopedic injuries are wont to do, imbalance in one part of the system led to pain and joint pathology elsewhere- her knee and her shoulder. Major Depression followed job loss, chronic pain, and family disruption.
Persuaded to try again, Jessica consulted an orthopedic surgeon in Alameda County about her shoulder pain. He told her there was nothing that could be done. She made the pilgrimage to Stanford, where an orthopedic surgeon performed the needed surgery, correcting 4 different problems. Heartened by competent medical care after years of incompetent noncare, Jessica will undergo surgery number 8 on her ankle, but this time with a doctor she trusts.
If a patient’s medical problems go beyond what the primary care doctor can do, it is specialist medical care which is nearly impossible to find. In order of frequency, the problems requiring specialist care are: 1. obesity; 2. chronic pain; 3. orthopedic problems; 4. diabetes; 5. hypertension; 6. cancer.

When a patient develops an illness requiring specialty care it is often months before they can be seen. If the patient is poor AND mentally ill, the chances are that they will not be properly evaluated, and if evaluated at all, they will NOT be treated.

Leonard Pickett is a personal friend. Seven years ago, a smoker attuned to the dangers of bronchitis, he went to the Kaiser emergency room in

Oakland with a cough. A chest X-ray revealed a lung mass. Biopsied, the mass was cancer.

So far, so good, at least concerning the medical response to Leonard's problem. Within hours of going to the ER, the diagnosis was established. From that point, things went terribly wrong. No further tests were done, yet Leonard was told that his cancer was terminal, and that "nothing more can be done."
Luckily, as an ex-serviceman, Leonard was eligible for Veteran's Hospital care. He went to San Francisco, where the Veteran's Hospital is staffed by Stanford doctors. These doctors did their own (complete) work-up. They learned that the tumor, although large, had not spread. They removed the tumor, and Leonard is very much alive today.

After recovery, Leonard pursued arbitration through the hospital where he had originally been "diagnosed". He wondered how many other patients, like himself, had been sent home to die when their cancers were treatable. The arbitrator (salary paid by the hospital) decided there was no malpractice. Likewise the California medical board decided that not performing standard testing, proffering a diagnosis for which there was not evidence, and sending a patient away without even a mention of hospice care, constituted "usual and standard practice."

Penelope Jones is a woman in her twenties who is assistant-manager at a local bank. She consulted me after months of depression. And, oh yes, occasional excruciating headaches, the worst she had ever had. Referred to a neurologist, an MRI was done (after weeks of negotiations with the insurance company). The radiologist reported a congenital malformation which would need immediate surgery.

By now you can understand why I was reluctant to send her to a neurosurgeon in Alameda County. You will also realize that I sent her to Stanford. The neurosurgeon there reviewed her MRIs and said, "The first thing I have to do is have these studies done again. We have found that the imaging studies that come to us from Alameda County are of such poor quality that they are useless."

When the studies were repeated, mercifully there was no 'congenital malformation', no need for surgery, only a few months interruption in this young woman's life. With some counseling, depression and headaches went away.

Doctors, like soldiers and police, are asked to make life or death decisions when they are tired, frustrated, distracted or just don't care anymore. Call these "conditions of maximum ineptitude." The temptation is strong – just turf this patient. Get her out of your office, clinic, emergency room. After all, especially with public service patients, who will ever find out? I don't know anything about the current state of doctors' training. Back in the day, in situations where we might hesitate about doing what needed to be done, we were taught to ask the question: "If this were your mother (or father or spouse or child…) would you do this procedure (or test or

admission…)? The implication, pressed upon us with the force of a million repetitions, was clear. Do the best you could for everyone.

Barbara Fredericks is a vibrant, healthy widow in her 50's. She is smart, does plenty of research via Google and the internet, and she has really, really good medical insurance. She awakened one morning with "the worst headache I have ever had." (Already, in the data base of medical students everywhere, red flags should be arising.) Both of her parents had died of cerebral hemorrhages. She went to the Emergency Department of the best hospital close to her. A workup revealed a cerebral aneurysm, likely a congenital defect, which could not be characterized by the hospital's somewhat antiquated imaging.
The next day, at a private imaging center, she got the high resolution scan that revealed the aneurysm to the millimeter, its location exactly. She still had the headache. She was referred to the nearby University hospital for evaluation and management. She was told someone would call her back. After a week, no one had called her. A few days later, she finally got through and was told it would be at least two weeks before anyone could see her. The headache got worse. She began to have visual changes, nausea, vomiting. She went to the Emergency Room at the World Class hospital some distance from her house. No, the aneurysm was not bleeding. Yes, the situation was very serious. She was scheduled for immediate brain surgery.

The Frustrations of Managed Care

Managed care, legally mandating that health care decisions be made by people with no medical training, who never meet the people whose lives they are meddling in – has been a terrible waste. It now appears to nearly everyone that it is, after all, a swindle. Health care costs continue to sky rocket, although the term "skyrocket" is peculiarly inept, because sky rockets go up and then come down. Not so the costs of health care.

Managed care dictates that doctors become business men, as if the "hidden hand" of the market could make health care equitable AND profitable in the United States, when it is not that way anywhere else in the world. The United States stands alone among industrialized nations in NOT providing health care for its citizens. The official reasons why this is so are stupid and shameful.

Conversations with senior administrators in the Alameda County Behavioral Health Care Services regarding the shameful disregard for adequate help for mentally ill people in the county inspired one of these worthies to say, “Why, we are insurance brokers, nothing more.”

Managed care is now the law of the land, trumping other laws under the aegis of profit for the few at the expense of the many. Public health insurance companies in the county have begun refusing to pay for medications which patients have taken for months or years, and without which they will again become ill. This is in direct violation of California statute, but the deal has been cut, and the watch dogs never bark, even when their noses are rubbed in the obvious.

Managed care has shrunk physician incomes. Medicine is no longer a way to “insure” a good living. For many young doctors, entering practice with school debts of $100,00 to $200,000, the practice of medicine will never be more than a subsistence living. In forty years, the cost of living in the United States has gone up from 1200% to 2000%, depending on what index you look at, or what cost you follow. Income, except among the top 1% or 2%, has increased about 300%. Patients still believe that physicians are among the wealthy, and they wonder why so few elect to go into public health. For the few doctors who do, lest a good deed go unpunished, the managed care companies stand ready to blame those who actually care for patients for the frustrations which the companies themselves have made.

More than anything else, it is money, or the lack of it, that explains why we cannot find doctors to work in Public Health in Alameda County. According to the Wall Street Journal, public health physician salaries in California are among the lowest in the United States. At the clinic where I work, we have a record of sorts: eight doctors in a row who were hired, and soon fired. Two were addicts, one was senile, one was grossly incompetent, two were hateful to patients, two were so bound up in their own problems they were ineffectual.

In 23 years of practicing medicine in Alameda County, I have met only one public official who showed an interest in any of this. When we met for the first time, and embraced, because we really are kindred souls and she is enormously good hearted, she asked me, “What are your ideas for how to solve these things politically?” I said, “I had rather thought this is your job.”

Why Public Mental Health Services Fail

Public mental health services fail for the same reasons that public medicine fails, for the same reasons that the criminal justice system fails, for the same reasons that public education fails. All of these public institutions, pillars of civil society, fail because they are constructed to assess and correct deviations from the middle class life of the American majority. Never mind whether this idyllic life is now mostly a simulacrum. In many of our minds it still exists. It entails a safe, happy childhood with both parents, as well as aunts, uncles, grandparents, ministers, priests, rabbis, mullahs, teachers, coaches. The people from this culture grow up in houses in the suburbs, or apartments in safe cities, more rarely on farms and ranches. They go to decent public schools and graduate from high schools with the expectations of jobs, college, families, and an even better life for their children. Their lives are orderly enough. Adventure is chosen or manufactured. Barring catastrophe, their pains are the expectable pains of choices plumped by plenty – what college to attend, what person to marry, what job to take. If there are scars, they are the healed or healing scars from excursions into the drug culture.

Many grow up without the complete idyllic picture, but still within its safety. Subtract a parent, add the "wrong" college or job, factor in enough expectable disappointments, and their grasp on the good life may slacken, but never completely let go. Most importantly, it is still subject to appeal, it still pays emotional dividends, the ticket can still be punched. The majority who seek public mental health services are denizens of another society. They are the ones who answer the question, "What do you do with your time?" with a single word, "Nothing." This is why the War on Drugs, by arresting growers, dealers, traffickers, cartel management and the occasional CEO, is seen as the enemy by some Americans who recognize these arrestees as full of the entrepaneureal spirit, illegal for sure, misguided perhaps, but still hardy champions of business and enterprise.

Well, that is one reason why health care systems fail. Here is another:

Over the last several years, as the state of California wends its hapless way towards becoming a failed state (with a projected budget deficit for the 2012 fiscal year already at 20+ billion dollars) I have had to examine the ethics of medical practice within a health care system that is increasingly lacking, and where still existent, damaged and increasingly corrupt. (Corrupt in a way that I shall try to explain as I continue with this statement.) At what point does a physician's role become so compromised that by continuing to practice, he or she succeeds in providing only a pretense of medical care, and thereby helps to prop up a political state which has abandoned the reality of care, while remaining intent on its own brand of good public relations? (Here I refer to, not the entire political state of California, but only Alameda County, where my experience is first hand. Around 1997, the state of California shifted the design and

maintenance of public health care to the counties.)

There are at least two answers to the question of a doctor's ethical responsibility in a failing, or failed, health care system. If a doctor's primary task is to aid in the relief of suffering, then there is never a time when a doctor can ethically withdraw his services, even in a failed system. There are many other reasons why the doctor may withdraw from such a system – financial, professional, personal – but such an action will always leave an ethical bruise on that doctor's soul. But there are many now who define a doctor's role without ever mentioning relief of suffering. For example, here is the latest (2009) Mission Statement of the administrative agency charged with running public mental health services in Alameda County, taken from their website (italics added):

Our mission is to provide strength-based, recovery and resiliency oriented, culturally competent, high quality, geographically accessible, integrated alcohol, drug, and mental health services to Alameda County residents of all ages.

Through a network of community-based and county providers, we provide prevention, treatment, and rehabilitation services to:

Promote recovery and resilience

Minimize services delivered in restrictive environments
Stabilize and manage symptoms and behaviors that are problematic for clients whether psychiatric in nature or related to substance use or abuse

Support clients in the least restrictive environment of their choice

Reduce the long-term adverse impacts on individuals, families and the community resulting from untreated severe emotional disorders, serious mental illness, and substance abuse

Reduce illness, death, disability and the cost to society resulting from conditions.

Provide crisis and recovery services following major disasters

(HYPERLINK "http://www.acbhcs.org/"http://www.acbhcs.org/ , accessed 27 November 2009).

In 2006, the state of California received an unpleasant Valentine's Day order from U.S. District Court mandating federal takeover of prison healthcare – the first time this had occurred in United States' history. Although the state has repeatedly gone back to court asking that the receivership be voided, it still stands, with no foreseeable end in sight. That California's inhumane treatment of its prisoners should be spotlighted on the world stage has apparently escaped the attention of the

public health administrators in Alameda County. Read again this goal from the Mission Statement quoted above:

minimize services delivered in restrictive environments.

It would seem obvious that California needs no further help in "minimizing services delivered in restrictive environments", thank you very much! I doubt that what the public mental health administration actually means by this ambiguously worded statement falls on the side of fewer services. They must be stating their decision to have fewer people residing in restrictive environments. (Mustn't they?) Yet the ambiguous wording points to one of the senses of what is corrupt in the public mental health care system: language used more often for rhetorical effect then to join in an effort to support the truth. I shall call this form of corruption Semantical Corruption. Another example of this type of corruption occurs to me: the scene between Alice and the caterpillar in Through the Looking Glass. There are numerous others.

Here I will state a conclusion bearing on the question of the doctor's ethical responsibility in such a "system" as I am writing about here, a conclusion I do not plan to support in any detail right now: given the ambiguity, even vacuity, of the Mission Statement (and I suppose many are like this), it is possible – (even, I would say, encouraged) – to practice medicine in a way which is nearly flawless on paper, but in fact accomplishes little if anything in reality. This is the second answer to the ethical dilemma posed. The truth of this conclusion is evident to some who have practiced medicine in a failing or failed system, otherwise not. This kind of corruption I call Corruption of Praxis.

A third sort of corruption within the system I call Corruption of History. For 23 years I have witnessed the erosion of public mental health resources in Alameda County. The longer it takes for a social system to die, the fewer there are who remember anything else, for example, anything better. What is currently reported takes on the onerous burden of becoming all that is possible. This is why it requires a child to see the obvious: the emperor has no clothes; the prisoners' health care is abominable; if you do not offer help, the helpless will melt away unseen.

There is a fourth type of corruption. Remember the song that goes like this:

Toe bone connected to the foot bone

Foot bone connected to the leg bone
Leg bone connected to the knee bone...

Thanks to the magic of Wikipedia, it's easy to report that this song, entitled "Dem Dry Bones is a well-known traditional HYPERLINK "http://en.wikipedia.org/wiki/Spiritual_(music)"spiritual song, used allegedly to teach basic anatomy to children (although its description is not anatomically correct). The melody was written by African-American author and songwriter HYPERLINK "http://en.wikipedia.org/wiki/James_Weldon_Johnson"James Weldon Johnson (1871–1938). Two versions of this traditional song are used widely, the second an abridgement of the first. The lyrics are based on HYPERLINK "http://en.wikipedia.org/wiki/Book_of_Ezekiel"Ezekiel 37:1-14, where the HYPERLINK "http://en.wikipedia.org/wiki/Ezekiel"prophet visits the Valley of Dry Bones and causes them to become alive by God's command." (Wikipedia contributors, "Dem Bones," Wikipedia, The Free Encyclopedia, HYPERLINK ""http://en.wikipedia.org/w/index.php?title=Dem_Bones&oldid=327226963 (accessed November 27, 2009).)

The song teaches a version of anatomy, and anatomy teaches the interconnectedness of the components of a system. By the time a little child sings Dem Bones he or she probably knows that when a bone is failing or failed, you take it to a bone doctor. And when the component of a social system is failing or failed, there is also a reasonable expectation that someone is responsible, and will respond responsibly. This token of social organization also goes by the name of the chain of command. Perhaps the most telling confirmation that a social system is failing or has failed is when the chain of command is failing or has failed. To tickle once more with the play of ambiguities, call this the Corruption of Oversight. To emphasize the point, in Alameda County, oversight is now an oversight.

In summary, I have mentioned four types of corruption at work here in the Alameda County public mental health system:

Semantical Corruption

Corruption of Praxis

Corruption of History

Corruption of Oversight

These four, each or in concert, lead to one more, the most insidious and damaging of all: Corruption of Good Faith. Writ large, this is why the old Soviet Union failed. The worker faked her production to

the production commissar, the production commissar faked her group's production to the factory manager, the factory manager faked the factory's production to the Ministry of Tractors, the Ministry of Tractors faked the amount of tractor production to the Deputy in Charge of Production, until the whole country seemed much better off than it was – and the whole world, believing somewhat the lies, went along with an insane arms race. From within a double-bind, the only viable option is to leave the field.

Patients

The sinking feeling I get meeting the young black man, schizophrenic illness, smoking shit, living on the street, less chance of SURVIVING than if he caught bubonic plague.

The rage I feel meeting the young woman with two, three, four, seven young children, no father for these children, no education for this mother, this perilous group an indictment of everyone it encounters.

The Excessive Love of Red Tape

The local mental health administration serves up this mission statement (2006):

To provide a comprehensive network of integrated programs and services for all people with serious psychiatric disabilities, regardless of age, ethnicity, language or geographic location; in order to minimize hospitalization, stabilize and manage psychiatric symptoms, and help them achieve the highest possible level of successful functioning in their community of choice; and to provide mental health crisis and recovery services following major disasters; and, in addition, to improve the quality of prevention, treatment, and rehabilitation services in order to reduce illness, death, disability and cost to society resulting from substance abuse.

This statement is a kind of pabulum, as bland and grey as the personalities of the people who wrote it. Copied from a chapbook for bureaucrats. Or quoted from Management for Dummies.

What makes the words offensive is the watermark, the echo from the unnamed source, quoted earlier: “We are insurance brokers, nothing more.”

Public officials are permitted public lies without consequence, except to the people who are harmed as a result. Having made the kind of statement quoted above, should not they be held accountable for every hospitalization for mental illness, every mentally ill homeless person, every crisis not met, every life squandered? Or at least, shouldn’t they cease and desist from publishing the kind of lies they do? Shouldn’t they beg forgiveness from those they have neglected? Shouldn’t they acknowledge that they have no record of public service that can be separated from their own careers and salaries, that they do in fact run a protection racket for their own jobs and this above and beyond everything else? How much do these bureaucrats spend on public relations, and why do they need it?

The hours of paper work that doctors do every day, and which is for not a few greater than the hours they spend seeing patients, is explained by bureaucrats as being necessary to satisfy the demands of other bureaucrats, and those other bureaucrats require more paper work to satisfy the demands of other bureaucrats, and so it goes, layer after layer of useless work done by useless people. (I am not suggesting that the people so engaged are intrinsically useless, only that their work is useless, except to burden others. It reminds me of the kind of made-work one reads about in prisons. First dig a large hole, then fill it in again.)

The mayor of San Francisco recently admitted that it would be cheaper for the city buses to be free for all passengers, because the financial cost of collecting fares, giving change, counting fares, catching cheats, patrolling, advertising fare changes, and so endlessly on and on, this cost is far more than is paid for by the fares themselves. This announcement by the mayor must frighten those whose major role is to keep the whole expensive, wasteful, useless system of fares intact. But to me it is a story of archetypal significance, a story that demonstrates that there are forms of work which are themselves forms of welfare, work that is useless for all and burdensome to some, and whose real purpose is to provide wages for those who inflict it on the rest of us. Most certainly it is not a transition from “welfare to work”, the quotation marking a recent program wildly popular among politicians and wildly injurious to many of its victims, but “welfare through work” the scare quotes now signaling a form of exploitation practiced by public employees upon the rest of us. Those who can, do, and those who can’t do, teach, and those who can’t teach work in faceless, numbered, soul-killing bureaucracies, welfare through work being the financial salvation of the middle class, social welfare every bit as much as tax deductions for the interest on home mortgages.

At the clinic where I work, the Director was recently challenged by one of the county administrators concerning the high cost of overhead at the clinic. The Director was quickly able to show the official that the high overhead was entirely due to the paperwork demands of this same administrator's bureaucracy. The county health administration is incapable of providing funds for health care without requiring, upon every increase, a greater raise in "accountability". The result then is that every "raise" is a penalty, and organizations that do more work at higher rates become poorer as a result.

Whatever their motives, the administrators of the mental health "system" in Alameda County have each year closed valuable mental health care organizations, no matter how useful these organizations were, or how venerable their track record in the care of patients. This pattern of action is tacitly approved by the Board of Supervisors. It would appear that these administrators are actively engaged in the demolition of the system of care which is their charge. I would prefer that they honestly acknowledge the path their actions have chosen. I would prefer that they publish a mission statement that tells the truth of their policies. I am sure if they did it would read like the following:
To oversee the gradual reduction and final dissolution of the system of care for people with serious mental illnesses. To maintain a public face of optimism and good will, in the knowledge that if we do away with all services the ones who need these services will go somewhere else. To show with adequate documentation that as services are reduced, so is the need for services. To apply the calming hand of public relations to the troubled waters of citizens' concerns. To impugn the motives and blacken the reputations of clinicians and administrators who argue against us.

Medical Economics

California has won the 'race to the bottom' in public health care in the United States. Public health physicians' remuneration in the state is the lowest of the 50 states. Even the historically prevalent two-tier system of health care has had to shift its financial base. The upper tier is now composed of people who can pay for their health care out of pocket, in cash. Private practice and small-group practice physicians in California are increasingly providing cash-only services because the insurance companies refuse to pay. They gamble that doctors are reluctant to invest the time and money to recover unpaid services. So far, they are winning the bet.

The pragmatics of medical practice follow the money. Medicine as an art is available for those who can pay for it. Increasingly, public health medical practice has become what I term “vending machine medicine”. In the public-health clinic where I work, fee-for-service physicians under contract to the county see between 30 to 50 patients in eight hours in order to fulfill their financial expectations. In part this is due to overhead – 53 cents out of every dollar received goes to it. 25 cents out of every dollar, or nearly half of overhead costs, go to administering the billing to the county.

In public health care, it is axiomatic that “if you do not have the services, the patients will leave.” Vending machine medicine rests on a corollary: “We have not yet found the bottom.” In other words, public health officials have learned that if they can provide some services, no matter how minimal, they can get by. The physician who sees 50 patients in 480 minutes, assuming she does not go to the bath room, take time for lunch, or answer the phone, spends 9 minutes and 36 seconds with each patient. For at least two decades, time management studies in the United States of insurance-driven primary care doctors have shown average visit times of 5 to 7 minutes. If this is the standard of care in primary care, I guess the only question that arises is how should the Psychiatrist spend those extra 2 ½ minutes? Indeed, by these markers of standard of care, the psychiatrists who see 50 patients in 8 hours should be seeing 68.

During the early years of “managed care”, medical costs fell because physicians’ incomes fell. During the current phase, medical costs are again rising, and at a rate faster than ever. In a futile effort to hold on to its political capital, “managed care” now pushes to restrict services to patients in every way, legal or illegal, it can get away with.

California remains a highly regulated state. Some would say its regulations are meant to favor individuals over organizations. Consider. Here is a California statute regarding the obligations of insurance companies to continue to provide needed medications to their subscribers:

CALIFORNIA STATE LAW AB 974 SECTION 1367.22
(a) A health care service plan contract, issued, amended, or renewed on or after July 1, 1999, that covers prescription drug benefits shall not limit or exclude coverage for a drug for an enrollee if the drug previously had been approved for coverage by the plan for a medical condition of the enrollee and the plan’s prescribing provider continues to prescribe the drug for the medical condition, provided that the drug is appropriately prescribed and is considered safe and effective for treating the enrollee’s medical condition.

Increasingly, several times a week now, a patient will appear who reports that he has been informed that his public health insurance is now refusing to pay for a medication which he has been taking for years. The volume of these refusals continues to increase. Each refusal requires 20

minutes of physician time to counter. In the modern currency of "billable patient visits" this costs the doctor 2.1 patient visits ($74.00) for each required authorization. (1 billable patient visit = $35.) But since it also reduces the amount of doctors' earnings that go to overhead by $52.50 + the overhead costs of processing the authorization, the simple act of issuing a prior authorization to a "managed care" company is very costly to the doctor and to the doctor's support people. And it does not help the doctor's morale to realize that it is costing him money to counter an illegal tactic on the part of a "managed care" company.

During the 1980s, the United States began the first full-scale industrialization of medicine in world history. Since then, predatory elites that base their power on clientist-relationships have perpetuated increasing misery, suffering and death. Medical care is separated from medical service delivery. Doctors' incomes no longer depend primarily on relief of suffering but on limiting medical services to preselected categories derived if not entirely then mostly by financial criteria.

The influx of immigrants and women into the medical profession signals the loss of physician control over their day to day practice, as well as the diminishment of income and status. Just as in the early stages of capitalism, thousands flocked from farms to factories, the industrialization of medicine has required a work force that is willing to work harder for less, while at the same time shouldering the burden of increased malpractice liability. Only the time scale is significantly different. What took many decades during the Industrial Revolution in Britain has been accomplished in less than one decade within medical practice in the United States.

Now, well into the second decade of the industrialization of medicine, we are already at the stage of "mature financial restructuring" and beginning to see growing outsourcing of medical practice: pharmaceuticals from Mexico and Canada; bargain basement surgical procedures from hospitals in the Third World managed, and at least where physicians are concerned, staffed, by Americans.

Care

The Philosopher proposes care as the salvation for those beings, human beings, who must each make their own way in the world. Those who do not seek salvation – by whatever word you name it – can skip this part.

Human being to human being does not exist without care. Human being to human being does not continue without the ceaseless negotiation of trust. Establishment, maintenance, betrayal and repair of trust is the inescapable dynamic of human concerns.

It can easily take a year, or more, to establish trust with a patient. Perhaps they do not know trust; perhaps trust has been too fragile a commodity; perhaps betrayal has been too prevalent. Perhaps they were thrown into poverty, which is the absence of care and trust.

Care in the domain of poverty entails all that exists in raising a child and maintaining a family. A family is not a program, and government cannot reconstitute programs as families. The best government can do is construct a space in which care and trust can be nurtured and grow. The rhythm is agricultural, not industrial.

Perhaps it is the case that what is ceaseless – the negotiation of trust – and what constitutes human being to human being – care – are always contingent, always only almost emerging. Whatever the status of these questions, their resolution is always postponed, always metaphysical.

The Purpose of Psychiatric Medicine

I recognized in medical school that there are two styles of medical practice. The kind that was taught in my medical school I shall call "vending machine medicine". These complex gestures in the realm of sick person and doctor are efficient. They probably serve, in some way, to maximize the benefit/risk ratio. Vending Machine Medicine is well suited to solve the variegated problems that human persons with diseases present.

Let me give you a sketch of how vending machine medicine is practiced. This brief glimpse should be utterly familiar. If you have been to a physician in the United States within the last two decades, you will recognize what I describe.

You are sick. Perhaps in pain, perhaps your body buzzes, thrums, ticks, burns, throbs with curious sensations which are evident to no one but you, subjective states which doctors call "symptoms". The doctor expects your symptoms, but even more is heartened to detect the infirmity of your pain, the swelling of your throb, the excoriation of the burning, the objective "signs" on the road to the first longed for oasis, the "diagnosis". Out of signs and symptoms is woven the "problem list".

If this is your first visit to a medical chapel, the problem list will be a transcription of your symptoms and a recording of your signs.

Before the oasis is reached, when signs and symptoms have coalesced in the doctor's mind, we have "impressions". Having won her

way to a list of “impressions” – like a litter of puppy diagnoses – the doctor will attempt to choose from the litter the pup that best fits the evidence. Usually this fitting process involves tests, joining the body and its flotsam and jetsam to the machine directly. The search for signs and symptoms is repeated, but this time at the molecular scale. Medical imaging is also likely to be called on, using the whimsical paradoxes of quantum physics to outline the sport of the body’s ailment.

Demoralization

The psychotherapeutic environment creates a space that affords connections during the entire duration of the therapy, whether the people participating are together or not. This is one way in which psychotherapeutic agency takes its toll. Study after study shows that some 25% of people who practice therapy of whatever persuasion are lost in the first five years of their service. Demoralization counts down the people in care, it weighs most heavily against those whose charge and nature lead them to caring, most often when it is their profession.

How I Feel

Weeks, months, years trying to find chronically ill people housing they can live in which is decent, not in a war zone, not infested with vermin, with heat and running water. Patients who run out of money in the second week of the month and go hungry until the next check comes. Patients who are sick and need specialty care and are turned away, or told, quite literally, to go home and die. Officials who offer pabulum.

The Wilderness

One could almost say we are witnessing a crisis, except that the crisis is slow moving and bears upon people whose marginalized status denies them the political benefits of alarmist rhetoric. A train wreck in slow motion then, where aboard the train are passengers who have been sprayed with a scientifically-advanced formula which makes them invisible. The train lurches ponderously off the track and its vast momentum carries it further than seems possible, and of that ghostly cargo, few will survive and none will be seen.

Unless the Invisible be a husband, wife, child, parent, someone once loved somehow, whose absence is material, palpable, odiferous, frangible, who will go on being unmistakably absent long after they are gone, the magic spray does its work so well that not only will their beseeching or peering or angry or pathetic visages not be seen, even the idea of them will be gone. It is obscene that we here in America, the fattest people in the world, have created so many ghosts. Is it not fitting, then, that this act, past and continuing, be called moral cannibalism? An obscenity, and too literal a one.

"Those whom the gods make mad, let no one succor them." Might this be a commandment in some apocryphal book, written just for them, the Invisible?

There are so many dyings each day, how do you know which one of them is death? I know a few people who can answer this question. I know many more who never ask it.

California, the Golden State. Which of us, having lived here and having come to know what goes on here, can see it as other than a wilderness of neglect? Where hope lives, it lives from the few. Even in the wilderness, sweet berries ripen.

Henri Montandon, M.D., Ph.D.

The above is the state of the state from a psychiatric viewpoint; I'm grateful that I only have to deal with the mental health of *one* son.

The Irony of Having Compassion for Someone Else's Loved One

So, even 20mg, if that's still what he's on, is detrimental to his state of mind, keeping him unmotivated and unrealistic in the real world. One can't help but wonder if the temporary doctor, Dr. Freeman, wouldn't or couldn't get the patient to the dentist if it were her own son. There's just not the same compassion when it's someone else's child. Some doctors need to try to remember why they presumably came into this field. Who

are they trying to help? Even if it's only themselves, that's OK, if they do it with a similar intent as displayed in the following poem (given to participants recently by Rhianna Babka, the Senior Service Assistant and her intern, Cole, from UCSF, who run the Sr. Center's Caretaker Support Group in North Berkeley):

I take my job to heart;
It's someone's life I'm dealing with.
I take my job to heart;
It's a privilege and an honor to assist.
I take my job to heart;
I am their confidant and respect them so.
I take my job to heart.
My time is spent soothing tears
And listening to their deepest fears.
I take my job to heart;
When it's my time of need,
Please send someone who will
Take their job to heart.

Adapted from a poem by Darlene Totten

Wednesday, November 26th, 2014

It is today exactly 2 months since Alex's 10 days of antibiotics were completed. And he's no closer to getting back to a dentist to have the oral surgery. I had stopped at UCSF a couple of Saturday's ago on my way home from the CAL NAMI conference where I'd shared this dismal tale. I took notes at the conference after noticing that I was the only mother there. I wanted to be able to share what was said with the other parents at our NAMI-East Bay support groups. Actually, I was surprised that I was the only Mom at our table. I sent the following to Liz Ribensdorf, the president of NAMI-East Bay:

Letter to Liz ed3 about Advocacy meeting in Nov 2014.docDownloadView
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To Liz Rebenzdorf Nov 19
Hi Liz,
I hope all is well with you.

I attended the meeting, I think put on by CAL- ACAP. There were so many organizations presenting, I'm not sure.

It was last Saturday so I made notes that I'm attaching here for you to give, if you like, to your NAMI group. I thought it was very interesting and productive.

Best,

Joan

Letter to Liz ed3 about Advocacy meeting in Nov 2014.docDownloadView
Reply, Reply All or Forward | More
Liz
To me Nov 19
What a thorough, wonderful report! I just read through it quickly and haven't digested it, but there's a lot of info and insight there. Could you possibly condense it down severely so we could use it in our next newsletter - I'm thinking of the parts about issues that appear to be shared across the disciplines and reports about Steinberg's next advocacy efforts. Let me know. We'd need something in writing by mid-December. Our meeting tonight regards genetics and etiology - you might be interested.
liz

Sent from my iPad
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<Letter to Liz ed3 about Advocacy meeting in Nov 2014.doc>

The Advocacy Meeting

HI Liz,

I wanted you to know that I attended the Advocacy meeting yesterday at the Green Hills Country Club in Millbrae. David Czarnecki the Advocacy Coordinator from CAMI, was kind enough to let me in even though I responded late. And food to die for! Had I been on the Titanic after a meal like they cooked at Green Hills, I would have happily gone right to heaven.

Apparently, they've been tossing ideas around the lunch table a couple of times a year for the past 4 or 5 years as a way to come up with pertinent issues to put before the Washington, DC legislature. So, in essence, it was a brainstorming session, spruced up with acknowledgements to various people who have excelled, like Stuart Teal, MD and UC Davis Professor who, among a long list of endeavors, changed adoption laws and brought mental illness and child development into the adoption arena, and Senator Darrell Steinberg, who has authored a number of Bills like AB34, SB82, et. al, and will now start an advocacy organization as he steps down from his senate seat.
When I heard they were honoring the senator, I became focused on somehow getting the information that I've been writing for the past 18 years about the mental health "system" into his hands, so I brought a few of my journals with. I wasn't really sure how I would do it, but the opportunity presented itself as he was leaving, and his parents were standing nearby, so I walked my 2010 book over to Mrs. Steinberg telling her I thought at first that she was his wife (and that was true), and into the hands of a receptive mom I placed my writing atop his new award that she was carrying, telling her that I would love to volunteer for his new

non-profit, wherever it is. And that's true too, because he knows the way to get things into law.

And my issues were three:
Include a knowledgeable parent or other **responsible family member** in medication decisions so the psychiatrist can learn the total history of the patient's reactions to medications, not just when the patient was in their hospital...
There needs to be **much more money spent on research** for new medicines that will work...
Put money into discovering the **etiology of schizophrenia** so a cure can be identified...

as we brought up problems at my table filled with 2 experienced psychiatrists---**Joseph Greene, MD** (CASA) and **Saul Wasserman, MD**---**Raya Ijadi Maghsoodi, MD** (CAL-ACAP) a young, exuberant child psychiatrist from LA, **Anjam Bahl, MD**, (CAL-ACAP) Fellow and 3rd year psychiatry resident, **Cassandra Zawilski** (UACF), **Nisha Ramsinghani, MD** (CAL -ACAP), **Kory Stotesbery** (CAL-ACAP), **Alex Stanley** (CASA) in San Francisco, and mom, **Joan Miro**, (CAL-NAMI) coming only with a background in BS and teaching credentials. Our prearranged group was consistently on task and empathetic to issues. One issue preordained by the Advocacy and Collaboration Strategy Workshop, was to include in the conversation problems and possible solutions for foster children. If Robert Holloway, MD, President Elect of CAL-ACAP and Marcy Forgey, MD, President of CAL-ACAP were making it this easy to be heard, I couldn't help but wonder where all the other parents from NAMI-East Bay were, who come to the monthly support meetings and share a lot of sadness.

Enough tears! It's time to ***Get Mad, Not Sad!***

But, before we started on our table problem-solving, each group represented at the conference introduced itself. "The California Academy of Child and Adolescent Psychiatry (CAL-ACAP), a state-wide umbrella organization that draws together the four regional councils of child and adolescent psychiatrists" was introduced by Stewart Teal, MD, who said issues ranged from child abuse to adoption and "brought mental illness and child development into the adoption arena." Karen Finan from CASA spoke about their growing organization saying they were looking for more volunteers to serve foster children. National Alliance for the Mentally Ill's (CAL NAMI) David Czanacki said NAMI was begun in the East Bay in 1977 and now "has 70 affiliates from San Diego to Shasta County, a movement that is grounded in our stories and our numbers...emphasizing hope and recovery." Michelle Beebe from United Advocates for Children and Families (UACF) listed some of their issues such as improving the quality of life, promoting national health care reform, the need to track legislation, supporting parents seeking information and resources and parents having the right to be heard respectfully. Let's Erase The Stigma's (LETS) Robert Holloway talked about people preferring "to hide their mental illness" because the world "is more disturbed about brain illnesses." He said that BRING CHANGE TO MIND is now combining

with LETS. Finally, Paul Yoder, the Legislative Advocate from CAL-ACAP, spoke about current issues in child and adolescent mental health in California.

The introductions were both illuminating and entwined. It was heartening to see that so many people had formed organizations toting different aspects of the same cause: mental illness. The one that spoke to me most relevantly was that of UACF represented by Michelle Beebe, as I had only recently endured another slap in the face from a doctor at Villa Fairmont Mental Health Rehabilitation Center--where my son now temporarily resides--who allowed me to come to their 'recovery' meeting and then screeched intermittently and loudly (like a cat), whenever I tried to tell her his reaction to different medicines. Witnessed by a dozen nurses, her screech finally turned into, "Get out!" and after being interrupted every 5 seconds at least a dozen times, ('though I was given 5 minutes to speak by the same doctor), I did leave, saying something about doctors needing to collaborate with the parent for the benefit of their patient who is my son. "He giveth and He taketh away." Is that what doctors think they are? And that was just an example of the most overt disrespect. Most of them ignore you altogether or just don't return your phone calls. When Beebe said, they "support parents seeking information and resources" and that "parents have the right to be respectfully heard," I wished she had given out the 800 number that she said they had.

Paul Yoder, the Legislative Advocate from CAL-ACAP gave a financial picture of state revenues that "continue to out-perform projections," with the exception of Medi-Cal spending. I'm not sure, but I think that means we're spending less than we thought we would, except for Medi-Cal. Politically speaking, he said, "Low voter turnout in this last election could have massive consequences...Mental health is not a priority." It's too bad that legislators have to have sick kids themselves for mental health to be a priority. "In California the Republicans were successful in blocking the Democrats from maintaining the 2/3 majority." There are "dozens of new legislators" and a "second wave of legislators who can serve up to 12 years in either house." "Housing is a priority," (instead) he said. Although "Senator Steinberg will soon be Citizen Steinberg, he will still be working on mental health issues...In the Senate, some stalwarts remain, e.g., Senators Beall, Leno, Mitchell and there are some newly elected hopefuls like Pan and McGuire. In the Assembly (there are) Bonta, Stone, Ridley-Thomas and Maienscheim," indicating they may be mental-health friendly.

He listed the following bills related to mental health issues that were authored by the legislator named in parenthesis:

AB 1455 (Campos) authorizes the superintendent of a school district, the principal of a school, or the principal's designee to refer a victim of, witness to or other pupil.....

AB 1866 (Bocanegra)

AB 1672 (Holden) Enhanced Student attendance review board reports

SB 22 (Beall) Would have required health...didn't get anywhere
SB 1046 (Beall)
vetoed by governor
this bill would give the insurance commissioner...

Treatment Authorization Request (TAR)

Medication of Foster Care Children: Legislation may be introduced in 2015 to reduce the medication of children in foster care. Several legislators have expressed interest.

Other issues:
Katie A. Mental Health Services
Intensive Care Coordination (ICC)
In-Home Behavioral Services (IHBS)
Early and Periodic Screenings, Treatment and Diagnoses (EPSDT)
(Medi-Cal Funding)
Mental Health Services for Special Ed pupils (AB 3632)
Proposal 47 Implementation
…216 State Ballot Initiative to Legalize Marijuana
Raising the Profile of Children's Mental Health
Health care for Undocumented Workers (Ricardo Laura)
Proposition 63
Foster Children Over-Medicated
Bio-social Model: It's more important to treat maladaptive models-needs a psycho/social component.
JV2-20 Health and Education Passport passed
…36-32 dropped and put on school district-less students were referred for mental health care
Inappropriate use of child protective system
Intensive Therapeutic Foster Care
IFFC Model
AB 36-32 money to achieve child's needs in mental health services

Yoder also made some general comments: We need to "identify the stigma early rather than pouring money into jail where the grown child is using crystal meth...Do parents come to see the doctor to get prescribed medicine? How do you change easy access to meds...If he's acting up, because of, e.g., getting bullied at school, getting calls from the birth mother and getting upset, the client may need therapy, not pharmacology. Don't just prescribe medicine. Licensing can work cooperatively with the medical board. They are very mechanistic and don't look at documentation."

KEY Dates
…12/1/2014 New legislation sworn in
…..1/5/2015 Legislators return in earnest
…..1/9/2015 Governor Brown releases his proposed

After the round table problem-solving session, a volunteer from each table stood up to address the problems articulated by their own group that they wanted solutions for at the legislative level. Some tables came up with the same issues:

Stigma
MSP-Access to care
Screenings and evaluations
School accessibleACT-more inclusive wrap-around services
LPS reform
Medication access vs. excess
Foster youth-better coordinated care
Child psychiatry shortage
Marijuana tax
Community education
Child psychiatry to the court
Screenings
Teacher trainings
Electronic medical records
Reforming of school-based services
Non-pharmacological treatment
E-prescribing of schedule 2
Thorough evaluation for medications

(The above are not necessarily in order of importance.)

Senator Darrell Steinberg received his award at the end of the meeting, and made a few comments about the state of the state. He mentioned that he'd grown up right around the corner from the country club but this was the first time he'd been inside it. He said, "The more we do, the more unmet needs I see. It may be that more people are coming forward. We see more of these (mental health) issues when people need help. It should be easy to get it, and we should have resources when they need it." He emphasized how important issues like homelessness and children and child welfare and under achievement in school and drug abuse and the plight of veterans are, while acknowledging "our inability" to deal with these issues.

"The irony in representative government," in finding someone to replace me (shouldn't happen), he said. "There shouldn't (need to) be somebody to replace me...This should be taken on by everybody." He referred to author John Milton: "Attention must be paid to this matter!"

He went on to say that he is resolved to "build my own mental health advocacy office, a leadership institute that encourages all the other stake holders," to include "housing and homelessness, child welfare, the justice department. Each legislator (must) take on at least one bill and the ideas should be provocative, but the substance is less important than getting everyone to take on one bill...That makes it clear that in the halls of power they are making it a priority. There's a lot of pent-up desires. We haven't got ahead as much as we had wanted. We get criticized by some. We're

> spending (only) 20% on prevention." He indicated that that the corollary would be more appropriate: "The goal must be not 20% spent on children and 80% on older people...it's the reverse.
>
> He thanked the group saying, "for dedicating your lives to kids" and making sure they don't have lives that are steeped in unsolvable problems. "Recovery is possible..."

The front door of UCSF Dental School after the Advocacy Meeting

I was told by two dental students who happened to be exiting the dental school at 6th Avenue and Parnassus Street that he could be seen in the second floor emergency room there during more normal hours instead of getting up at 4am as one must do for Highland's dental program.

The Public Defender

Yesterday morning (the Monday before Thanksgiving) I called Molly McClure, the Public Defender, back. She'd left a message on Monday, about having spoken to Alex earlier in the day, and he said he no longer wanted to leave the hospital.

> Hi Joan, this is Molly McClure, public defender for Alex. I did review his chart this morning. And I did meet with him at Villa Fairmont this morning. He told me he wants to stay at Villa Fairmont. He told me it's ok to talk to you. He says there's nothing wrong with his tooth. I did note from his charting that he's not complaining about pain or swelling or anything. So, I've done all I can for him. So, give me a call if you have any questions. My number is…271…Thanks.

I wasn't surprised because he already did the same thing once before. Perhaps he's thinking that if he goes home I'll somehow make him have the oral surgery. He was always pretty smart—loved by his science teachers—and knows what's going on even in his altered state.

Each time I've called her on a Friday from Villa, so Alex could ask to go home, he would ask for the writ hearing with me there, while I put the cell on speaker phone—since he doesn't touch dirty phones—(he who didn't take showers for two years). Note that he has been on the higher dose of 20mg plus 2 of Abilify since October 2nd.

So, he would ask to leave Villa perhaps because I was there, but when Molly would pop in the following Monday, I wasn't there, so the high dose was able to have its say and he would change his mind. Truthfully, it was only the first month on the lower dose of 15 mg—all of September—that he really insisted to me about getting him out of there. (He was transferred to Villa on September 10th.) But, I was too fresh out of surgery and wouldn't have been able to take care of him. The Physician's Assistant after my surgery said I needed 3 months to recover, so, until October 22, I wasn't supposed to sit for more than 30 minutes, bend, or twist, and all that, until the spine fused. So, I couldn't take care him until October, 22nd. But, there is no reason he can't come home now. It's November.

I can take care of him again. I will take the responsibility of getting him to the oral surgeon since Villa isn't. I'm not willing to have him lose his eyes or his life. They just need to lower the meds from the high of 20mg of Zyprexa plus Abilify so he can think.

I was hoping that Molly would hear my plea and direct me as to how he might get to the dentist using a legal framework. But, this was the second time he changed his mind from a Friday to a Monday, so, she was probably annoyed. And I can understand why she was kind of curt with me this time when I called her back and tried to explain that he's now on too high a dose to be aware of his circumstances. She quickly said I "should talk to his doctor about that." I wonder if she meant the one that screeched. I didn't go into detail about what happened when I tried to inform the doctor about his medication being too high at the recovery meeting. In fact, Molly was about as receptive to hearing any more about Alex as Freeman was. She wasn't quite as nasty as Freeman, M.D., for sure, although she did cut me off and hang up before I was finished telling her what she needed to know about the abscess. She didn't want to know any more. She did take a moment to mention, however, that **she couldn't find anything in his chart about an abscessed tooth.**

The Day Before Thanksgiving

That comment about not being able to see anything in the chart about the abscessed tooth made me sit up and take notice, and that's why I'm still typing at 2:30am on the 26th of November, Tuesday night /Wednesday morning. **It took me almost the whole day until I finally realized that if they left that out of the chart, they left that out intentionally, so they could say they weren't told, and therefore didn't know the importance of getting him to the Maxillary Department for oral surgery ASAP.** I knew they *did* know because Uday of their transport team, was told to ask the dentist's receptionist, Natasha, for all the papers that pertained to Alex's dental visit and I stood behind him when he did. And Natasha gave them all to him. I was only given a copy of the referral to the oral surgeon:

Michael Knoll, D.D.S., M.D.
Alameda, CA 94501

I just remembered that I had cut off a piece of the referral with the surgeon's address to keep for myself, and pasted it into my address book, and gave Danielle the rest of the paper on which was written the referral. This is who Dr. Sharma uses which Danielle, Villa's social worker, asked me for the next time I saw her. She needed it to give to Highland's dental department, she said. But, it never happened. He wouldn't go because no one convinced him to go, like they did when he went to the ER for antibiotics, or the dentist for the x-ray. They stopped putting effort into getting him to the oral surgery. **They are keeping him at the higher dose, too high for him to deal with surgery anyway. And they don't even know that the higher dose of medicine is what's keeping him from going. Or they don't care.** I had written them a thank you note after Villa's Sheila and Uday took him to the dentist so they seemed to think they did what they had to do and put it all behind them, and forgot about Alex's need to have surgery or lose his eye or other body organ when the infection returns. It's not *IF* the infection returns. No, I'm told that's a given. It's *WHEN* the infection returns. But, as far as the nurses and doctors at Villa are concerned, as long as the face doesn't get red again, they will be able

to get paid by Medicare, Medi-Cal and also get his Social Security check without making an effort to convince him, without getting him to his surgery. I know **I've told just about everyone with whom I've spoken, about the necessity for his oral surgery: his nurse on every shift, Brian, the clinical administrator, Danielle the social worker, Yolanda the receptionist, Sheila the driver and discharge planner. Speaking is one thing. But, now it's time to get the word out in writing to everyone else. And that's what I'm about to do this morning. It can't wait another day. They just don't care. And it's my job as a mother to let them all know that waiting so long is just not acceptable.**

Did Sharma, DDS, tell them they could wait over 2 months until the redness from the infection returns? Somehow I don't think so. But, I'll go there again after the Thanksgiving weekend, and ask her.

When I finally got up on Wednesday morning, after staying up until 3am Tuesday night, I was in a frenzy about what to do, so I decided to write to 7 on your side, thinking they might help. I also forgot to take any of my medicine, including the pain killers and the blood pressure med. I called my old friend in New Jersey, Devorah Ahavah, just to hear her voice and after she'd heard enough of my woes, she told me she'd have her husband, the dentist, call me back. A few hours later, while I was composing the letter to the TV station, Steve called. At that point, I boiled over. I thought I was talking to Devorah, but it was Steve. I wanted to know exactly what might happen and he reiterated what he had already said two months before, that "it's a very dangerous situation. He could die or he could just lose his eyes, or the infection could travel in the blood to another body part." I was yelling. I didn't want to hear that same warning again. So, by the time I wound my way over to Villa to express myself and tried to bring their neglect to their attention, my blood pressure was higher than usual, but I wasn't aware of that until much later, in the evening, after I left Villa and tried to calm down at a Berkeley laundromat, keeping busy with 4 loads of wash and then realized I locked myself out of the apartment when I went home to eat something between washing and drying.

Before I went back to Villa the Wednesday before Thanksgiving, to bring this issue up to the Director on Wednesday afternoon, I wrote to the news program, 7 On Your Side:

7-On-Your-Side Letter Written On Wednesday, November 26th, . Exactly 2 Months After The Antibiotics Were Administered:

> Today is exactly two months since my son came off of a 10-day trial of antibiotics for a tooth abscess. My best friend of 55 years married a dentist who told me two months ago that you "can die from an infected tooth or he can lose his sight." The issue here is that the seriously mentally ill are not being properly taken care of in hospitals that exist for taking care of the mentally ill: Telecare Corporation, in this case. I'm just trying to keep my son alive until some wonderful pharmaceutical lab pays attention to the etiology of schizophrenia and does some helpful research resulting in medicine that actually works rather than overdosing the mentally ill with anything that calms them down while life passes them by. Attached is a recent journal that depicts a situation going on now with my own son who is "being cared for" at Telecare Corporation's Villa Fairmont Mental Health Center, and who had two teeth fall out right there during a previous admission from

December 2009 to April 2010. Nothing was done then and one of those teeth is now abscessed. The problem is that they keep him so over medicated while hospitalized (20mg Zyprexa plus a little Abilify), that he is not able to see the need for the oral surgery that was identified more than two months ago in the ER at Eden Hospital (Sept. 17th) and referred to an oral surgeon after being seen by his own dentist, Dr. Sharma (Oct. 7th) of Berkeley Family Dental. But, when the psychiatrist (then Nicholas, MD) kindly lowered the dose to 15mg at my request, on only my son's second day (Sept. 11th) at Villa Fairmont, Alex was able to travel from Villa to the Eden ER by ambulance (Sept 17) willingly, and shortly thereafter went willingly to his dentist (Oct 7th) who told Alex, me and the Villa representative, Uday, that he needed oral surgery right away before the abscess returns.

During one of those appointments my son was on the reduced dose of 15mg. But, since I had written 3 letters of complaint in one week:

1. about a nurse at Villa refusing to give Alex his blood pressure medicine because my son wouldn't let her take his blood pressure every night for 5 days,
2. about Dr. Nicholas raising the dose back to 20mg in retribution for my writing the first letter,
3. about ways to get Alex to the oral surgery he needs,

the doctor quit and Villa replaced him with another psychiatrist who refuses to even talk to the parent. On the very same day (October 2nd,) that the director, medical director, social worker and doctor received my letters, Nicholas willfully returned the medicine to the higher original dose, 20mg, plus keeping the additional dose of Abilify that he added when he lowered the Zyprexa so now Alex is on more medicine than he was at Herrick where I complained that he was on too much, telling me that the lower dose didn't make that much of a difference, and shortly thereafter, he quit. I, on the other hand, told him that it did make a difference, if only because at 20mg he didn't know I was his mother, and at 15mg, he did, and I was able to get a hug. At 20mg, my son says someone else named, "Cest" is his mother.

So, in brief, the issues are:
doctors' unwillingness to get information from the parent/family member **even when the patient gives consent**
Over-dosing the patient just to keep them quiet, rather than finding what dose of what medicine actually helps them
The social worker saying, "I do what the patient wants," but at the same time **letting the severely ill patient** (who thinks he is flying a space ship and saving 'all the children') potentially **die or lose his sight from an infected tooth** that he should and would see a surgeon about **if the dose of medicine were not so mind–alteringly high.**

I'm inclosing some relevant information from my most recent journal that includes letters, conversations, etc. My intention is to bring attention to this issue today. Toward that end, I am planning to bring my tent to Villa Fairmont and set it up in the lobby to bring attention to this matter. I only care about letting them know that they have ways to get my son to his rightful surgery at a reasonable hour at UCSF, rather than at Highland Hospital where one has to get in line at 4:45am and for which he refused to get up at 4am two weeks ago. As soon as I

> get to Villa I'm going to make signs like: "Patient's rights are the ones that keep them alive." "Hospitals are supposed to help the patient stay healthy." "Please get my son to the oral surgeon before he dies here." "He doesn't need another course of antibiotics now, so they won't work when he really needs them; now he needs oral surgery at UCSF!"

After writing the letter, I drove directly to the hospital to see the Director, Dr. Bruch, to explain to her what the issue was. Yolanda, the receptionist, knocked on her door and she came into the lobby. I tried in an urgent, but low voice, to tell her that his nurse, on Thursday, kept telling me that his eye isn't red and he's not in pain, so, therefore, it's not an emergency. And that the nurse, when I arrived at their doorstep at 4:30am four Friday's before, when he was supposed to be escorted to Highland, said something similar. So, apparently, the nurses felt that they could ignore the warnings of the dentist, I said.

Dr. Bruch didn't want to hear anymore. In fact, she simply repeated what the other nurses had stated, that it's not emergent on this day before Thanksgiving. I begged to differ, but she wouldn't hear me. She started with the antics, just like Dr. Freeman had done. I could sense from whom Freeman had gotten her audacity. Bruch started shaking her head and talking over me. That made me have to talk a little louder. Then she insisted that I needed to leave. I replied that I wasn't planning to. I had brought a new tent which I'd already placed on the receptionist's desk, explaining to her that I am planning to set it up here in the lobby until such time as I was able to get a reasonable, courteous response from her, with the end result that she was going to make sure my son didn't get maimed or killed from the abscess, although I didn't really know how to set it up because I'd never used it before, but, it was enough to just place it on Yolanda's counter and simply say that I was going to set it up. But, that didn't do it. There was no conversation forthcoming. I could only hear her shout, "No, you're not setting up any tent! Get out! or I'll call the Sherriff!" was her response. Then she told me that I would no longer be allowed to visit Alex. And an order about my having lost that privilege was soon placed in his chart.

I was a bit shocked that I would no longer be allowed to even go inside Villa to visit him, or to check his face as I had been doing for the past 2 months, only because I let Dr. Bruch know that they were being negligent. It was she who started yelling first. But, she didn't like what I had to say. And I didn't like that she didn't want to hear what I had to say. And when she threatened to call the Sherriff, I said, "That's OK, I'll call," and I called 911 instead, and the paramedics and ambulance arrived, and there was a lot of loud conversation because Alex didn't want to go, so he got upset too, and Bruch didn't want the paramedics to come in, and she wanted me to leave, so everyone had different points to make. And the one in charge of the paramedics stood in the hall with his 5 buddies, and a lot of equipment, asking me a lot of questions. I had to lean against the corner walls after a time, because I felt I was fading, while he decided what to do. One paramedic assured me that they would be taking Alex either to UCSF or Kaiser's ER. But, then I think the boss paramedic, decided that it would be better for his own employment future, not to go against the hospital who didn't want Alex to be removed from Villa to be seen whenever the UCSF Dental School would open after the holiday, which would probably not be 'till Monday. I hadn't checked as to whether the dental

school would be open on Thanksgiving, and I guess I should have, but it sounded like they might not be open. As the paramedics were leaving I took one shot of the bed they were supposed to use to transport Alex, but Dr. Bruch came back inside the lobby and, seeing me with the phone camera, said to take no pictures, so I didn't take any more, just this one, to show that the ambulance team was there.

.

I had had dreams of setting my tent up right there where the paramedics left their bed-on-wheels, but I was ok with not doing what I came there to do, because the Wednesday before Thanksgiving wasn't really a good day to take him to Kaiser after all, the paramedics had concluded rightly, because he'd have to wait until UCSF could take him after the weekend and they can't leave him in the emergency room more than 24 hours. So, it was bad timing, not a well-thought-out plan.

Anyway, I just wanted to bring it to Villa's attention, because they'd already had the information from his dentist for months and hadn't done anything about it, and apparently weren't planning to take him to surgery. How do I know? **because they *didn't* take him**, so I simply brought attention to the matter. Thank you, both Mr. Milton and Senator Steinberg, for helping me do that for my son. I hadn't predicted, however, that Bruch was going to need to get retribution. But I guess that's the cost of doing business with unfeeling people. She kept threatening to call the sheriff from the beginning because she didn't want to hear what I needed to tell her. And the Alameda County Sheriff's office was only down the block on 150th St., and with everyone leaving, I wasn't sure it was worth staying. I'd already brought the urgency of the situation to Villa's attention, hadn't I? Whether they would do something for Alex or not, was on them. After thinking about going to jail, I decided that jail was not in my best interest, because I hadn't really finished recuperating from the surgery (Dr. Montandon had written that it takes a year and it's only been 4 months.) and I'm still very slow and physically unfit, so I probably wouldn't be able to tow the mark in a cell, although on the other hand, Topol, it would be a new experience and you get free food without doing the cooking, and actually, free rent, too. It might have been interesting, if I were going to be with a large group of protestors, but by myself in jail, it didn't sound like fun. Plus, I'm just too old for that kind of experience. And they probably don't treat inmates like guests.

I'm going to have to go back to the dentist, Indu Sharma, again on Monday to see if she wrote orders for Villa that are different than I'm aware of. Maybe her orders for oral surgery weren't clear. I'm trying to give them the benefit of the doubt. I was already at Berkeley Family Dental only last week, but Dr. Sharma couldn't come out to talk to me, 'though I waited a half hour after telling her receptionist, Natasha, the situation. I imagine she doesn't want to get further involved. After all, she didn't really want to see a mentally ill patient to begin with. She probably feels that she did her job just by writing the referral. But, was there an expiration date on the oral surgery referral? Was the urgency clear? Did it say when the patient *had t*o have the surgery? I will have to find out. I think the referral probably implied that he should go to oral surgery right away, but maybe it didn't sound like a mandate or maybe it was just implied in the hopes that anyone who cared about the patient, would have the sense to follow through. In any case,

I did bring it to the director's attention, at a cost. They're going to make me pay. And paying, I am. I needed to recover from the hour or so of the shouting match, so I drove to the laundromat to de-tox and get my mind off of it. But, of course, I couldn't. So I went home between loads to grab something to eat, and the upsetness started to show when I left my house key in the apartment, and headed back to the laundromat.
Now I was stuck. My son, Brenden, didn't return my calls from the laundromat so I could get back into my place using his key. My apartment custodian, who said he would meet me at the Freedom gas station back in San Leandro, at 9:30pm, didn't show, after he said he'd be there in a half hour. I waited an hour at the station which is right down the hill from Villa Fairmont, so I couldn't get my mind off the situation, and then used a very darkly lit pay phone on a desolate E. 14th St. to ask my friend, Liz, if she could put me up and put up with me, for the night. So, that's where I woke up on Thanksgiving Day, at Liz's house in Hayward, grateful that I had a friend. After breakfast I was able to meet Miguel, the custodian, who said he forgot about my key situation when his boss called him, and I went home and simply sat down and wrote some more. It was too upsetting to think that the infection might be coming back now that the 2 months had already passed.

I cancelled my Thanksgiving plans to go to Brenden's new house since he couldn't return my call or text in time to meet me and give me my apartment key. So, I told him I slept in my car, with the hope that he could feel a little worse than he felt, 'cause he already texted me that he felt badly, especially since he said he was going to write a proper letter to the social worker earlier in the week and didn't yet do it. He likes to do things properly. But, I, on the other hand, wanted attention to be given to their negligence!

Instead of going to Brenden's for Thanksgiving, I decided to accept an offer to meet an old friend and co-worker, who now lives in Roseville and called me on Thanksgiving afternoon, and was mad at her daughter, too, so we met halfway in Vacaville where we had a lovely Thanksgiving Dinner at Hometown Buffet complaining about our kids, and then went to BEST BUY for Black Friday festivities so I could buy Alex a new TV just in case he does live through this horror story. And, fortunately for me, KQED had a TV program this weekend about how to meditate, so I tried to do that on Friday night in order to keep my sanity.

My Other Dear Son, Brenden, And His Choice To Be Professional

Brenden finally came through after a week, and emailed me his letter to Danielle and I embellished it. I can see the value of keeping the attitude cordial, which I can't seem to do. So, I added a few more details and hopefully, he will send it to Danielle with my edits and more detailed explanations:

> Dear Danielle,
>
> There are a few issues going on simultaneously that we are struggling with, to make sure Alex stays as good as he can be, not only mentally, but physically healthy.
>
> Firstly, the tooth abscess - Alex needs to see a dentist ASAP before the abscess

comes back and gets worse. It has dire consequences. It has been over two month since Alex was seen at the Eden ER in regard to that diagnosis. We spoke with you about how to get him seen and you suggested that your staff would take him to Highland at 4:30 am to be treated.

Our Mother, Joan Miro, came by last November 7th, at 4:30 am to ensure Alex would be able to see the oral surgeon. But his nurse at the time wasn't around when mom called first and the nurse who answered the phone, Amy, wasn't aware that Alex was to go. Then they asked Alex if he wanted to go to the dentist while he was sleeping, and of course, he didn't want to go at that time of the morning. When Mom arrived at the door, she wasn't given an opportunity to talk to Alex to motivate him. And it appeared that no one else had motivated him as they did the last time. Of course, the last time that he was willing to go to the dentist he had been on a better dose, a lesser dose of Zyprexa, 15mg., for those few weeks in September, so that he was more willing to do what he needed to do. The higher doses don't even allow him to know that his mother is his mother, much less understand what's important.

There are a few Dynamics going on:
After consulting a couple dentists, we know that an abscess is a huge health risk with the infection very likely to travel in the bloodstream to other organs once it comes back. And the dentist says it will return. The antibiotic is only a temporary fix. The nurses don't seem to be aware of that. The 5th tooth from the back on top is especially close to the eyes. We don't want him to lose his eyesight and there is a very high probability that he would, once the infection returns. His nurses seem to think that he's OK now that the antibiotic worked. But, we all should be aware that that is not the case. The dentist says the infection will return and we are told by dentists that it returns in one to two months. When Dr. Sharma, his dentist, gave you the referral, she recommended that oral surgery be done BEFORE the infection, the redness, returns, because the surgery won't be able to take place while the infection is in the mouth and will have to, again, be treated with antibiotics, which will simply prolong the situation and not make it better. It's common knowledge that repeated trials of antibiotics simply lessen the ability of the antibiotics to work, so we don't want the infection to come back so it has to be treated with antibiotics a second time. It's already an emergency now. It may not look like it to the eye untrained in dentistry. I don't think that the dentist, Dr. Sharma, who took the x-rays, who wrote the referral, intended for him to wait until the infection returns again, so Alex has to be treated repeatedly with antibiotics instead of going to surgery. But, that's what the nurses seem to be concluding, that they are just going to repeat the antibiotics when another redness appears. That's what's dangerous, because you don't know if the infection will get into the blood and travel to the eyes or anywhere else, before anyone even pays attention to his face.

You mentioned that you want to take him and you have a system to use Highland. If we can realistically get him there at 5AM? Or if there are better times? He's never been a willing early riser, so that in itself is a reason that he wouldn't be willing to go. From what I saw last time, when he went to the dentist in the afternoon, he was very willing to go, probably because of the time of day and his not being on 20mg for very long.

My Mother and I are also willing to take Alex with a day pass to see a dentist. UCSF has an excellent dental school that can serve Alex at other, more flexible, hours in the day. I'm told one just has to go to 6th and Parnassus on the 1st floor and they will arrange for him to go to the second floor dental emergency room during regular daytime hours. It's very easy and it's a dental school. So when would be the best day that your staff can do it?

B) The other huge challenge is his motivation to be healthy, see a dentist, change clothes and live outside a locked facility. My Mom, who has been his most consistent caretaker over the past 18 years, has recorded how the higher doses of medicine (over 15 mg) anesthetize him more, deplete his motivation, and generally make him lethargic, and easily frustrated and according to his psychiatrist at Herrick Hospital, Dr. Fitzpatrick:

> I have no intention of doubling it or increasing it. I understand that excess causes acathesia or side effects. Yea, My sense is we're on a good trajectory. (part of a message on Mom's phone.)

Again we don't profess to be physicians but we have done enough research documenting Alex's behaviors on different levels of meds. By documenting Alex's varied behaviors based on meds, my Mother can show that there is a correlation of—the higher the dose of meds the less motivation Alex has to do anything. We have learned, if we are asking him to change his clothes, see a dentist, participate in groups, etc., it becomes more difficult for him when he is on over 15 mg of Zyprexa.

Danielle, with you as the social worker, we are hoping that you can support Alex and represent his best interest. Currently the most pressing issue is for him to see a dentist before the infection returns. We don't want another course of antibiotics for him for the same problem that could have been taken care of after the first course of antibiotics.

So what are the next steps? We need him to see a dentist this week before his tooth abscess gets worse. So are you and your staff able to take him this week? Otherwise my Mother and I can bring him to UCSF on a day pass.

Again, all this planning is somewhat contingent on the dose of meds Alex is getting. He can deny all services and support if he lacks the motivation due to the higher doses of meds. Trying to get him motivated to go anywhere on 20mg is like asking him to touch the ceiling after you've tied his hands to his feet. So, what we are asking is for the new doctor to do what Dr. Nicholas kindly did, lower the Zyprexa if only for a few weeks, so he will be willing to go to the dentist as he did before. I don't know if you are aware, but he was on 15mg when he went to the ER and only on the fifth dose of 20mg, after 3 weeks on 15mg—Sept. 11 to Oct. 1— when he went to the dentist, based on starting the 20mg. the night of Oct. 2nd.
Please let us know the plan for this upcoming week. We appreciate your support. Any way that we can be included in Alex's team meetings we are interested and willing to participate anyway we can to build a partnership of care for Alex.

Thanks much,
Brenden

I guess I really need an attorney because this is urgent, scary, upsetting and my stomach is in knots. I don't want to go along with playing roulette with Alex's life as Villa is doing. He needs to go to oral surgery ASAP. My neighbor and friend, Charles, just stopped over to get me to write another article for the Berkeley Times about renaming the library, and I told him I'm too upset, so he referred me to his attorney who, he said, handles health care cases:

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The Monday after Thanksgiving 2014

The medical assistant at the oral surgeon's office that Dr. Sharma referred me to in Alameda, told me that I "just have to make an appointment and the hospital has to take him, or let you take him." So, *that's* the way it works. We don't have to go with their Highland program because it's good for Villa and Highland. He can go to whatever dentist he needs to go to, she said, and Dr. Sharma referred him to Dr. Michael Knoll, DDS, MD, in Alameda. So, she offered me an appointment for December 11th at 11am. caoralsurgerycenter.com.

No wonder no one at Villa protested when I told Danielle that I'd made him an appointment with Berkeley Family Dental for October 7th. She knew the rules. It's just that I didn't. I was just doing what any mother would do, making an appointment, since he already had a dentist. So I thought. But it took 20 days to even get him seen at the dentist, because when I called to make the appointment right after the September 17th ER visit, Sharma's assistant, Natasha, said he wasn't a member. But, I remembered otherwise. None-the-less, he wasn't in the Delta Dental database in Berkeley, CA, Natasha said. Upon my insistence that I'd signed him up when I signed myself up, a Delta Dental representative looked into it, and called me back a week later saying that he had only been put in their home computer's database a year and a half ago, but now he's in all of their computers across the country, so the Berkeley dentist will be able to see that he's a member. And that's why it took so long from the ER visit at Eden Hospital on September 17th, to the Berkeley Family Dental visit on October 7th. But, it was right after the dental appointment, when I gave Danielle the requested paper referral, that she told me Villa uses Highland when their patients need a dentist. My plan was to follow through with Dr. Knoll, but I didn't know I could, so I passed the ball to Villa. I didn't know that I didn't have to. And look what happened. We are now over the 2 month projected time that the abscess will return and Villa appears to not care about any abscess unless and until the infection does come back. They dropped the ball; they haven't done what they were supposed to do. No, they stole the ball from me, and then they dropped it. Yes, they made an "appointment," or at least established a time that they would take him to Highland's Maxillary Oral Surgery Department, but **they didn't *DO* it.** And the nurse that morning reiterated that he was OK and didn't need to go. Did they prepare

Alex to go like they did when he did go to the regular dentist? I don't know, but his nurse when I arrived at 4:30am at the Villa door certainly succeeded in making me feel that it wasn't that important, at least to Villa. I repeat:

> His nurse said through the intercom that Alex said he didn't want to go. (Who the hell would want to get up in the middle of the night to go to surgery?) "He went back to sleep," she said. And she said that when she told him his mother was on her way, he replied that he didn't know who that woman was. I said that a dentist already informed me that this could be a very dangerous situation; he could lose his eye. Minimizing my comment, she replied that he still has his eye, and they're closed because he's sleeping soundly. Somehow, I didn't appreciate the humor. It showed her disregard for Alex's health and safety. I inquired whether the doctor had prepared him for this dental visit as they had last time when he did go to the dentist for x-rays on October 7th—of course, that was at a reasonable hour during the day—and she avoided answering. I was in no state to pursue the conversation further, standing out in the early morning cold, so I left.

I went to Brenden's new place last night to update him and was reassured when Monica, his lovely girlfriend, gave me a compassionate hug. I just wanted to make sure he got this journal and to tell him he could edit the letter a little, but to send just the letter that he wrote and I embellished, to Danielle today. He said he would. He also assured me that Alex's face wasn't red last night when he visited him at Villa. Brenden didn't know that my privileges to visit Alex had been revoked by Dr. Bruch, so I told him that it was all on him now to go there more often in order to check on his potential eye abscess.

Today I made another trip to Berkeley Family Dental after my caretaker support group, and coincidentally enough, I had no problem talking to Dr. Sharma this time. My original intention was to sit outside her office door close to closing time, and it was a bit after 4:30pm when I walked out of the elevator and saw her in the hallway heading for her door. I took a breath and said, "Hi Dr. Sharma. I just need a little more information, if you don't mind. The nurses and doctors at my son's hospital seem to think his abscess is like any other infection that antibiotics can cure, you know, like taking Cipro for a urinary infection."

"No, it's not the same," she cautioned. "The infection is still there, even though you can't see it. It's not like a UTI. The tooth needs to be extracted A.S.A.P."

"Can you write that down somewhere for me, so I can give them that information?" I handed her a crinkled up envelope and a pen. She said she'd write it on a copy of the referral, and she asked Natasha to pull it off the computer and wrote, "Plz extract A.S.A.P." under her original note that said, "Plz evaluate & Tx tooth #5.

Talking about extracting, it's been a slow process, but we're moving right along. I wonder if the Berkeley Police would be so kind as to go to Villa with me and just extract him from their care. I'll send the chief an invitation.

This is definitely affecting me. My stomach is still in knots. It was hard to eat even a delicious steak dinner tonight. I've already lost 25 pounds since I called 911 on August 16th when Alex was taken to the Alta Bates ER. Sleep is erratic. I know I'm being compulsive about writing but I have to put it all down on paper. I've been frantically

going non-stop since he had to go to the hospital, calling to find out what organizations may be able to help, recording what's going on, since the two month period was over, especially now that I'm not allowed to see him. I have to stop and put the photos and film into the journal and send them out to everyone and anyone. I am just having a hard time understanding how the county can contract out to an organization like Telecare Villa Fairmont, an organization that isn't up to par, with doctors and nurses that don't know or care whether their patients get sicker or even die under their care, with doctors who can't read the recommendations in the transfer orders, of other medical practitioners who also are doctors and dentists, with doctors who don't feel compelled to get valuable information from the family that they can use in the care of the family's loved one, with social workers who don't follow through in their care of their patients while talking the words that declare that they care. They just don't walk the talk! I was so happy to have this son and I am not happy to be made to lose him like this!

Why is it so hard for the average health-care worker to understand that a mother's children are her little angels. Please get my son to surgery ASAP, Villa. Do the right thing. Just pretend he's your own child and ask yourself, "What can I do to help him stay alive so he can still be around when someone discovers a cure." And do it!

Etiology of Schizophrenia

And a cure can be found if learning institutions **do studies on the etiology of schizophrenia.** How can there be medicines that actually work without knowing what the cause is? Money for research must come forward before many more people have to suffer. Money is there: Private foundation money. Government money. Public-health grants. How much longer are we going to step around and over the street people on our way to the theater? Everyone can see them sitting and lying at the curb downtown and some of us even give them money. But, quarters or even dollar bills aren't enough to reduce the public's guilt as we all pass by. There needs to be real housing for the homeless that is always available because someone is always in a negative cash flow. If you've become homeless due to losing your job, you will soon become mentally ill out on the street. If someone has become seriously mentally ill with schizophrenia, e.g., without anything to do with employment, they need a place to live, too, where it's clean and sociable, with activities and good food. There has to be enough decent places in which to live at any point in time, because at any point in time there will be companies that downsize and toss people out; there will be people becoming ill who can't help themselves; and there will be people who are just going through unfortunate life-style changes. There needs to be a community of homes, boxcars or apartments that are placed in or near services that will help them move forward/get better so they can recycle back into the normal community. It's really not that hard to conceive. And it's a lot better than having ill souls lying on the street in an unsightly pile of human refuse to be stepped over, picked on or otherwise harmed.

'Hell'p!

Alanah's 19th Birthday is today, December 8th, and I didn't even send her a card because I'm still preoccupied with Alex's tooth.

I was almost deceived into thinking that the County of Alameda was going to help. I'd called on Friday to Health and Human Services at the County and someone got right back to me on Saturday. That was impressive. It ended up that they said he's not an Alameda County client, he's a Berkeley Mental Health client so the person, Tony Saunders, referred me to the BMH Website. I was in no mood for jokes. I wrote back to the county:

> This has been a joke, right? Below this paragraph is the BMH website that you sent me to. There are 6 things you can do, it says, to make a complaint. Step #1. Call 510-981-6585, which just gives you a loud busy signal no matter how many times you call until 4pm when they close and then you get the tape that says they're closed. #2. Complete a complaint form online; but it can't be filled out online. So they make it difficult by your having to go to BMH to get one and then mail it to where you picked it up: a 2180 Milvia St address. #3 Says to call 510-567-8137 which answers "You have reached the County of Alameda. The number you have dialed is not in service." #4 Patient's Rights Advocate- says call 1 800-734-2504, and you get another tape that says "no one is in, so leave your name and phone # and facility where you're located." #5 is the appeal notice of action or complaint resolution... Forget it, I give up, and I'm not even a consumer! but I get the point: There is no help for a Berkeley client. There is no way that a consumer would even get to square #3. Why are they wasting people's time with these fake help sites, especially when they are dealing with life and death issues! Thanks but no thanks for your "help."
>
> http://ci.berkeley.ca.us/Health_Human_Services/Mental_Health/Problem_Resolution_Information_for_Consumers.aspx ,
>
> Mental Health Division
> Mental Health Division
> print printable version
> Problem Resolution Information for Consumers
>
> Berkeley Mental Health Services desires to support you in your mental health recovery. We would like to help resolve any problems you may encounter receiving Berkeley Mental Health Services. If you have a problem, you may want to try handling the problem directly with the person. However, if that is not possible, we have six (6) different ways you can use to resolve your complaint. Making a complaint will not adversely affect your services at Berkeley Mental

Health.

Call the Berkeley Mental Health Consumer Complaint Line at (510) 981-6585 English X5097, Spanish x5098.
Complete a Berkeley Mental Health Consumer Complaint Form. Forms are located in the Waiting Room at the clinics at 2640 Martin Luther King, Jr. Way and at 3282 Adeline St. or they can click here and use our online grievance form (or click here for the grievance form in Spanish). Forms can be printed, filled out, and mailed. Completed forms can be sealed in an envelope and returned to staff at the clinic or mailed directly to:

Mental Health Administration
.2180 Milvia Street.
Berkeley, CA 94704
The Alameda County Consumer Assistance Office – Call the Alameda County Consumer Assistance Office at (510) 567-8137 or fax (510) 567-8130 to ask for information, help or to file a complaint.
The Patients' Rights Advocate – At any time you may ask for help and information from the Patients' Rights Advocate Office. If your problem has to do with a lack of your Title IX patients' rights or to help you to know if it is a patients' rights matter, call the Patients' Rights Advocate at 1(800) 734-2504.

Appeal a Notice of Action or Complaint Resolution – You may appeal if you receive a Notice of Action letter saying that you will not receive services or your services will be reduced or stopped. You may also appeal if you feel that your complaint filed with the Berkeley Complaint Line or the Alameda County Consumer Assistance Office was not resolved to your satisfaction. Call the Consumer Complaint Line in Berkeley at (510) 981-6585 x5097 or the Alameda County Consumer Assistance office at (510) 567-8137 to ask for an appeal.

State Fair Hearing – At any time, you may request a State Fair Hearing regarding a problem or if you are sent a Notice of Action (NOA) letter. To ask for a hearing fill out the Request for State Fair Hearing form on the back of the NOA or call: 1 (800) 743-8525.
(revision: Oct, 2011)

--- Originally sent by asanders2@acbhcs.org on Dec 8, 2014 8:47 AM ---

Hello Ms. Miro,

> I am following up re the email you sent.
>
> Can you please provide me with your son's full name and date of birth? If you specifically respond to this email the email message will be encrypted and secure.
>
> If your son is a client of Berkeley Mental Health the problem resolution process can be accessed on this web page: http://ci.berkeley.ca.us/Health_Human_Services/Mental_Health/Problem_Resolution_Information_for_Consumers.aspx ,

Lord help us! Berkeley is in Alameda County so why can't the county help if Berkeley Mental Health can't? BMH should have to give up their funding and give the money to another agency if they are not available to help people, which is shown by their putting up a fake web page to make it look like they're available to help. At least the county got back to me right away, even on a weekend. I'm going to ask the county if Alex can be transferred to their jurisdiction. Forget Berkeley Mental Health. The only person who has ever been able to talk to him from BMH has been the nurse, Peggy Higgins and they've made her unavailable to Alex for the past 2 years.

Tuesday, December 09, 2014

A Gwen from Patient's Rights called. She said someone from the state of California told her to call me. It must have been Friday when I was calling 211 and the different offices in Health and Human Services. 510-835-2505 is Gwen's number. She sounded authentic, like she really wanted to help, and said she would talk to her supervisor. I wanted to give her this journal, but she said she knew enough about it and challenged some of what Villa was doing like not letting me see Alex. She said I needed to talk to the conservator, not to Villa.

Since Gwen told me to speak to the conservator, I called Mr. Renzi. The essence of what his response was,

> "It's **not** what I'm willing to do; it's what I'm able to do based on the parameters of my position. I **can't dictate to you or to them**. I'm sure that Brian or the doctor will be able to take care of this. He (Alex) chose **not** to go to the dentist. **I don't** know how effective that is**. I don't** know what happened when you were there. I'll see what they can do to get him to go to his appointment on Thursday."

That about said it all. He let me know ambiguously that he could or would do nothing to help Alex get to the dentist. I picked that up by his using or implying the use of the word 'not' a half dozen times in just one short paragraph of speech.

He called me back after speaking to Danielle telling me Danielle said they tried a few times to get him to the dentist. She just spoke to him again about the appointment, he said, she said. He has the right to refuse or consent. I asked, "I thought you could override his consent, as the Conservator."

"Yes, that's true, but when the referral first came to the office, some doctor made the observation that he (Alex) could make medical decisions on his own."
I asked, "When was that? I mean, what was the date? "
"I have to look it up. The information that we have in our office is that he can make medical decisions…and that came to us on September 15,th" Renzi said.
"OK, then hear me out," I said. He arrived at Villa on September 10th. On September 11th, Dr. Nicholas was his doctor, and he wrote a new order for his medicine to be lowered from 20 mg. to 15 mg., and Alex took the first lowered dose on the evening of September 11th. So, that means that on Sept 15,th he had been on the lowered dose of 15mg of Zyprexa for 4 or 5 days, depending on the time of day the doctor wrote that Alex could make medical decisions. Therefore, that means that when he's on 15mg. of Zyprexa, he can make his own medical decisions as to what he wants to do or not do. It doesn't mean that he can necessarily make medical decisions when he's getting 20mg or 30mg or 40mg or 80mg of Zyprexa, does it? Because at the other doses, his mental health is altered and his reasoning ability is challenged (at 40mg he's catatonic, at 30mg he's very angry and agitated and at 20mg he doesn't even know I'm his mother, and he wouldn't necessarily be able to make those medical decisions himself. Logic tells you that he can only make medical decisions when he's on the dose that he was on when the doctor evaluated him—on 15mg. and only on 15mg. So, it sounds like the new doctor will need to lower the dose to 15mg. A.S.A.P., so Alex can again make his own medical decisions regarding having surgery or losing his eyesight, his brain or his life.

The conservator just went into rote, repeating that the doctor doesn't think it's emergent to have the oral surgery, because the infection went away and he's not in pain. I'd heard that message before; it sounded like a taped message. I replied that that must have been the reason that all the nurses were ignoring the dentist's referral. They have been told by the doctor, either Freeman or the new one, that the surgery isn't necessary. How can they go against what the dentist said? Do they have the authority? Are Villa's doctors also dentists? It sounds like they are not even very good doctors, much less dentists.

"You should have the dentist call Villa," he suggested.
"I had a hard time even getting the dentist to accept him as a patient much less asking her to write an additional note on the referral. Some people are reluctant to work on the mouth of a mentally ill patient." I doubt if she'd call, but your doctor can always call her, I should have said. Then I thought about the surgeon the dentist referred him to. Maybe he would call. But he hadn't even seen Alex yet.
Gwen from Patients' Rights went to see Alex the very next day and called me back. She said that "Villa is going to work with you on your visiting privilege. He doesn't want a Writ hearing. We did talk with him and he doesn't want to go anywhere. He wants to stay at Villa." She said that, "he's adamant about not going to the dentist." That wasn't anything new to me, but I wanted to give her some new information. I asked her if she'd asked Alex if he wanted to lose his eyesight and become blind or go to the oral surgeon and have the tooth fixed. She said she didn't put it like that. Why not? I said that the dentist told me and wrote again on the referral that he has to be seen ASAP or the infection can go to his eye or other nearby organs. I'm sure Gwen felt that I was unappreciative of what she did. I'm not, but at the same time, everyone is missing the

point. It's not about whether he wants a trip to the dentist or not. It's a matter of whether he wants to go blind or not.

I e-mailed the social worker, Danielle, the next morning to clarify the situation for her:

> I was made aware yesterday by the Patient Advocate that Alex wasn't prepared to go to the dentist, so I postponed the appointment until you can make him aware that he should go. It's now scheduled for December 22nd, at 3:30pm. Please note, also, that the appointment is just for a consultation, not the actual surgery. Alex should be made aware of this. I asked the assistant to Dr. Knoll, M.D., D.D.S., if the doctor would call Villa to explain about dental abscesses, and she said that he would only do that after he's seen Alex. So, the challenge here is simply to replicate what you already did when he went to the dentist (last time). He had been on 15mg for 3 weeks (right) before you were able to get him to go to see Dr. Sharma. And then Dr. Nicholas raised the dose back to 20mg and left Villa.
>
> In order for that to happen, (Alex understanding that he needs to see the dentist,) his new doctor would have to have a somewhat less than a blimp-sized ego, as Dr. Nicholas showed that he did, by having lowered the dose, if only for 3 weeks, at my recommendation. I would encourage you to speak to the psychiatrist and let him or her know that Dr. Nicholas, on September 15th, wrote that Alex was able to make his own medical decisions. This is according to what the Conservator, Mr. Renzi, told me yesterday. The point that I am trying to make in the following paragraph is that Alex is different when he's placed on different doses even of the same medication. The logic:
>
> Please note that on December 15th, Alex had been on the reduced dose of 15mg. of Zyprexa since December 11th, (four nights) when Dr. Nicholas was kind enough to reduce it, after I told him it was better for Alex, and Alex was able to recognize me as his mother on the 15mg. dose but not on the 20mg. dose. I'm sure the doctors realize that people are different and act differently on different doses of the same drug. As far as Alex is concerned, I have documented that at no Zyprexa-0mg,-he is totally bizarre and that was when I had to call 911. At 10mg. he was the best, that is, able to go out for walks, go to the stores (I have cashiers and security guards at Walgreens and the Berkeley Bowl who give me reports, and friends in the neighborhood, of him acting and dressing appropriately.) At 15mg he is OK too, able to dress, act and talk to both me and our neighbors in a non-threatening manner. At 20mg he's more out of this world, in that he's more on his space ship and saving all the children at any point in time, and doesn't recognize me as his mother. At 25 to 30mg. he's unreasonably and easily aggravated, agitated and angry over things like noises caused by the sewing machine, my cooking or even hearing my voice, to the point of his putting my sewing machine out of the apartment. At that high a dose he doesn't dress appropriately either, like wearing a bathrobe that he found at People's Park and not wearing pants underneath, and in that attire he went outside for 30 feet to the garbage receptacle. He didn't even notice that the robe wasn't closed. If a neighbor or policeman had seen him then, he'd have been taken to jail for indecent exposure. And at 40mg., of course, you should have proof in your own chart that at 40mg.—which he was on in December of 2009 after being

transferred to Villa from Dr. Thomasini's 'care' at John George—a couple of his Villa nurses told me that he couldn't even move, to go to eat in the cafeteria, for a week. So, he was just about catatonic at 40mg.

Of course, he wasn't actually as catatonic as he was when Dr. Economy, with Director Segalove's, M.D., permission, in May of 1997 did put him into a classic catatonic state on an overdose of Haldol, Risperdal, Zyprexa and Cogentin against the transfer orders that came via Mr. Mogey, the social worker at Herrick, and after seeing what they did to Alex, immediately allowed him to be transferred to the Kaiser, Hayward ER and then he was again transferred to John George for another round of their wonderful care.

In a nutshell, that is how different doses have affected him. I only asked Nicholas to reduce it from the 20mg. that Dr. Fitzpatrick, at Herrick, insisted he stay on until Villa might do the reducing. Therefore, it doesn't take a PhD to be able to conclude that if Nicholas could state that Alex can make his own medical decisions when he saw the result of Alex being on 15mg. of Zyprexa for 4 days, then Alex should be able to make his own medical decisions when he's on 15mg. of Zyprexa. However, that doesn't mean that Alex can make his own decisions and display good judgment on 20mg., 30mg., 40mg. or no mg. It only means that Alex can make his own decisions when he's on 15mg. And since that paper was filed in the conservator's office, it serves as proof that Nicholas wrote that Alex can make his own medical decisions for himself when he's on 15mg. of Zyprexa and 2mg. of Abilify. Therefore, I would think that the new psychiatrist can trust that information and allow Alex to be placed back on the lower dose of 15mg. so that he can better judge whether he wants to have a tooth removed or whether he would rather lose his eyes or something else whenever the abscess goes in the blood to travel to the organs.

Please pass this logic on to the powers that be. And maybe they can start thinking of Alex as a human being who is capable of making better judgments at 10mg. or 15mg. and put him on 10 or 15mg. to see if he will save himself from making a poor choice. Not being able to identify me as his mother at 20mg. is a dead give-away as to his mental status at the dose he is on presently, 20mg. plus 2mg. of Abilify, the dose that Nicholas put him on right before he quit. Wouldn't you agree?

Joan Miro 510-418-8568 HYPERLINK "mailto:joan.miro@att.net"joan.miro@att.net

What Alex Really Wants

I find myself always needing to take notes so I keep blank paper and pens in my purse. And while filing the other day, I came across a paper that I'd written on September 13th, 2014, three days after Alex's admission to Villa and 2 days after his taking the lowered dose of 15mg., and the first day he called me 'Mom' and gave me a hug since my surgery in July:

"Mom, maybe we'll go to Santa Cruz. How many miles is that? Then we'll come back and restart the world. It's been a while since I've been on vacation."
"You're right. The last time was when we went camping at Lake Chabot just before you got sick, and we ended up leaving the campsite after dinner because you were afraid of some animal or the sounds of an animal, and we drove to the Alta Bates ER. But you were too tired to wait in the lobby so you went into the van and fell asleep. Then I left too, to join you, so we weren't in the waiting room when they finally called your name at 5 am."
"Yea, call Jerry and see if he wants to go. It has to be a driving vacation though, not a flying vacation."
"But, you can't drive," I reminded him.
"I can drive sometimes. Maybe we can go on a family vacation—get out of this area. Maybe Brenden can go."
"But, you'd have to be good."
"What does that mean?"
"I mean 'well.' You'd have to be well. You have to eat, dress nicely, pee in the toilet. Just this morning (while I was cleaning your room,) I found toilet paper with poop on it in your drawer. No one wants to be around someone who does that," I said. "How are you feeling?"
"I miss my family. Maybe I can come home and we can go on vacation. Most of the family is dead, so I feel sad." And then he turned to me and said, "When you're feeling better, Mom, I can come home and we can go on vacation."
(Putting my hand on his shoulder,) "That's a good idea," I said .

That tells me fairly simply and clearly, that he wanted to come home as soon as 2 days after the doctor released the stranglehold that the higher dose of 20mg of Zyprexa had on him, and he was able to realize who I was. He exhibited *awareness* in that he knew that I still hadn't recuperated from surgery, saying, "when you're feeling better, Mom." He showed some *motivation* by planning and thinking about doing something, "…we can go on vacation," in the near future. So, obviously, the lower dose of *15mg. was better, enabling him to understand more of what's going on in the real world.*

So, why would Alex's psychiatrist raise the medicine to a higher dose right before resigning from Villa? Why would he do anything if he were quitting his job? By writing the paper that he gave to the Conservator on September 15th, day 5 of Alex's stay, stating that Alex was now well enough to make his own medical decisions on the lower dose of 15mg., and then raising the dose 18 days later to 20mg, to where Alex didn't even know who I was—and Dr. Nicholas knew that Alex didn't know who I was because I told him on day 2—Nicholas had to be motivated by something other than compassion or professionalism. It was certainly premeditated and my guess is that he was going to show some vindictiveness for my letters by making Alex incapable of making good decisions, but stating that he *was* still capable. Why would he send the paper to the conservator when Alex was on 15mg, stating that Alex's judgment was good enough to make his own medical decisions, and 2 ½ weeks later, raise the dose to 20mg so Alex can't use good judgment, as evidenced by the fact that he doesn't even know his mother? 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.

Who Are Mental Hospitals Supposed To Be Helping Anyway?

Patients? or are they just warehousing the mentally ill to keep them away from the 'normal' people? The actions and conversation of doctors, nurses, psych techs and any others who are in contact with patients let us see the level of customer service that is deemed appropriate by administration.

I don't think there is any more I can say to help Villa see that Alex is better on less medicine, 10 or 15mg. Because whether he is better or not better is obviously not of concern to their doctors or administrators. Their only concern is their own betterment. They apparently haven't learned much about the concept of customer service because the needs of the staff outweigh the needs of the patients. Why else would one find staff congregating in the nurses' station talking to each other instead of in the patient areas to converse with isolated patients. Why else would the faces of employees remain somewhere in the range of uppity-and-unapproachable to annoyed-and-amused looking when patients do approach them with their concerns. Why else would a nurse refuse to tell me where I could find a fork so my son could eat the chicken broccoli dish I made for him? Why else would they speak more harshly to the patients than they do to their co-workers? And why else would doctors refuse to listen to the learned observations of the parent who needs to inform them about how their patient responded to the years of medicine doses that are recorded by the parent but had not been seen in the hospital setting.

The disinterest in patient care that permeates that organization must come from the top. It's heard in the conversations of many of the nurses, like when I asked the nurse for the fork, because I'd forgotten to bring one for his daily food treat, and the nurse told me, "No, I don't have a fork!" in a tone that said, "How dare you ask me for a fork; don't you know that's not what I do?! instead of telling me where I could get one—at the dietician's office down the hall. The many nurses who were short and impatient answering a question for me, but took loads of time looking in the chart for the third or fourth time, to see if Alex gave me permission to have information (hoping I wasn't on the 'give info' list), when I would ask about his medication. The many times that I was made to wait long periods of time to ask them a question, because they would keep their eyes down pretending they didn't have peripheral vision, even though they could have looked up to make eye contact, when they weren't busy with something emergent. Their unwillingness to even help Alex to use the phone, so he could call for the writ hearing—because he won't touch a phone; it's dirty— and needs to use the speaker on a cell phone and I'd disconnected mine because I valued their pizzas more. When I'd asked Nurse Stephany if I could use her cell phone, she was very cursory and in a how-dare-I-even-ask-her tone told me that nurses don't lend their cell phones. But, I'd been told by Molly McClure, the patients' public defender, that staff would help him to call if he wanted to call for a writ. Only Brian would lend me his phone to call the public defender's office. He was the only accommodating person I've met there. Over time, I grew to realize that there was a nasty, unhelpful attitude among staff and it was systemic

and acceptable, because it reflected the climate of meanness in the organization. And they knew they could get away with it.

Why? Because the political system lets them. It's that simple. Telecare takes care of the lower rung of society, the people who at some point in time have found themselves out of control, so mental health employees feel they can do whatever they want to do or feel they need to do, because the mental health system is performing that service for society; they feel they have earned free reign to do whatever they want to protect society from the "crazy" people, as we all know they've been called. And they've even figured out how to get around government intervention if there is any.

Take OSHA, for example. One Telecare employee told me that when the Occupational Safety and Health Administration (OSHA) arrives for their unannounced visits at Telecare Gladman Hospital, the intercom operator has a specific make-believe doctor whose name she announces over the loudspeaker which alerts employees so they can take a moment to clean up their act: "Dr. Cohen, please call the main office." It's a specific doctor's name who doesn't work there, so it's code for the purpose of letting employees know that OSHA has arrived to inspect the premises and the going's on, the Telecare Gladman employee informed me, as I admitted him to Kaiser Hospital in Hayward—where I worked part-time on evening shift while teaching public school during the day. We both giggled at how the hospital was able to get away with the deception. My giggle was an act, to be sure, because Alex had only recently been discharged from Gladman. It is a wonder how the scene stayed in the back of my mind for more than a decade just to pop to the front as I think now about how they are able to get away with under-serving and abusing the patients they are getting paid to help.

Another scene that comes to mind is my entering Gladman to visit Alex back in the late 1990's, and while waiting for him to come out of his room, I was approached by a few patients whose intentions were just to be friendly and have someone new to talk to. At any point in time most of the employees would be engaged in conversation with each other behind the nurses' counter. As one young lady in particular tried to engage me in conversation, a psych tech or nurse came over to us and abruptly grabbed the patient by the arm, without warning, yelling, "Get away from her! You know you're not supposed to talk to other patients' visitors!" He aggressively pulled her away, pushed her into a nearby padded room and locked the door from the outside. She hadn't even been aggressive. She was just being hospitable. There was no warning, no words, other than the nurse going into over-kill. I haven't noted that level of abusiveness at Villa Fairmont, but the nursing personnel aren't overly pleasant either, except perhaps to each other. I take that back. Just this week as I entered the patient hallways, one patient I knew came out of the bathroom lettting the door bang. I was about to say hello to him when an even louder male employee came close to us and threatened him with, "You'd better not bang that door again or you'll be back at John George banging their doors!" Telecare seems to hire people who have an intimidating countenance and forget to tell them who the customer is.

As Senator Steinberg said in November, 2014, at last month's Advocacy meeting,

"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. If the political system doesn't pay attention to the plight of the mentally ill, than this country is no better than Hitler's regime, say I. And keep in mind that Hitler paid attention to the issue, but in a demonic way. So, it's not just about paying attention to the issue; it's about doing the right thing. Does everyone have the right to live or not? Are the mentally ill able to fend for themselves or do they need help? Should a bigger chunk of tax money be spent to help them or should it go, as it now does, to help the wealthy? Was tax money really used to bail out the banks? That says all that needs to be said about the value this country places on people fortunate enough to make a lot of money. It also says, "The hell with the average American!" and "Forget about the people who are too mentally ill to provide for themselves." Can the mentally ill help themselves or do they not need help from others? Do the more fortunate people like to step around them as they lie on the pavements or do they see a benefit even to themselves, in making sure the ill are more comfortably housed? Should our country lead the way for providing for the less fortunate and sick or just leave things the way they are? Can there be funding for much more research to find the etiology of the various mental illnesses or should our country continue to sweep the problem of being mentally ill under the rug?

How do I feel? Not too well, but I guess it could always be worse. I'd best get my final arrangements set up so Brenden won't have to do everything like he did for his father a few years ago. I don't want Brenden going on Facebook and posting pictures showing everyone how he could dance in the Philadelphia Mummer's Parade right after the funeral because he needed some relief after making all the burial arrangements.

I don't know exactly what the agenda of Monday's meeting with Danielle and Brian is, only that the Patient Advocate, Gwen, did speak to Danielle about Alex's rights to see his mother, I imagine, so perhaps they will reinstate my right to visit if I do or don't do something or other. I would prefer to know the agenda before meeting with them. So I will write to Brenden first to let him know that I'm not interested in meeting with them if it's only about my visiting privileges.

> Hi Brenden, I just called Kaiser after-hours advice because I've been having trouble catching my breath, and I wanted their opinion about whether it's my medicine all-of-a-sudden, or the stress about the abscess, so the nurse put me through to a psychiatrist who told me—after I told her how Villa isn't moving ahead on this, and is ignoring the dentist's referral by using the excuse about "Patient's Rights" after their doctor, Nicholas, put Alex in an unreasonable state of mind by raising the dose to 20 mg. of Zyprexa, plus adding the Abilify, so he can't even think—that the dentist, Dr. Sharma, needs to write a letter directly to Villa about the need for Alex to have oral surgery right away. Remember… Sharma said to me that the antibiotics didn't take the infection away, alluding to the fact that the abscess is just dormant, but still there. In fact, she verbalized that it's still there. "It's not like a UTI. The infection doesn't go away because of the antibiotics," she said. The psychiatrist said it should have been enough that the dentist wrote, "extract tooth ASAP," but since it wasn't, she told me to calmly ask the dentist who already saw him (the oral surgeon won't call or write Villa until

> he sees Alex), to write a letter that states the reasons that the surgery has to be performed ASAP. The Kaiser psychiatrist said that Villa needs to have it in writing from the dentist so they can realize that a dental abscess is not like a medical abscess and that it can get into the blood without making his face red or putting him in pain. Because the doctors at Villa seem to still be under the impression that the antibiotic in September took the infection away and it's not enough for me to tell them what the dentist said. They have to see it on the dentist's letterhead. I guess that'll be proof in court, too, when Alex dies and I sue Telecare. And it's for sure that I will! I would really prefer that they not maim or kill Alex rather than having to sue them.
>
> I have been having a worsening problem with trying to get a deep breath. It's been going on at least a week. My chest is too tight from the stress. Especially since Villa is contributing to Alex's unwillingness to be seen by any surgeon, simply because Villa's Dr. Nicholas malevolently raised the dose too high before he quit. It's higher now than it was at Herrick and over the years, 20mg of Zyprexa has always been too high, making him unable to see reason, but keeping him quiet and in bed. Villa doctors seem to be the only ones that have to prove that they are the boss. They must be very insecure in their positions at Telecare.
> Love,
> Mom

I'm only going to meet at all, if the doctor is also there and is a willing listener or reader, and I get a chance to talk to her or him about their reducing the Zyprexa to at least 15mg. so that Alex can regain his reasoning ability and realize again that I am his mother. I would explain that it was only on the 15mg of Zyprexa that Dr. Nicholas wrote that Alex could make his own medical decisions. That's what he was on—15mg.—on the date the conservator said he received that information from Nicholas, on September 15th, 2014. On no other dose of medicine did Nicholas say that Alex could make medical decisions on his own, and that includes 0mg., 10mg., 20mg., 30mg. 40mg., etc., and everything in between.

We all know that patients display different degrees of behavior and mental acuity on different doses of a particular medication. That's why doses are changed by doctors, based on what the nurses and patients, themselves, see in the behavior, therefore Alex should not be on 20mg. or more in order to make his own medical decisions. We should have to see how he decides when he's placed back on 15mg. and the 2mg. of Abilify that Nicholas added to the mix on September 11th. If they are willing to discuss that issue as well, then I would consider coming to the meeting. Otherwise they can maim my son without my being there. I don't want to hear about this doctor also not wanting to hear what I have to say. And I don't want to see Alex while the infection is slowly torturing him and I can do nothing about it. I need to get away from this for my own health and safety. This is parent abuse and I refuse to be abused!

Nicholas placed him on the lower dose, then added a small amount of Abilify, because I told him that I saw that Abilify worked the best of any medicine in a combination in 2007, when Richard Slawsky, M.D., at John George put him on the 100 Clozapine, 10Abilify and 17.5 Zyprexa. So, Nicholas added that small amount of Abilify when he reduced the Zyprexa to 15mg. But, he neglected to discontinue the Abilify when he

raised the Zyprexa back to 20 right before he quit. If Alex doesn't even have the cognitive ability to know who I am at 20mg of Zyprexa, how then, can he make his own medical decisions on the higher dose of 20 plus 2?
Villa people must get a big laugh over seeing patients in these erratic circumstances. I sensed, when Freeman was questioning Alex at his 'Recovery' meeting, that she was tongue in cheek about his dressing habits. I remember, too, how overtly funny something was, when I was trying to get inside John George and the lobby ladies were giggling at another patient, as I tried to report in Act II scene III. Psychiatrists have to stop going to Walmart to buy their degrees! They actually need to go to a credentialed university and go to classes where they can take notes on the latest research, where they can be challenged by instructors who are actually doing research, and who know about and are willing to talk about other research that is being done, and to explain how the mental health system *should* work. Why are college instructors telling psychology students to read only page 15 to 20 for the exam, or even worse, telling them that they only have to listen in class and not read the text at all, when students should be devouring the entire text book, other assigned reading material *and* listening? Trust me; I've had a few psychology students from Cal rooming with me over the past several years.

It looks like the complaints I registered with the Joint Commission were acknowledged earlier this week. Apparently, the commission has some say with the Sutter/Alta Bates' Herrick Hospital, but not Villa Fairmont.

> To: me Dec 22 at 6:10 AM
> Monday, December 22, 2014
> Joan Miro
> Regarding: Sutter East Bay Hospitals
> Incident #12159AXC-62282SHM
> Dear Ms. Miro:
> Thank you for sharing your concerns with The Joint Commission regarding Sutter East Bay Hospitals, a Joint Commission accredited organization. We take seriously all issues that may reflect noncompliance with Joint Commission standards. Your concerns have been incorporated into our quality monitoring database and we will continue to track the performance of this facility over time. By monitoring patterns and trends, we can see if performance improves or if the organization continues to have quality and safety issues.
> The Joint Commission does not assess specific care of an individual patient, thus we are unable to tell you if appropriate medical care has been provided. Instead, our evaluation focuses on processes and policies that are required within our standards. You should understand that our purpose is to help improve the quality and safety of care.
> Thank you for sharing your concerns with The Joint Commission. This information will be used to strengthen the oversight activities of The Joint Commission in its mission to improve the quality of care in its accredited organizations.
> Please include the incident number indicated at the top of this letter on any future correspondence regarding this matter.
> Sincerely,
> Office of Quality and Patient Safety
> complaint@jointcommission.org

To me Dec 22 at 6:09 AM
Monday, December 22, 2014
Joan Miro

Regarding: Villa Fairmont Mental Health Rehabilitation Center
Incident #12149OHC-52272XXQ

Dear Ms. Miro:
We are writing in response to the concerns you shared with The Joint Commission regarding Villa Fairmont Mental Health Rehabilitation Center.
We have reviewed our records and determined that it is not currently accredited by The Joint Commission. Therefore, we have no authority to evaluate the information you reported.
Thank you for bringing your concerns to our attention. We encourage you to contact the organization directly for resolution. You may also want to contact the State Department of Health to see if they can address your concern(s).
Please include the incident number indicated at the top of this letter on any future correspondence regarding this matter.
Sincerely,
Office of Quality and Patient Safety

The Need For 'Emergency Status' In Order To Make The Dental Visit Happen?

I don't get why both Danielle and Brian are in agreement that, "It has to be an emergency," before Alex can be taken to the dentist. In fact, when he went to the dentist on October 7th, it wasn't an emergency then, only 11 days after the antibiotics wore off. But, it was as much of an emergency then, as it is now, and he was willing to go. Why is that? The 10 day trial of antibiotics had been completed on September 26th. And he was ready, willing and able to go to the dentist because he was told by the doctor and/or the director why he should go and he needed to go and was going. And he did go. So , whatever they said to him just has to be repeated. But, for some reason, the people at Villa, who did their job on October 7th, refuse to do their job again. The entire situation that happened in October simply has to be repeated. In fact, he was already on the 20mg. dose of Zyprexa when he agreed to go and did go to the dentist . But, he was only on the 20mg for 5 days from the evening of the 2nd of October to the evening of the 6th of October when he took the 5th pill of 20mg. To spell it out, that's the 2nd, 3rd, 4th, 5th, and 6th. The only difference is that he was on the 15 mg. dose for 21 days before then. So, what has to be repeated is the lower dose of 15mg for 21 days, then the 5 days of 20mg and we'll see if he will do what he did before. It's that simple. Maybe before then, when he's still on the lowered dose for only a week, they could interest him in going. They

could at least try. Otherwise, let him get the 20mg out of his system for 21 days, and during that time—while he's on the lower dose— talk to him about the benefits of going so he doesn't go blind or lose what's left of his brain since the teeth are so close to those organs. Give him a reason to go to the dentist so *going* sounds better than *not going*. Whatever they said before they can say again. As I recall, I heard that it was Freeman, M.D. and/or Bruch, M.D. who were involved then. Why haven't they continued being involved since he went to the dentist on October 7th to try to get him to the oral surgeon? It's emergent! If the doctor then insists on raising the dose again, after 3 weeks on the 15mg., as Nicholas did on October 2nd, then raise it and ask him again on the 5th day after he raises it, if he will then go to the dentist. I have found that just changing the dose, itself, enables him to see things differently, which causes him to do things differently.

Which brings me back to the meeting that Brenden and I had with Danielle and Brian two Monday's ago, December 15th, at which time we discussed that I had made a second appointment for Alex to see the oral surgeon for the following Monday, December 22nd. I told them it was for 3pm so we wouldn't have to rush and we could get him to the dentist in time. I expected that the appropriate Villa personnel would again make an effort to talk to him as they did on October 7th. The appointment was actually for 3:30pm. Brian said that Brenden and I could take Alex out on a 4-hour pass in order to get him to the appointment. He excused Villa from providing the transportation since, "It has to be an emergency," he said. Given this new status, why was it an emergency last time, on October 7th? Hearing him make that comment, I suggested that Dr. Sharma, DDS wrote that it was emergent simply by writing "extract tooth #5 ASAP" on top of the original referral written on October 7th, which only stated, "evaluate tooth Fx #5". The additional, *'ASAP'*, itself, written 2 months later, should indicate to anyone some degree of 'urgency' simply because it translates to 'as soon as possible.' 'ASAP' certainly doesn't mean 'wait for the face to turn red,' or 'wait for the patient to get sick with a high temperature,' or 'wait until the patient again complains of pain.' No, it simply means, take him to the oral surgeon for a consultation before any of these things do happen, in other words, take him AS SOON AS POSSIBLE! But, both Brian and Danielle kept saying it wasn't an emergency, therefore Villa can't do anything. "They need to have in front of them the emergent condition," Brian repeated a few times. That can't be true because it wasn't emergent the last time. Or it's just as emergent as it was the last time that they used the Villa Van. In other words, whatever confirmed that it was emergent—
the last time Villa got involved with the dental appointment— is emergent now, almost 3 months later. By October 7th Alex had already had the 10 days of antibiotics which ended on September 26th. And since the abscess can come back from dormancy in a week to 2 months, it should be considered more emergent now since they have let almost 3 months go by.

I suggested that perhaps a letter from the dentist stating the degree of urgency and the consequences of not treating the infection as emergent would help prove that it is urgent—explaining that I'd recently spoken to a psychiatrist at Kaiser who suggested that I should get a letter from the dentist which would, indeed, show the urgency—but Brian said, "Nothing that the dentist can write will bear on what happens."

None-the-less, when I left the meeting, I still stopped at Sharma's office, after putting together a beautiful candy, cookie and cake centerpiece at Whole Foods, to sweeten up my request for her to go the extra mile and write the letter. Although she was at the reception desk when I entered, and appeared impressed and delighted with the Goodie Table Centerpiece and was receptive to writing a letter when I explained that the people at Villa still didn't want to understand the urgency, I haven't yet heard from Dr. Sharma and almost two weeks have already passed. But, I will go back to her office after the Christmas weekend and check on the status of her letter.

I understand that everyone with whom I've spoken at Villa, from Director Bruch to Clinical Administrator Brian Gilbaine, to Social Worker Danielle Vosburg, to all of Alex's nurses still don't get the urgency of the matter no matter what I say, I understand that by all of them saying that it's 'not urgent,' they're just reiterating what information they were passed from above, and they think they can pass the buck back to Brenden and I. And that's what they did at the meeting. And that's not going to work because they can't pass their job on to me. They gave us the job of getting Alex to the dentist by telling us we could take him out on a pass for 4 hours. They think they could get out of the responsibility that way. They think they can put the burden of responsibility back onto our shoulders. But, the reason they can't is that they hold the key to Alex's going. And that key is how much medicine they give him. They haven't been interested in what I have to say about medicine. So, if they insist on passing the buck, they would also have to pass the key. I could get him to go only if I am in charge of the medicine. But, they didn't offer me the key to reducing his medicine dose along with the pass to go out. And he will only go if the medicine is reduced, because right now, at 20mg. plus, he doesn't go, isn't willing and won't go outside to go anywhere. And that's just the way it is. If they wanted to relinquish responsibility for getting him over to the oral surgeon's appointment, they would have to also relinquish responsibility for the amount of medicine that they are giving him, because they go hand in hand. They can't tie his hands to his ankles and tell him to touch the ceiling. It's not possible, yet that's what they've been doing all along. Why they are not enabling him to be able to go to the dentist, I don't know. Why they are not helping him to go, I am not privy to. Why they want the infection to come back in order to then take him forcibly to the dentist, I don't understand. Apparently, they don't understand the relationship between doses of psychotropic medicine and the ability of the patient to think, to be able to show good judgment and to act appropriately.

On the other hand, since it doesn't really take a genius to see that there is an inverse relationship between higher doses and the ability for the patient to make good decisions about health—to the point where catatonia sets in at 40mg. and Alex can't even move. I repeat, at no Zyprexa, he's completely off balance, but at 10mg. he's the best he can be, 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. This knowledge is all attained from simple observation of Alex over many years of watching and making notations whether visiting and interacting with him or being at home and interacting with him. The doctor doesn't even have all this information because some of it came about from observations not in the hospital setting. That's why I want to give her the

information that she doesn't have, because I have it. But, for whatever reason, maybe the Villa doctors just don't want to know anything that comes from a parent. They may still think that parents are the cause of the schizophrenia. My own fears are kindled in thinking that the doctor wouldn't want to know, because that means that she may put him on yet higher doses that will hurt him, i.e., make him angry, agitated, unable to think and move. And that may impinge upon the status of his already high blood pressure. I don't want to see that happen. And I'm not paying the $1,125.00 so they can hurt him. According to the oath they took, they are not supposed to hurt him. Their job is to help him. And they are not helping him. They are ignoring him because they don't 'know' how to get him to the dentist. Rather, they don't want to know. The administrators don't want to tell the doctor to lower the medicine. They don't want to be the ones to step on the doctor's toes. And they don't 'know' what else to do because of patients' rights. So, if they are not able to get him to the dentist without hurting him—without waiting for the infection to return—they need to be humane and simply let him be released out of their care. Because they either don't care about their patient or their egos are too big to digest, much less listen to, the information that the parent knows and wants to tell them.

How do I know this? How do I know that they don't care? Because, after the meeting with Danielle and Brian on December 15th, when and where I told them that I made a new appointment for Alex to be seen by the oral surgeon on the following Monday, December 22nd, ***Danielle didn't even tell anyone that there was an appointment*** for the following Monday at 3:00pm! When Brenden and I arrived a little before 3:00 pm on that same Monday, we were expecting that Danielle would have already made everyone aware of the dental appointment that we informed her about the previous week at our meeting. Brenden even wrote a follow up email:

> From: Brenden Anderson <brendenlanderson@gmail.com>
> Date: Monday, December 22, 2014
> Subject: Alex Anderson Dentist Appt.
> To: Danielle Vosburg <dvosburg@telecarecorp.com>
>
> Hi Danielle,
> Thanks for meeting with my Mom and I last week.
> I know it can be difficult to communicate with my Mother. She is literally "at wits end," giving all her time and energy to help Alex be as healthy as possible, physically and mentally. My Mom's approach may be abrasive, but please understand that this is the cumulative results of her dire concern for Alex for the past 19 years and having continuous barriers in the system at many junctures.
>
> As you could imagine, especially if you have children, that losing your child to any illness, including mental illness, is devastating. Even under the duress of being Alex's care taker (maid, cook, pill giver and motivator), her main focus is to get him into the healthiest state.
>
> Currently the most urgent health risk is his tooth abscess. Between the referral from Dr. Sharma and consulting with other doctors there has been a consensus that the infection from the abscess WILL spread through his blood. My Mom's aggression you witnessed is her extreme concern because a few dentists have told

her Alex can lose his sight or even die once the infection spreads through the blood to other organs. I understand that she is stressing herself out with those thoughts, but there is truth to her concern.

I understand that you also want Alex to see the dentist and you can't force him until it is "emergent." I don't agree with forcing him either, but based on the dentist who has evaluated Alex, it is emergent. Unless we need to see him pass out or be in extreme pain first? So even without using force there needs to be some strategic planning/organizing.

Which is why we feel that the only option at this point, other than facing extreme emergency is to slightly lower the Zyprexa dose. Over my Mom's 19 years of administering his meds, observing his behavior, and documenting the results, she understands that lower doses, specifically 15 mgs, allows Alex to be more motivated to participate in activities (changing clothes, taking walks, shopping, seeing doctors, etc...). Higher doses keeps him more confined and "the Truth" doesn't allow him to do things.

That is why we feel it's worth trying him on 15 so we can see if he can make decisions. Were you able to check in with the doctor about this scenario? Have you been able to check in with Alex about going?
You were able to get Alex to go on October 7th, when he went. Is there any way we can use some of those tactics?

We will be coming in soon for the day pass to see if we can get Alex out. If there is any way someone could prep him?

Thanks for your support! Please share any feedback that you may have.

Thanks,
Brenden

Yet we were made to wait for 20 minutes while a big crowd gathered in the nurses' station to hear for the very first time, on the very date and time that he was due to leave, that Alex was supposed to have a pass to leave for the dentist. But, there was not even a pass yet written. They had to get the doctor to then write the pass, which she did, and while the several nurses, administrators and doctor were congregating behind the locked nurses' station door, they wouldn't allow Brenden or me to go past the station to be with Alex to try to get him ready, not until too late to get to the appointment. We missed the appointment. We needed 25 minutes to get to Alameda by 3:30pm. Add to that waste-of-our-time, that Alex wouldn't go out for any reason. He needs advance warning to do almost anything. That point is made clearly in *'Surviving Schizophrenia,'* the standard reference book on the disease, where E. Fuller Torrey describes that behavior as a characteristic of the disease. No one on staff had even bothered to talk to Alex ahead of time, like they did in October, when he did willingly go to the dentist on the 7th. In fact he was thrilled to leave Villa to go to the dentist in October.

If Danielle and Brian thought they could pass the buck to us by making a charade of the problem, making believe a "day pass" would handle it, then stepping back and not doing their job of treating it as an urgent referral to take care of a patient's health, they're

dealing with the wrong mother. They are still responsible for the outcome. The onus of responsibility remains on their shoulders. The only way they can shrug it off is to let Alex out of their facility. Alex should have been prepared by staff to go to the dentist. But, Alex, himself, had not been prepared to go out and the staff wouldn't let us come inside to get him prepared, and the staff were, themselves, not prepared that he was going, until too late to get to the 3:30pm appointment. I went to the dentist's office, myself, just to tell his assistant that my son wouldn't come because Villa didn't prepare him to go like they did before—and I was 25 minutes too late to even use the appointment for myself. I would have had to pay the dentist the co-pay of $150.00 in cash, above and beyond Alex and my Delta Dental insurance, because I didn't give his office the 24-hour notice necessary to cancel, like I did the last time he didn't go, so Barbara, the dental assistant, could arrange for another patient to fill the spot, but Dr. Knoll's assistants were nice about it and didn't ask me for the money, because they knew what I was being put through by Villa Fairmont.

It's only Villa that wasn't nice, and still isn't nice. But, forget nice! More than that, Villa didn't do its job! as a health care provider! And they never planned to do it; had no intention of doing it! It wasn't important to them as shown by not even informing anyone on duty of Alex having a dental appointment at 3:00pm on December 22nd. Can I conclude that the doctor, herself, wasn't even informed, because she hadn't even filled out the paperwork before our arrival? The only conclusion to make out of this chaos, is that it's only important to *me*, because I don't want to see my son suffer *when* the infection comes back. And I'm told, it's not an 'if,' it's a 'when.' And they expect to get paid for this inexcusable customer service? For some unexplainable reason their business office is still asking me for the $1,125.00 for December. But, it hasn't come forth**, nor will it**, because, as Alex's payee, they are not going to see his social security money unless and until Villa takes him to the dentist in a timely manner ***BEFORE*** the infection returns**! Please *G-d,* find someone who can help me get my son out of this ghastly, do-nothing, mentally-ill, prison-like holding cell!**

'Hell'p!

I wrote to the director, and she returned my letter right away.

> me
> To kajones@telecarecorp.com Dec 31 at 2:58 PM
> I've been trying to connect with someone at Villa who can help my son get his tooth taken care of BEFORE the abscess returns any time now. Cynthia Saunders at the main office said she would ask you to call me, but I was able to find your email just now.
>
> I have it from a few dentists, including Alex's, that the abscess will return and

can do damage to his eyes, brain or whatever organ gets the infection when it comes out of the dormant state from the antibiotics that were administered from September 15th to the 25th. Everyone at your facility with whom I've spoken, including Danielle, Brian, Metavina, Jess and other nurses, keeps saying that he's not in pain, is sleeping well, etc., and are generally disregarding the danger to him, but no one at your facility is a dentist. I can only presume that the information they are handed is coming from one or more of your doctors. I haven't met the new one and I don't plan to be subjected to any more of your 'recovery' meetings. I'm a quick learner.

The dentist wrote it has to be extracted ASAP and Danielle has that information in her possession, and has had it for a few months. But, for some reason, your doctors don't see ASAP as 'urgent.' None-the-less, it is urgent and, I'll tell you plainly, I'm presently looking for an attorney. If he is harmed by the negligence that your staff has been demonstrating, there will be hell to pay. My son is suffering enough. "DO NO HARM" are some words your doctors should be familiar with. That's how urgent it is when I hear dentists saying what they are saying. I don't buy that it's not urgent.

My logic-- in regard to the abscess that was identified by the doctor at Eden's ER on Sept. 15th, and again on October 7th when Uday and Sheila took Alex to Dr. Sharma's,DDS, office-- is in the attached papers that I've been writing since your Dr. Freeman showed her disrespect and downright meanness to me, at a "recovery" meeting back in October. You can verify that with any of the daytime nurses who witnessed her screeching. In retrospect, I'm grateful that she was so unprofessional because I had stopped writing in the last year or so, but her ridiculous, mocking behavior made me pick up the pen again.

The question that gives away Villa's negligence in this matter is, 'Why was taking him to the dentist urgent on October 7th, when he was willing to go then, and not urgent three months later when he is not willing to go?' Your psychiatrists must know that the amount of medicine a patient takes is a factor in both his behavior and thinking ability/judgment. You may know that the high dose (for Alex) of 20mg of Zyprexa had been tempered with a lower dose of 15mg for the 3 weeks before he went to the dentist, but when Nicholas left, he vindictively upped the dose back to what he was admitted to Villa on. Yet, Dr. Fitzpatrick at Herrick projected that they would be reducing the Zyprexa once he got to Villa. That has all gone into in my notes which you may choose to peruse or decide not to be bothered with. But, I will give them to the judge. They usually like to read.

Sincerely,

Joan Miro
510-857-7937

Dec 31 at 2:58 PM
Kathrine A. Jones
To

me
CC

Brian Gilbane Cynthia Saunders Dec 31 at 4:22 PM
MS. Miro,

Thank you for your emails outlining your concerns. I know that Brian Gilbane, our Clinical Director, met with you and your son's Social Worker on December 15th in our Large Conference Room. Believe me when I say that we are aware of your concerns and have been working diligently with Alex to address them. I reviewed his chart today and found four instances where appointments had been set for your son, the most recent being 12/22, and he has refused to attend. I understand that his brother had also agreed to help get Alex to appointments as well. As wAs explained to you on 12/15, we cannot force your son to attend the appointments and a judge has not deemed him incompetent to make medical decisions. At this time, there is no good cause to do so. I know it is hard as a parent when your child has a health condition that, at some point, could experience an exacerbation. Alex is an adult and we must abide by his wishes at this time and for the aforementioned reasons.

My hope is that between the consistent work and engagement both Nutsing and Social Services is doing as well as your son's involvement who attended the 12/15 meeting, we will see Alex make the choice to go to the dentist.

I want to thank you again for your concerns and I am more than happy to schedule a meeting with you in the New Year upon my return to the office on 1/5.

My hope is that the New Year will see movement on this issue and your concerns addressed. Alex is at the helm of his recovery and I assure you that we will continue our thoughtful and heartfelt conversations with him about health and recovery.

Most Sincerely,
Kate Jones, RN, MS, MSN

Sent using OWA for iPhone

I waited few days and then just sent Ms. Jones a page or two from my journal below, that shows what I was thinking and what came up since I received her e-mail that I'd already been writing about. I sent her everything below from the journal including the addendum to HIPAA.

OK. Indeed. That's good. She did get the email in the afternoon, and got right back to me; maybe I never sent it to her at midnight, just to Brenden. She replied a couple hours after receiving it, so she may not have read the attachments, therefore she has a minimum understanding, although she could have read them in those 2 hours. It was just this 100+ page journal. So let's look at this. She said, they "are aware of" my concerns. I'm not sure about that, because she doesn't make mention of the high dose of 20mg. that is incapacitating Alex at any point. That was ignored. And that is my main concern. So,

she's saying that she's aware of my concerns because it sounds good, but she's not really aware, if she neglects to mention either the dose or that she's going to get the doctor involved.

Why do I feel like I'm hearing an echo of what I've heard before? Because she is simply reiterating the already established chant: "and he has refused to attend…we cannot force your son to attend the appointments," yet no conversation ensues about getting the doctor involved to consider lowering the dose of Zyprexa to 15mg., much less the 10mg. that he was fine with at home, so that he can make better judgments. That's what I can't comprehend: how they can reiterate and keep focusing on what they apparently think is Alex's refusal to go to the dentist. Is Alex refusing to see the surgeon? Yes. Is Alex refusing to go blind? No. Is he refusing to live? No. That is, does he want to go blind or die? No. Has he asked to speak with Dr. Kavorkian? No. Has he tried to overdose with enough medicine to kill himself? No. Maybe they should be asking him that. I know that answer is 'no.' In fact, I know that he wants less medicine. I know that he wants to live, because he has said so on many occasions, and I have it in his own handwriting from his prolific writing. He's not suicidal. Far from it, he wants to live "forever." Maybe I should send them a copy of the pages I've saved to show that he's not suicidal. When I cleaned up his room after his last 5150 in August, I wiped each of the many hundreds, maybe thousands, of pages strewn around the room on the shelves, floor, and in the drawers, and filed them in newly purchased decorative boxes according to how many words were on the paper and if it made sense to me.

On the other hand, she did hint at what I might do: "and a judge has not deemed him incompetent to make medical decisions." I wasn't aware that I could bring this information to the judge without Alex asking for a writ hearing. The writ dance has happened too many times for the public defender to want to take part in it again. Alex speaks into my, or Brian's, cell phone, set on 'speaker' on a Friday, and by Monday, when Molly McGuire arrives on site, changes his mind, (because I'm not next to him), about going to the hearing. So, he's kissing up to me and then saying 'no' to the writ. I've been thinking about going to the court again, just to leave my notes for the judge, and have gone there a few times, but it was not in session, and I really didn't know what I would need to do to get the judge's attention. I do understand that Molly Maguire doesn't want to be further involved, because she said so in her taped message, "So, I've done all I can for him." Therefore, I would have to go around her, and I'm not sure that doing so is kosher. Of course, my methodology has not always been kosher anyway, it's more "60's." After all, I was 16 when I saw J.F. Kennedy mesmerizing the crowd at the Bala Cynwyd Shopping Center just across the street from Philadelphia. But, on my own behalf, I do whatever I have to do to "bring attention to the matter," because it's a life or death issue. And I'm the mother, so it's my responsibility.

He still deserves to be in good physical health even though he's disabled and not able to make good judgments for himself at high doses of Zyprexa. It's certainly questionable and suspicious, that Alex's first Villa psychiatrist, Nicholas, M.D., would have raised the dose back to the higher Herrick-issued-20mg. dose, just at the moment the Villa doctor was resigning. If they would be willing to address that issue, we could talk further, but if

Villa doesn't want to address the issue of their overdosing their patient, with more medicine than he even received at Herrick, I have nothing more to say to them. Expecting Alex to make good judgments after being given twice as much Zyprexa than he was taking at home, is like expecting the comatose Jack Nicholson character in One Flew Over the Cuckoo's Nest to make good decisions after his brain surgery. Although institutions for the mentally ill can no longer do brain surgery, they are still allowed to obtain similar results with higher-than-necessary doses of medicine as proven by Dr. Segalove's and Dr. Economy's villainess attempt to overdose him in 1997.

Maybe I should call my old friend Sherry, who is still a family-court judge in LA, to ask her how to approach the judge at the court behind the John George Psychiatric Hospital. She had called me, right before our 50 year class reunion in 2012, asking me to meet her near NAPA where she vacations annually, but that didn't work out. She must have forgotten she invited me, because when I arrived at her hotel she was out with her friends, and didn't respond to the note I left with the concierge. She called a couple of times after that to apologize, but I'm devoid of a forgiveness gene, especially when she said I could have 30 minutes to tell her what's going on in my life because her husband would soon be home. That wasn't the kind of conversation I had in mind—a speech about my accomplishments—so, I told her I'd send her a resume. Instead, I answered her request by saying that all she needed to know was that I'd been molested at 4 years old, a couple of years before I'd even met her, when we quickly became best friends for many years thereafter. She replied, "Oh, so that's what was wrong with you." That surprised me, because I didn't know that I let anything show. I certainly learned quickly that no one wanted to hear about it. And then, of course, she hallucinated that her husband was all-of-a-sudden at the door. I wasn't surprised that she could be a judge, because they have to read mounds of information, and that's what she did best. She would have novels stashed under her desk, hunkering down with them, instead of listening to whatever the teacher was saying. When Sherry asked me if I knew she had to negotiate her way out of flunking algebra with Mr. Neerenberg at Northeast High, I wasn't surprised. But, that's how we left it. I guess I could dig up her number. Maybe I will; maybe I won't.
I wonder why Villa doesn't realize they can declare an emergent situation to override Alex's refusal to go to the dentist...? for their patient's own safety. His going was emergent *before*—on October 7th—and they were able to get him to the dentist. Of course the full effect of the 20mg dose hadn't taken place at that time, only 5 nights after he'd been on the lower 15mg dose for 3 weeks. It's more emergent now because the infection will be returning at any moment since it's more than 3 months since the course of antibiotics ended. Leon Rodriguez, Director, Office of Civil Rights, under the Department of Health and Human Services, wrote an addendum to the HIPAA LAW: "to prevent or lessen a serious and imminent threat to the health and safety of a person…"

The addendum follows:

> 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.

The HIPAA Privacy Rule protects the privacy of patients' health information but is balanced to ensure that appropriate uses and disclosures of the information still may be made when necessary to treat a patient, to protect the nation's public health, and for other critical purposes, such as when a provider seeks to warn or report that persons may be at risk of harm because of a patient. When a health care provider believes in good faith that such a warning is necessary to prevent or lessen a serious and imminent threat to the health or safety of the patient or others, the Privacy Rule allows the provider, consistent with applicable law and standards of ethical conduct, to alert those persons whom the provider believes are reasonably able to prevent or lessen the threat. Further, the provider is presumed to have had a good faith belief when his or her belief is based upon the provider's actual knowledge (i.e., based on the provider's own interaction with the patient) or in reliance on a credible representation by a person with apparent knowledge or authority (i.e., based on a credible report from a family member of the patient or other person). These provisions may be found in the Privacy Rule at 45 CFR § 164.512(j).

Under these provisions, a health care provider may disclose patient information, including information from mental health records, if necessary, to law enforcement, family members of the patient, or any other persons who may reasonably be able to prevent or lessen the risk of harm. For example, if a mental health professional has a patient who has made a credible threat to inflict serious and imminent bodily harm on one or more persons, HIPAA permits the mental health professional to alert the police, a parent or other family member, school administrators or campus police, and others who may be able to intervene to avert harm from the threat.
In addition to professional ethical standards, most states have laws and/or court decisions which address, and in many instances require, disclosure of patient information to prevent or lessen the risk of harm. Providers should consult the laws applicable to their profession in the states where they practice, as well as 42 CFR Part 2 under federal law (governing the disclosure of substance abuse treatment records) to understand their duties and authority in situations where they have information indicating a threat to public safety.

We at the Office for Civil Rights understand that health care providers may at times have information about a patient that indicates a serious and imminent threat to health or safety. At those times, providers play an important role in protecting the safety of their patients and the broader community. I hope this letter is helpful in making clear that the HIPAA Privacy Rule does not prevent providers from sharing this information to fulfill their legal and ethical duties to warn or as otherwise necessary to prevent or lessen the

risk of harm, consistent with applicable law and ethical standards.

Leon Rodriguez

Why can't the Patients' Rights organization, that is holding Villa hostage to their rules, write a similar addendum to their rules when the health and welfare of the patient is not being taken into account, because the patient is unable to understand and won't listen to the dentist who is prognosticating that an abscess is a dangerous situation? The doctor should be doing whatever she can, and that should include *lowering the dose back to where her predecessor wrote that Alex could make his own medical decisions*, because, according to the addendum, "…providers play an important role in protecting the safety of their patients," the doctor is the only one who can do that. And Nicholas wrote that his patient could make his own medical decisions on September 15th, when Alex was on 15mg. So, *if the rules enable patients to make their own medical decisions* ***at any dose*** *of any medicine,* once the doctor has written that he can make his own medical decisions after evaluating him at a specific dose, maybe *there should be addendums to those rules, too,* to limit the ability of the patient to make medical decisions on only that particular dose that the patient was on, when the doctor wrote that the patient could make his own medical decisions. Because, truly, the entire range of Zyprexa that has been researched—2.5mg. to 20mg.—cannot support the conclusion that is presently being used: that once a doctor says the patient can make his own medical decisions, the patient can make decisions no matter what dose he is on, of that medicine or any other medicine the physician changes the prescription to. That's ludicrous, unconscionable and unprofessional, and I'm having a hard time believing that's the rule that is adhered to, according to the Conservator, Mr. Renzi, who told me that it is.

Brenden wrote back to me after I emailed him that I didn't remember seeing him this holiday season.

Jan. 3, 2015
Brenden
To me Today at 1:06 PM
It's not about me not talking to you or not caring about you. It's that I cannot engage in the extreme stress level. From my perspective you are hurting yourself and ultimately causing dis-ease. So I can't participate in that. It will wear on me. That is why I shared the meditation. I can engage when stress is managed in a healthy way.

We have different ways of communication to get what we want. I don't feel that "dramatics" is the way to reach our goals. That does not mean I'm against the results you want. I just don't agree with your tactics. I have yet to see those strategies work. Plus it's not my style. I can only help and support in my way. If that's no help to you and Alex, then I will let you do your way.

I read your emails below. They are great! You were to the point and hit it on the head. The reality is this issue is bigger than you and Alex. We are between a rock and a hard place. It's patients' rights versus incompetence.

I understand that you want to save him and you are fighting for him the whole way. But there is systemic protocol that prevents your desired results.

I get it! So what you are doing is correct. The system is messed up. That is not one person. Dysfunction needs to be addressed and changed systemically. Unfortunately big ships turn slow.

So the next step is an attorney to see about parental rights and the definition of him being able to make "medical decisions", yet he is in a mental ward. That is an oxymoron. The attorney can serve notice that they will be morally and financially responsible for any deterioration in health due to the abscess.

I know it sounds absurd but Villa is protecting Alex's right to go, or not. That is why this is an extremely tough spot to be in. So I don't believe that individually they want the worst for Alex (and you). They feel they are doing their jobs. It's the system that needs to advance.

I get that a change in medication is the only chance for him to possibly be willing, although that's not 100% for sure. So we have to continue to push from all ends.

1) Get Alex to understand and be willing to go
2) Keep talking and sending emails that 15 mg of Zyprexa is better
3) Contact an attorney to send a letter that of negligence for not making this an "emergent" issue
4) Research foods and holistic remedies that can help Alex and bring them to him

All of these things work simultaneously until there is a break through. And to manage all of this, you need to have ways to release the stress, gain calmness and be healthy so that ultimately you achieve the clarity to get everything you want for Alex and in life.

So that is where I am. I can help with things. Email is the best way for me to communicate right now. I'm willing to support you in ways to relieve some stress by suggesting activities, lessons and meditations. But I can not be around the stress now or any more.

I love you and hope that you achieve the awareness to attract the results you wish.
Love,
Brenden

Brenden,
I think you should stay away from stress, if that’s how you feel about it.

As far as I'm concerned, I've been taking care of Alex for so long, going on 19 years since his breakdown, and it's been extremely stressful since he got sick, so this isn't the first time it's been stressful, but I don't see any alternative to taking care of him. I can't just let him be on the street or on his own where he is not properly provided for. There were other places that didn't keep him safe and I was able to get him out of those places at those times. My need to keep him safe, and as good as he can be, is deeply imbedded in my cell structure. I'm sure it stems from my not being kept safe by my own parents. In my mind, keeping your kid safe, is the main thing a parent is supposed to do. Once he lost his own ability to keep himself safe, just when he was about to begin his adult life, I found myself taking over again, to provide that service. And, actually, I never had the opportunity to let go because he got sick just when he should have been separating himself from me. None-the-less, I still feel bound to take care of him. I couldn't live with the idea of his being hurt more than he has already been hurt by this incredibly debilitating mental illness. The stress, for me, is not as debilitating as it is for you, because it would be even more stressful for me to think that he could be hurt further by those who have the power to hurt him and should be helping him, yet whose intention is apparently to hurt him while they, at the same time, state that they are helping him. Did I send you the letter that the head of Villa sent me, which alludes to the conclusion that "he is at the helm of his recovery"? Is that some kind of bad joke or is she deluded into thinking that Villa has actually done something helpful? They have consistently ignored the fact that he functions better on less medicine and have raised the dose of the Zyprexa and added Abilify. I wouldn't put it past them to have actually raised the dose even more than they are admitting to, more than the 20mg. of Zyprexa and 2mg. of Abilify. I wish I could get a vial of blood from him to have analyzed. He displayed unusual behavior today and yesterday, refusing to visit with me both times and turning down all the food I brought. And, he told the nurse to throw the food out. So, he's a bit more antagonistic and not himself, showing that they raised the dose of something. No, I trust Villa not.

I had made another appointment for Alex with the oral surgeon when I went to his office on December 22nd but didn't tell anyone about it because of the holidays. I guess I should have added the information to my previous letter to Kate Jones, but I didn't, and now the appointment is tomorrow. So, I have to let her know although I have no expectations for any help from her especially since she thinks Alex is already "at the helm."

To Kathrine A. Jones Today at 11:22 AM
Jan. 5th, 2015

Dear Ms. Jones,

There is another appointment with Dr. Knoll in Alameda scheduled for tomorrow, Tuesday 1/6/15, at 3:00pm for Alex Anderson. The only possible way he will go is if your doctor lowers the dose of Zyprexa today to the 15mg. that he was on before Dr. Nicholas raised it. The lower dose in his system for 3 weeks is why

Alex was willing to go to the ER on Sept 17th and to the dentist on Oct. 7th. If your doctor will dig down to find the humanity to lower it so he doesn't have to take a chance to go blind, that would be appreciated by all of us, even Alex, who doesn't know what's up at 20mg. He's certainly not at the "helm of his recovery,"; he's more like a rudderless cast away at this point in time. He was getting 10mg at home last year and doing a lot better than he is now. He was happy to get out to go to stores or take a walk. Now he's a recluse, more isolated than he was at the lower dose. Now he's not talking much, yet at 10mg he was doing much more talking to me, neighbors, the security guard at Berkeley Bowl and the cashier at Walgreen's. He changed his clothes everyday on 10mg. and took showers on his own.

I don't know why Dr. Fitzpatrick at Herrick pushed it all the way up to 20mg. right away and set the stage for all doctors to follow. It certainly wasn't the result of any conversation with me. The only one-way conversation Fitzpatrick had was the recorded message he left on my phone which I transcribed onto page 29 of the journal. The reason I called 911 to begin this nightmare was because Alex showed signs of not taking the medicine altogether, not because the dose was bad. And he stopped taking it because I had to leave for a couple weeks and my replacement was apparently only interested in extorting money from both me and my brother. I had to have the laminectomy none-the-less, and I certainly have been made to pay for it by seeing my son in these dire circumstances since July. I complained to the Joint Commission about Fitzpatrick not being willing to talk to me, and I am complaining about the same thing at Villa since your Nicholas, MD, raised the dose back to the unnecessarily high 20mg. before he quit and Dr. Freeman refused to hear what I had to say altogether, and in fact, bullied me. This is a chance for you to set the record straight so that he may be able to be at the helm of his recovery.

Thank you for your assistance in talking to the psychiatrist to help my son get out of the danger that he is in presently.

Joan Miro

It's 6am on Tuesday, January 6th, 2015, and I'm getting up to print this journal and take it to court to see if I can connect with the judge or even Molly McClure, the public defender. I stopped at both dentists yesterday. Dr. Sharma still hadn't written the letter, 'though 3 weeks have passed, so I suggested that I could write it and she could fill in the blanks, so that's what I'm doing now. Natasha told me to e-mail it to her.

Natasha, please ask Dr. Sharma to fill in the blank space re what can happen if he doesn't get the tooth pulled urgently . I'm going to court this morning to give it to the judge.

me
To
dr.sharma726@yahoo.COM
Today at 7:13 AM
January 6, 2015

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. What is likely to happen is his going blind or losing what functioning of his brain that he still has or_____ By not showing an understanding of what I have already written and given to the Villa Fairmont Hospital representative, Uday, on October 7th and rewritten 2 months later—that he must have tooth # 5 extracted ASAP— when the mother asked me again to describe the urgency, whoever is responsible for him is not doing what is in the best interest of his health.

Sincerely,

Dr. Indu Sharma, DDS

I'm going to run over to the dentist's office by 9, the printer by 10 and to the court before 11am with this letter that the dentist's assistant is printing after she fills in the blank, and either give it to the attorney or to the judge.

(scan final letter that Dr. Sharma edited and signed; basically she used the first paragraph of my draft.)

I'm sure Dr. Sharma has other things to do, and she did take the time to edit and sign the letter that I'd just written. I was disappointed that she left out the gory details, but I

accepted it gracefully, thanking Natasha for her time with a tip with which she could unfortunately only buy one cappuccino. I was further disappointed that she didn't have any letterhead paper.

I wasn't really sure what I was about to do when I finally got to the court above Villa. I just knew that something had to move forward to get him to the dentist. It was almost 11am when I saw the Villa transport van leaving its space in front of the court. I said 'hi' to Sheila and asked if the judge were still inside the building. She said he was, so I knocked. After all that running around, I was almost too late. An older gentleman, who had a lawyerly presence, opened the door and asked what the issue was. I said, "I'm the mother of a patient at Villa who needs to have his ability to make medical decisions for himself overruled by the judge. Here is a letter from his dentist stating that it is urgent for him to go to oral surgery, and he's not willing to go even though he needs to."
"Why won't he go?"
"Maybe because he doesn't have to, and he's not in pain at the moment, but when the abscess comes back, it could blind him. He's on too much medicine to be able to make good judgments and the doctors won't talk to me."
He read the letter and said, Why don't you give this to the attorney, Molly McClure? We have policies at court that say we don't give information directly to the judge until the attorney sees it first."
I said that "Molly already is off his case having left a message saying she's 'done all she can do.' But, if you need to show it to her, that's OK with me."
"Here, let me give you another book," I said as I reached into my computer case.
"That's OK, I can see to it that both of them see it."
"That's nice. Thank you very much."

I guess I did make it, but just by the hair on my chinny, chin chin. So, now what? I had only the doughnut in my blue bag that I brought for Alex, and his socks that I'd stolen from him to wash over the weekend, so I drove down the hill to Villa. After last Friday's angry rejection of his bagel with the whole works—fresh salmon, cream cheese, avocado, pickle, lettuce and tomato and the subsequent weekend treats, without even looking at them—I knew I only had a chance to connect with him with his favorite fried apple fritter.

When I walked in the main door and said hello to Villa's receptionist, Veronica, I wasn't really sure why else I was there except for the food and socks. I couldn't ask to see him, because it wasn't visiting hour, but she said to give the bag to the nurses at the station. I did that, and then sat down in the lobby, exhausted, wondering what to do next. It was only then that I remembered the 3:30pm dental appointment. I told Veronica that I wanted to speak to Director Jones. She said I would need to call and make an appointment. I replied that I'd been e-mailing her and wondered aloud if she'd gotten back to me this morning. I put it more clearly: "Do you have wi-fi in the building that I can connect with so I can see if she wrote back?" It was then that Veronica showed me her Villa-imposed-limited-customer-service hand. I guess they don't think about the parent as a customer—as a part of the package. They don't have to treat parents in any other way except as the 'public.' She said they only had wi-fi for patients. I "would have to go down the hill to Starbucks," she said. No, thanks. There must be another way to

find out if Jones had responded to me. She picked up the phone and found out that the director was "in a meeting." OK. So, what's new? I continued to sit there contemplating my strategy. I was tired from all the running around since 5am. I usually get up later. My mind was racing around for a connection so I could figure out how to get Alex to the surgeon by 3:30pm. But, I sat in quiet contemplation. The racing inside and quiet contemplation on the outside seemed like an oxymoron. I felt like an oxymoron. How could this happen? Why wouldn't the administration have already talked to the doctor about his need to see the dentist? Why were they making it this hard to keep my kid alive? In the Rights for Individuals in Mental Health Facilities, Admitted Under the Lanterman-Petris-Short Act Handbook from the California Department of Mental Health, it clearly states (p. 20) "You (the patient) have the right to be free from abuse, neglect, or harm, including unnecessary or excessive physical restraint, isolation, or medication." Here I emphasize the words 'unnecessary or excessive…medication,' that is, the 10mg.-higher-than-necessary dose of Zyprexa. He was able to take showers, eat well, take walks, jog, dress appropriately and interact with me and other people on the 10mg. dose that he was receiving before going into Herrick. Double that dose and he hasn't been doing those things. The other word that I emphasize here is 'neglect,' meaning they neglected to take him to the oral surgeon after the emergency room doctor on September 17th, and the dentist on October 7th, both said and wrote that he needed to have the tooth extracted ASAP.

The clerk at the court, Mitch, to whom I gave both the book and the letter yesterday, Tuesday, January 6th, did give it to Public Defender, Molly McGuire, as he said he would. She just called me to let me know that, "There was a case 2 years ago about a patient needing a tooth extraction and this is what you would have to do: The doctor has to make a physical appearance in the courtroom to talk to the judge."
Oh, please, I thought, but I didn't interrupt her because I've learned that a rebuttal turns her off.
"If a patient has to have a major extraction, and if the patient doesn't agree to the procedure, that's what would have to happen," she continued.
Maybe she didn't know that if the doctor will lower the medicine, Alex might change his mind because he will be able to think more clearly, but I didn't say that either.
"I called Nicolas Renzi, the conservator," she said. "I told him that he should start the medical authorization, and he should get a letter. I would touch base with Renzi," she suggested to me. "If you could get Dr. Sharma to come into court to say this needs to be done?"
I said she has a very busy office and it took 3 weeks just to get her to sign a letter that her assistant typed.
This is "how the system works," she replied. "She has to testify, then the judge can make a decision."
There was more conversation than this, but it's all I could get down, trying to listen and type while she was talking. I only got 80%. I did tell her that Alex's doctor, only yesterday, was willing to lower the medicine, but apparently, it hasn't taken effect yet. She said she saw the notes from the doctor and let me know that, "He said it's ok to talk to you and look at the book." I hope I didn't write anything bad about Molly. She sounded like she's intending to read it. I guess I should watch what I say about attorneys.

The idea of anyone else reading my notes, with the exception of Dr. Montandon, of course, my co-author, has been a strange one, that is, no one wants to read notes. I've been keeping notes since Alex got sick, so that I, myself, could read them to remember what medicine works and what doesn't. Then it also became a way for me to get the thoughts that I had, out of my mind and the stress out of my body. It's still more of a journal and only a few journals are actually of interest to most people, like Ann Frank's. That's actually the only one I can think of. The rest are probably of scientific value, written by people who are getting their PhD's or doing other sorts of research. I see no reason that anyone would be interested in the boring recitation of anecdotes about a sad story that's daily becoming even sadder. Most are afraid they'll feel the sadness and take on the depressing thoughts that emanate from the frustration of being between a rock and a hard place. We're all brainwashed to strive to be gay and enjoy life! People have their own depressing sagas that they save for their own group therapy sessions. The story of trying to get a tooth pulled, so the hero can continue to be living his normal life in the grip, the hell, of schizophrenia, doesn't sound inviting even to me.
None-the-less, the un-do-able was done. The un-happen-able, has happened. I met with the psychiatrist yesterday. She's young and darling. She's from Brazil. Dr. Dovale. It sounded like a French name to me, at first, so I was apprehensive about possibly meeting another Freeman after that weird bullying session with her in October. But I needn't have been, because she was sooo nice. As soon as I got home, I texted Brenden:

> "The doctor is lowering the dose."
> "Awesome. Did you talk with her? Let's pray Alex goes to the dentist."
> "I haven't yet recovered from the conversation I had with her. She invited me into her office. It was Danielle who got hold of her and told me to talk to her. I wish she had put that meeting together a month ago. She really should have suggested that we meet like we did, without all the official 'recovery' bullshit and all those other nurses present, where the doctor has to protect her image. It was just she and I.
>
> And she just happened to be nice and was glad to know that he was better on less medicine because she didn't like what she was seeing on 20mg. I guess their first thought when the patient isn't good is to give more medicine without knowing how he might be on less. They just shoot him up to maximum and then decide what to do. I told her that he takes showers on 10mg. and changes his clothes on 10mg. It was just a matter of talking face to face. She'd already heard that I wanted less, but didn't hear the reasons why. They left out the details that I'd already written about to Danielle. I already put the info in writing many times. The administrators should have read their e-mail and told the doctor so she could have made this decision long ago.
>
> She said she won't give him any tonight, then tomorrow she'll start the 15mg. She explained about the half-life to me, that after 24 hours there is still half the dose in the blood, so tonight, when she doesn't give him any meds, he'll still have 10mg., she said, then the next night they'll do the 15mg. I refrained from correcting her because I knew that Zyprexa has a 36 hour half-life, not a 24, according to Phillipe, a Lilly pharmacist many years ago. That's probably better anyway, because there will be

somewhat more than 10mg. in his blood tonight when they don't administer any Zyprexa, so he doesn't have to bounce from 20 to 10 to 15. Anyway, I cancelled the dental appointment for today and rescheduled it for Thursday of the following week. Barbara, at Knolls office, was nice about it again, even though it wasn't 24 hour notice. But, if he is willing to go out sooner, I'd like to take him to UCSF's Dental School with you before Thursday, because we're really calling it close. Because Dr. Knoll won't do the surgery; he only looks at it first. And that makes sense for him, but the dental school will do it all. I don't want to have to go through this more than once! I found my way into their hospital ER last Sunday after approaching random people on campus, who had a tag or a white coat on, and who looked like they might know something. You just have to go to their hospital ER and after an evaluation they can take us into the dental school from there, according to the ER's intake nurse. The dental school building was closed but the gym in the basement across the street was open and busy. Their security guards were helpful, too. I may go back this week to talk to dentists or teachers when the school is open."

The Importance Of Communication Between The Parent And The Psychiatrist

I couldn't help but wonder what made each of the 3 Villa doctors with whom I'd spoken take the stance that they did. Two out of the three did listen to me, I mean, were willing to hear what I had to say. And both of those chose to hear me in a private room rather than communicating in a 'recovery' conference where everyone is on stage. That makes me think that it may be the official setting of the 'recovery' meeting that presents the problem in communication between the parent and the psychiatrist. Most of the work that psychiatrists do is normally done one on one, so perhaps they are not as comfortable in a crowd.

My journals were another issue. Nicholas was a bit more agitated when he saw my writing, but Dovale wasn't and, in fact, asked if she could read it. Fortunately, I'd printed 3 copies, so I gave her one. So, why did Brian, the clinical administrator, presume that doctors need to receive information in simple, clear footnotes, because they don't want or have time to read? It's not the first time I was told that. But, Dovale wanted to read the 'book,' she called it, and apparently can read in more than one language, because she already speaks Portuguese, besides English, and probably some others too, since she likes to travel and is obviously smart.

Being sociable may be an issue, too. After Brenden said he couldn't handle being around me when I was so upset, I was determined to stay calm. I wasn't really calm, as proven by the fact that I left my pocketbook with keys, money, credit card, etc., in the lobby next to my chair, when the doctor came over to show me into her office, but I tried to act calm and speak calmly. And I became calmer after speaking with her and seeing that she was at least willing to hear what I had to say. But, I wasn't calm enough to remember to grab my purse from the floor beneath the Christmas tree on my way out. No! I was so excited because Dr. Dovale said she was heading right into the nurses station to write the orders

to lower the dose. We hugged at least 3 times, both in her office and in the hall.

And why were both she and Nicholas willing to give me some time to talk to her and to actually listen to what I had to say? I think that they both had enough self-esteem and confidence to want to know more, just in case they could learn something that they didn't already know about their patient. I've learned that people who don't want to learn, who like things just the way they are, who refuse to change, have personal problems that they haven't yet overcome and can only handle things when things stay the same. So they think. They want the world to remain flat. That's how they want it. That's how they know it. And that's how they know their place in it. So, Nicholas and Dovale were above that, and still willing to learn, even though they already had advanced degrees.
On the other hand, the other psychiatrist was not willing to be told anything. She liked things the way they were, where she could be queen and everyone else had to bow down. She never really left the 'street mentality' behind, even after getting so many certificates and degrees, which are not just proof of learning but acknowledgements of a new status. On the street, one has to know one's place, and she went to graduate school to make sure her place would be at the top so she didn't have to get kicked around anymore. There's a reasonable explanation for every kind of behavior if one really wants to understand it. I don't fault her; I feel sorry that her life was so difficult that she doesn't want to learn anymore. She's afraid of losing her status. That's why she said, "It's *my* license on the line!" as she tried to shut me up, yelling, "Get out!" But, there's always something new to learn. Nobody knows it all. Except, of course, my Alex. He thinks he's a doctor, too, G-d bless him, yet he didn't even graduate from high school. He somehow received an imaginary doctorate degree, compliments of schizophrenia. I don't argue with him about it because it comforts him and enables him to feel better about himself. He knows it all and doesn't have to or want to learn anything else. We can thank the schizophrenia for that, too. And, indeed, not wanting to know is indicative of mental illness, because learning helps to put all the puzzle pieces together in the right places so you don't have to struggle to make them fit. They just do and it all works out.

If everyone in mental health, with all the knowledge they've each accrued, would work together with the parents and relatives of the mentally ill, who have also learned from their own life experiences as well as school, and could communicate and share their composite knowledge with each other, a lot of issues could be solved. Of course, that means that physicians and administrators, who are more studied in the field, would still have to respect the learning that parents have ingested over many years, from being around, teaching, observing, helping and communicating with their ill children, and be willing to find out, ask, listen to and understand what the parent needs and wants to say. That way, doctors wouldn't have to limit their knowledge to textbooks, and only what happened at the previous admission to their own hospital, but could expand their knowledge of the patient to what happened at other facilities as well as at home. And they should welcome a bigger data base so they don't have to figure out what's going on by trial and error, because over the years, what they are about to try may have already been tried, and there is information available that the physician should and would welcome so they don't have to again put their patient through what didn't work before.

"In the end" we have to "be humble enough to find our way forward," I heard Nancy Pelosi say, under the leadership of the new Speaker of the House, John Baynor, as I lay exhausted from the experience of trying to figure out how to get my son to the dentist. While watching Baynor accept the gavel of the newly elected 114th Congress, I heard someone say, "This is the day the Lord hath made; let us rejoice and be glad." "Amen," I said, acknowledging, too, that whatever happens is what happens, yet where there is life, there is hope. What Pelosi said of course pertained to the democratic system: a hope "that the ideals that unite us are stronger than what divides us." Then Baynor expressed a wish that, "All I ask is that we disagree without being disagreeable." It was then that I realized they were talking about the mental health system, too, because all of those expressions were for the purpose of working together to "preserve the things that we hold dear." Although mental health doctors, nurses and other workers in the system chose that occupation for their own good reasons, parents didn't choose to donate their children to the study of mental illness. The children simply became ill for reasons unknown, and parents were made to suffer along with them. Therefore, parents also are a part of the system when their children, the patients, are involved. So, the parent is also a customer in the system to be treated with the same respect and courtesy with which the patient is supposed to be treated. The parent can be of assistance to the treating doctor when the patient is too ill to know the answers. And that's why parents need to be included in the conversation. And that's why there needs to be a conversation between family member and doctor, before any decisions for treatment are made by psychiatrists. "Humble" refers to the doctor's attitude so that he can sit down with the less educated, but involved parent to develop a plan for recovery that will enable the patient to be the best he can be. We all have to work together like they do in Congress and "disagree without being disagreeable."

The Subpoena

The Public Defender, Mollie McClure, called back to say I had to talk to the public guardian and ask him to call the County Council to ask for a subpoena for the doctor. Shortly thereafter, Renzi, the conservator, returned my call to say that he called the dentist and was told she wouldn't be in until Friday.

"That's odd, because she doesn't make appointments on Fridays," I said.

"She won't be in tomorrow and will be in on Friday," he repeated. "She has to be willing to testify in court. If we are able to do that we can pursue this. I'm just calling you back."

"Personally, I don't think this is something she would be willing to do," I said. "It's not like I've been her patient for 20 years. I'm afraid she would have to be compelled to testify. So, Molly McClure said I should ask you to speak to county council."

Then, Renzi said, "I don't do that. You would have to talk to County Council yourself," he insisted, so I asked him for her contact information which he gave me saying, "Shanna Connor can get the subpoena if Dr. Sharma won't come into court on her own." Renzi said he has "to interview Alex and submit my report along with the medical authorization in order to get the court order. You have to go through steps 1 & 2. It's a procedure, (that has to be followed) in order to get the order that it's a medical necessity." He was educating me about all the work that goes into it. I couldn't help but wonder why he

hadn't educated me earlier about how to do this. We'd spoken enough times; he already knew the situation.

I apologized for the additional burden on him and asked him why they couldn't just use Skipe to allow the judge to witness what the dentist had to say. I had already been part of a court hearing several years before, after my automobile accident, where the opposition's attorney was only present by using a phone.
He said, "That's not how it's done. So *you* would have to speak to County Council," he repeated. "They can't justify having it done if they can't get a court order."

Shanna Connor returned my call Thursday, too, while I was in the dental office lobby, talking to Dr. Sharma's accountant who was sitting in Natasha's usual seat, which cut our conversation short, so I just gave the accountant a copy of the journal instead, to explain everything to Sharma, so she could get a sense that it might be important for her to testify, and hurried down the stairs from the office still on my phone. I told Connor that Renzi said that I had to call her. Her reply, "He told you that?" made me sense that she was taken aback. My guess is that Renzi isn't an attorney so I can't blame him for not knowing the rules. I'm really not trying to blame anybody; I just want to get Alex to the oral surgeon before his life becomes more intolerable. I briefed her about the doctor having just lowered the dose 2 nights before, so that maybe he'll be able to have better judgment without even needing a court hearing. She was a good listener, had an empathetic sound to her voice, which indicated to me that she had a handle on the situation and said she would be in touch.
I didn't visit him on Tuesday night because I was too tired after spending all day running from dentist to printer to dentist to court to doctor to meeting friends for lunch in Berkeley and back to Villa in San Leandro, but I did catch a glimpse of him walking in the patient corridor. He looked like he'd looked all weekend: aggravated, focused on his thoughts and frustrated. It wasn't visiting hour, neither when I met with the psychiatrist nor when I returned again from lunch to retrieve my pocketbook that the receptionist, Veronica, had saved for me. They do have a few nice people working there. And I didn't plan to hang around for four more hours until the evening visiting hour. I could barely work up the energy to drive home again after the 2nd trip to Villa. But by Thursday night, January 8th, when I did visit him, Alex was already looking and feeling better. I texted Brenden:

> I saw him tonight. It's 22 hours after he got the first 15mg. pill. He was very subdued but aware and loving. He noticed changes in himself, saying they were on the inside, because he could feel it, rather than on the outside where you could see it. I think he said his color changed on the inside, but not on the outside. At first he was saying his skin color went from normal to green, and I felt faint, before he told me that it was just on the inside.
>
> When I first arrived, he asked if I would mind watching TV before he came out to visit with me, because he had to finish meditating. He was nice about it rather than rough. On the higher dose, he'd usually be downright rude, telling me to leave his room because he was meditating. Then, he said I must be his great grandmother, Joan. I felt like it. At least

he recognized me, more than he did before. I noticed he was more calm; before he was always on the verge of angry, after being on the higher dose for 3 months. He seemed relieved now, more relaxed.

He did a lot of talking. I wish I could have written it down, but he couldn't lend me any of his paper, he said. Apparently, it was too valuable. He was carrying his file folder filled with papers with several words listed in a row, and neatly piled on both sides of the enveloped folder, as he stood talking to me, showing me the words, telling how he was able to write today, whereas he hadn't been able to write for a long time. I asked how long a time, and he said "a few months." That itself, was telltale because that's how long he's been there.

Friday, January 9, 2015

I did go there again tonight, just to check on him, and I guess I shouldn't be surprised, but I am. Yes, he looked and sounded better without the high dose of Zyprexa on Thursday night, but how will we really know it's because she lowered the Zyprexa to 15mg., or if it's because she raised the Abilify dose by 5 mg. By Saturday afternoon he didn't look as well on the 7.5mg. Abilify dose given on Friday night. He wouldn't get out of bed and lay there biting his nails obsessively.

1/5/15	Monday night:	20mg Zyprexa	2mg Abilify
1/6/15	Tuesday night:	0mg Zyprexa	2mg Abilify
1/7/15	Wednesday night:	15mg Zyprexa	2mg Abilify
1/8/15	Thursday night:	15mg Zyprexa	5mg Abilify
1/9/15	Friday night:	15mg Zyprexa	7mg Abilify
1/10/15	Saturday night:	15mg Zyprexa	7mg Abilify

Dr. Dovale hadn't informed me that she was going to raise the Abilify dose at the same time she lowered the Zyprexa. I didn't even talk to her about Abilify. Why would she raise it? First of all, how can you know what's causing what, if both medicines change at the same time? I only learned about the Abilify tonight, Friday, when I watched Alex take the medicine at 8:30pm and asked Nurse Jess what she was giving him. It's hard to pry the information out of Jess. You have to name each medicine and ask how much of it he's getting and what day each dose was started. Just asking, "What is he getting?" doesn't enable her to tell the whole story. She's less than attentive to what I need. I wondered why. I also wondered how high they were planning to go with the Abilify. I thought it was high enough already at 5mg which was administered the night before I talked to him. And I do know that 10mg was as high as he could stand it, when it was administered in combination with 17.5mg. Zyprexa and 100mg. Clozaril, by Richard Slawsky, M.D. in March, 2007 at John George. That was the best I'd ever seen Alex. But, when it was finally tried again by BMH's Dr. Fuchs in 2010, he wasn't as good on it. So, I need to find out how high she planned to go. We hadn't discussed replacing the 5mg. of Zyprexa with 5 more mg. of Abilify, but apparently, that's what she did. Maybe she was trying to do what she thought would work best for him. I'm not questioning her intentions, I am questioning why she didn't say anything about raising the Abilify because finding the best combination of meds for Alex at this time, wasn't the point.

We've been trying to do that for almost 20 years and we still haven't found it. What the point was and still is, is to put him back on the dose he was on when he made the decision to go to the dentist on October 7th. I guess Dr. Dovale didn't know that. And now she's gone. But, her legacy lingers. The new psychiatrist, Dr. Beatty, who will come into play next week, will no doubt think that the addition of more Abilify was necessary, so he'll think about increasing it, too. Of course, I'm just projecting. Who really knows? Dovale told me last Tuesday, January 6, 2015 that she'd be leaving the next day. Jess also said that there is no doctor on staff right now, not until sometime next week. I wonder if their accrediting body would find that OK, to not have a doctor on staff for almost a week. Although she presented as a more concerned physician, she was no better than the others as far as communicating with the family is concerned.

Apparently, none of them are to be trusted. 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 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 effected 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 effect 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? And 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 to 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?

In chapter 8 of <u>When Someone You Love Has A Mental Illness</u>, Rebecca Woolis writes: (p. 190, 191)

> Few programs, or even hospitals, for people with a mental illness have well-developed statements of philosophy or guidelines for the staff's contact with families. Even fewer have thought about what the role of family members could be if we all worked together toward the same goal.
>
> Let us assume that we all want people with mental illness to function as well as they can and to have the best relationship possible with their families. This could most likely be achieved if programs and hospitals interacted with families in the following way:
>
> 1.During the admission procedure or preadmission screening (if one exists), prospective patients/clients would whenever possible be advised of the program's policy and philosophy of maintaining contact with families.
>
> 2.Admission agreements would reflect this philosophy.
> 3.Families would be contacted when a relative was admitted. Information about the program and how families could participate would be provided, both in written form and in family orientation meetings.
>
> 4.Background information would be requested from the family.

5.Education about mental illness, support groups, and family skills training for dealing with a relative who has a mental illness would be provided for families; alternatively, referrals would be offered as to where such education and support could be found.

6.A forum would be established whereby periodic exchanges between family members and treatment staff would occur in order to:

- •inform the family of the current focus of treatment and what the family could do to support it
- •share concerns about the patient's progress
- •update one another on discharge plans

7.Whenever treatment conferences were held, consideration would be given to inviting family members or soliciting input from the family. Significant results of such conferences would be conveyed to families when no family member attended.

8.Families would routinely be informed of any significant changes in the status of a client in the program.

The above quoted book was first published in 1992, 23 years ago, so the information isn't new, yet these things are still not done at Villa Fairmont or even Herrick Hospital at Alta Bates, for that matter, because it's not mandatory. Hospitals only have to follow the law. Apparently, they get out of doing whatever they can if it's only humane to do it.

Secondly, how can Telecare Villa Fairmont be allowed to operate a facility like this anyway, the way they do...having doctors work there for only a month at a time and then leave? What kind of continuity-of-care is that? Operating in this manner doesn't even give the psychiatrist time enough to get to know all their patients. There's up to 36 patients under one physician's care on C-Wing alone. It should be outlawed. There can't be appropriate care going on there with their 'a-new-doctor-a-month-club' operation. And the reason Villa can't get qualified physicians to choose to work there long term, should be investigated, too. They are just stabbing in the dark. Maybe Dr. Dovale wasn't so good after all. For sure, it was sneaky to raise the Abilify without explaining why, while she hoped my advice to lower the Zyprexa was correct! It's important for Alex's *LIFE*—that is, so he can stay alive until a better medicine or cure is discovered—to make the dose as *low* as possible to medicate the schizophrenia, *without causing additional side effects from higher doses*—so he can again have the good judgment to go to the dentist.

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. 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 way 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. And the family is usually available and anxious to consult, especially when their family member is so mentally ill that he doesn't even know what medicine he's getting and can't speak for himself.

Tuesday, January 13, 2015

I got up early again to get to the printer when he would open at 9:30am, but he was no where to be seen until an hour later, so I just waited in the van editing. And his stick drive wouldn't take the information from my computer so I had to print an older edition. When I arrived at Villa just before noon, knowing I'd be too late to talk to the doctor, the meeting day had been moved to Wednesday, anyway. One would think they would have informed everyone ahead of time. I gave a manuscript to one of the nurses to give to the newest psychiatrist, Dr. Beatty. I'll check tomorrow if he gets it, when I again try to go to the meeting. While talking to Danielle, I was informed that the previous doctor, Duvale, *was*, indeed, told about the reasons that I wanted the medicine reduced. Dr. Duvale told me last Tuesday that she had only heard that I wanted the Zyprexa reduced to 15mg, but was never told why I wanted it reduced. But, Danielle said, "She knew." There you go. That slight discrepancy tells it all. It says they don't even listen to each other. It says that the information that they get from parents has no value. It says somebody's lying. I could read a lot more into it, but I'm not going to waste my time. The medicines that patients get just aren't that important to the people who are responsible for prescribing them. They just don't care if it's the best dose, so they simply keep the dose high so patients are less of a problem. I don't even want to think about it anymore. If Alex goes blind or gets otherwise hurt, they will bear the responsibility. That's all I know.

I did get a chance to stop at the San Leandro Police Department to ask them if they could help me get Alex to the dentist, but she said it's not in their jurisdiction. She referred me to the Alameda County Sheriff's Office down the hill from Villa. Since I'd already been told by a clerk there that they couldn't help me with him, I wasn't sure. But, I went back anyway and presented my case to a different officer. She said to call the desk on Thursday morning and explain what I want them to do, and they might be able to get an officer to talk Alex in to getting into my car to go to the dentist. At least to get him in my van so we can go to the 4th appointment I'd made to see the oral surgeon. Both police offices were very nice about it.

Getting A Sense Of What To Do As We Close In On Four Months Since The Antibiotics Were Administered

I called Kaiser and spoke to an ombudsman in San Leandro, Kim Welty. She listened. You can always feel the compassion when someone cares. She suggested that I "might need to step back and focus on his dental care, on how to collaborate on how to do that. What do you think might help him in being more participatory in getting to the dentist." She said I "might want to put a meeting together with just the doctor, the social worker, Brenden, myself and Alex, so that it would look important to Alex to talk about the tooth."

In the meantime, I had to cancel the dental appointment for today, Thursday, January 15th, because when I broached the subject with Alex yesterday, he nixed it immediately. He's not going to the dentist, he said assertively. He just doesn't hear the rest of the story about the infection waking up and going where it will. He's not in pain, so he's convinced he's fine. Of course, they bolstered his confidence with the additional 5mg. of Abilify as she reduced the Zyprexa by the same amount. But, I think Abilify is a stronger medicine because you don't need as much. So, we're pretty much back to where we started. Thank you Dr. Dovale. Dr. Knolls' assistant was very nice about it again, and we made a new appointment for the end of the month, the 26th, exactly four months since the end of the antibiotics. Is it possible that it's not coming back? Would dentists just say that it comes back to bolster their business? I can't imagine that. And, certainly, my best friend's husband, Steve Gurzoff, D.D.S, who was the dentist Alex saw when he lived with them in 1996, just after he first became ill, would have no incentive to lie about it. No, the infection is coming back.

Monday, January 19th, Martin Luther King, Jr. Day

The infection must be moving to his brain because in the last few days that I've been visiting, he's been very hard to have any conversation with. Like, there's nothing left of him. He just lies in bed while I visit and doesn't say much. He needs to get out of there if they can't help him. The higher dose of Abilify which, I'm told, is still at 7.5 mg, has not helped and is not making him any better. They should make the Abilify disappear because he's worse. And maybe he's worse just because of the Abilify. Hopefully, Shanna Connor, from County Council, will return the call I made to her on Friday, before the long weekend.

I became really upset tonight and called Villa at 10:30pm. Jennifer, his evening nurse, told me that the Abilify was DC'd at 9:30am this morning, but he did take the morning meds right before the doctor wrote the order, and he won't get any more. Dr. Beatty discontinued it. Thank G-d and YEA! for Dr. Beatty. So, Brian was wrong. Again, it appears that the doctors *can* read, and *do* read when they want to. OK, now we'll see. Maybe I should pay them for the past two months that I've been withholding the money. No, I said I'd pay them when they get him to the dentist. That's the objective…the dentist.

Tuesday, January 20th, 2015

Arriving on C-Wing, I found Alex up and busy doing his writing and making lists of pertinent words at 7:30pm, only 11 hours after not getting the 7 mgs of Abilify. No longer bedridden, he was able to eat the salad I'd bought at Kaiser's cafeteria after my x-ray. Maybe he ate it because it was packaged as a purchased salad instead of the similar, but homemade one I'd prepared and served him in a plastic container the night before, which he didn't eat. One of the girls, Shannon, who likes to talk, hung around in the living room area as he ate standing at the counter, and moved next to him as he was finishing, so he took the clue and gave the rest to her. I hadn't brought much, just one salad, and we were sharing it, but he doesn't mind giving away his own food to whoever asks.

Wednesday, January 21st, 2015
AM: Metropolol (50mg.) plus a new bi-polar med
PM: 8:30pm: Fish oil (2 large capsules), Depacote (2 x 500mg. tablets), Zyprexa (15mg.)

Compassion and how it seems to work

Dr. Yonabayashi's office woke me up at 9:30am, because the Kaiser ombudsman, Kim Welty, had called her. Gosh, they do have humanitarians there, after all. Her medical assistant gave me the names of two doctors who were somehow connected to Kaiser that Alex could use at Kaiser:

Dr. Hipolipo in San Leandro @ 510-352-2632 and Dr. Patrick Creevan in Livermore @ 925-443-5980 who works out of Pleasanton and Santa Clara.

I could tell Welty was compassionate from her tone even though she had advised me that he would have had to be in a Kaiser facility for her to help. But, that's what compassion does. It hangs around in one's head longer than just the first moment it hears of a problem, way longer than it has to. Of course, since it's already implanted in the heart, when it hears a sad story, the vibrations go to the brain to be instructed as to what else it can do, and then the impulses arrive at the finger tips to dial the numbers that connect to whomever can help. So, it's not just the heart, but the head, the hand, the ears and sooner or later it takes over the whole body, doing what it can to solve the whole problem that had at first touched just the heart. And that's how compassion works, because I don't know Kim Welty, and she doesn't know me. But, compassion doesn't have to know. It works alone, in the darkest hour, when the less than compassionate are still asleep.
By the time I got to Alex, he sounded much happier. I couldn't make sense of what he was saying, but at least his demeanor was pleasant. And he said a few times that he's ready to come home.
"I feel perfect. I'm healing the world. I keep it safe around the house. I'll be with you soon. Try to break out of that cycle. Whatever is puzzling you. You can use Alex resources. I have everything you need to survive. I just found a new lava. It's gonna get you worked up. It breaks down and becomes love. That's in Sinai-i. My mother, 'Crystal', borned me as a key. That's what a heal is, and when a key is in good condition, they can heal everything. But, I can't heal with all the wine in the house; you

have to take the wine out. When you used to come in from Sinai-i, it used to glow."

Thursday, January 22nd, 2015

Alex made an announcement when I first walked in tonight. It was unexpected, 'though not surprising. He said, "I'm ready to come home." He was very talkative and explained the workings of the world to me. The reason was simply that the medicine had stopped bothering him. It had been a muzzle keeping him silent, holding him down, making him bite his fingers incessantly while he contemplated the inner workings of his thoughts. Now he's free of the overdose. He insisted that I walk with him up and down the halls while he explained what was going on.

This was one of many statements he made to me: "I'm seeing signs of grandma. Her getting through has to be in space…by somebody…and it's great grandmother's flying truck." He's still not making enough sense for the normal world, but at least he's able to verbalize what he's thinking. He's had a lot to say since the Abilify was discontinued. You can bet he was still thinking these thoughts at the higher doses, but he was too under-the-influence of the chemical assault to speak.

The Customer

Who is the customer for psychotropic medicines? Whether one says the "patient" or "society," the basic question that needs answering is 'Who is the customer?' Are psycho-pharmacutical companies providing the arsenal to immobilize the mentally ill because CEO's think that's what society wants? Or is the government going to organize itself to help the mentally ill because they realize the ill are the actual customers, the ones who are suffering, and need help? Shouldn't we be vigorously trying to research and invest money into finding the causes of mental illnesses and to find the medicine that works in order to make the patient able to cope with life instead of escaping from it? Can we spend money to invent medicines that will help ill people to see reality? Or will we just continue to use the mentally ill for humor-filled hours of TV comedy as the official Berkeley station comedian did last Halloween? If we say "society is the customer" then here we are. This is what we have because that is what many doctors are presently thinking or doing: keeping their patient subdued, quiet, still—a prisoner of his mind, thanks not only to the disease, but to the overabundance of medications poured into his body—altering his brain chemistry, not to help him, but to help the rest of society by putting the sick person out of commission with higher-than-necessary doses of medicines that don't work anyway—that haven't even been designed to cure the particular mental illness. How could they have been invented to help, eg. schizophrenia, if the psycho-pharmacologist, the psychiatrist, the researcher doesn't even know the cause of the illness? It makes sense, that one has to know what cause one is trying to eradicate, in order to find the appropriate solution, doesn't it? As evidenced in a recent script made into movie episodes—when the criminal was caught, the FBI agent threatened to recommend a mental institution instead of jail, so the killer could be overdosed and unable to escape—showing that everyone knows and accepts that it's OK to do that.

Saturday, January 23, 2015

Last night I arrived at Villa just in time for the evening administration of meds at 8:30pm. They were the same medicines, but this time I asked about the morning medicine since I can never be there at 8am. She was coy, Jess, saying a word that didn't sound like anything close to the Atenolol that he used to get. I asked her to repeat it a few times, until finally, she shoved the paper under my nose. "Metropolol," I read. That's fine, I thought, remembering that Nicholas changed it from Atenolol, when Nurse Jennifer wouldn't give him the 25mg. night-time dose, because he refused the blood pressure cuff at night, after already having the pressure taken it in the morning. Metropolol was OK, I thought. "Anything else?" I asked, to continue the pursuit. She said another word that I couldn't quite decipher, so I asked again, and she added that it's a "mood stabilizer."
"What about the Depacote?" I asked. "Why does he need two mood stabilizers?"
"I have to take the next patient," she said, to avoid revealing any further secrets.
OK. What's this about? I didn't want to hang around just to find out. I'd heard enough anyway. I could smell something wasn't kosher and really didn't want to know. I didn't want to get upset again. I was only there to make sure Alex is aware that he has another appointment with the oral surgeon for Monday. I'll have to read the Amador book, I'm Not Sick; I Don't Need Help, to learn how to say the right thing to Alex so he'll go. Because when I mentioned another appointment, as I said good bye to him, he followed me to the nurses' station and leaned over the counter blurting out for all to hear: "I'm not going to the dentist!" OK. I'll have to check what this new morning medicine is. I replied, "You can't come home without first going to the dentist," and walked out. My plan now is:

Call Sheriff's office Monday morning to see if a policeman can come over early Monday afternoon
Get Brenden to come over
Find out if this new medicine is inhibiting him. How long ago did they start it?
Google the new med
Send Jerry a manuscript and ask if he would come here to talk to Alex.

Sunday, January 25th, 2015

Patient's Right to What?

Does 'Patient's Rights' mean that he has the right to commit suicide? Because, if he doesn't get the infection out, suicide or blindness or some other horrible consequence, that he is not fully aware of, may be on the agenda. Tonight when I broached the subject, he just replied that his "grandmother will take care of it, because I'm flying her star and she won't let it get bad. She'll handle it."
I told him, "I heard her say you should go to the dentist." I sometimes get on his wavelength to see if he'll buy it. He replied that he can't go to the one by Alta Bates, letting me hope he might go to a different one. It sounded hopeful. The one who is waiting to see us is in Alameda, I informed him. So, that's the first I've heard him say anything without an emotional charge. He wasn't his usual angry, just said he'd rather

not talk about it, so I said I'd be back tomorrow.

I need to leave another message with the County Council, Connor. Maybe she'll show up tomorrow to help get him out. I'll definitely call the Sherriff's office to ask for a police officer. Maybe text Brenden to show up, too. I still couldn't get Jess, the nurse, to tell me about the new medicine he's been getting every morning. She was evasive again, saying I should go to the recovery meeting and ask the doctor. I reminded her that I have Alex's permission to know, and that she, herself, can tell me. "Are you refusing to tell me what's in his chart?" I said. Finally, she replied that she's not really his nurse tonight. So, why didn't she just tell me that first? Is she making a show to entertain her co-workers? Oh, now I get it. Jess had been one of the nurses sitting in at the first recovery meeting where Freeman, M.D., was successful in disrespecting me in front of the staff, so Jess feels that she has the OK to continue that disrespect and indeed, has been mocking me continuously since then. "Jennifer is (his nurse), and she's on break," she said finally. I looked at the clock: 7:30pm.
So, I said, "I guess I'll wait 'till Jennifer comes back," and turned to leave.

Another nurse opened the door for me taking the opportunity to remind me that, "We have to respect Alex's right not to go to the dentist." I didn't reply because I didn't know her, but it sounded like they had all been informed of Alex's situation in regard to his rights. I wanted to know whether that right that they were espousing was the right to go blind or to die. Because Alex has said on numerous occasions that he wants to live. In fact, that he expects to live "forever." So, to set the record straight, he has no inclination towards suicide, yet this abscess problem could take him to that destination: dead. Therefore, I resolve, this is not about his right to die, because he's not ready to die and doesn't want that outcome. I doubt if he expects to go blind either, but that could happen, according to the dentists. Therefore, I contend, it's not really about his choice to go or not to go, to the dentist. It's about his right to see, to live, to have healthy organs without them being infected and causing difficulties for him. And he wants all of those abilities. He has never said nor indicated in any way that he wanted to not be able to see, or didn't care if he were blind or not.

So, this issue doesn't fit into those niches. Going to the dentist has nothing to do with his rights. He just hasn't been made to understand. It's hard for him to understand because either the schizophrenia or the medicine is standing in the way. He's not buying in to the idea that he has a problem, without either having the pain again that validates the infection, or without having the proper people who he respects, explain it to him or ask him to do them a favor and go with them to the dentist. And secondly, he doesn't want to know. He said, just this week, during one of my lectures, that "no one can predict the future." And that's not exactly true.

After waiting twenty minutes in the lobby, I decided that I'd waited long enough and left, bumping into the very same Nurse Jennifer outside as she was carrying her dinner tray to her car. I took advantage of the moment to ask her if she remembered what new medicine Alex was getting in the morning. She didn't know off hand, she said, and was "just leaving for dinner break." I couldn't help wondering if this moment were the actual

beginning of her dinner break even though Jess said she was already on it 20 minutes before. I didn't pursue it further.

Monday, January 26th, 2015

Today was the day of dental appointment #5. I still had hope. Today is also 4 months to the day since the end of the antibiotic treatment and the last dental appointment that I'm going to make. Apparently, the abscess can take more than a few months to wake up and do damage. Alex was surprised to see me so soon after my last visit, only 18 hours ago, when I brought the weekend pizzas. He figured something must be up. I called the Sheriff's office and was put through to the sergeant who listened to my plea. He didn't interrupt. It was almost noon when I called, but he said to proceed in the following manner: I should try to talk to Alex myself first, then, if I didn't make any headway, call back and he would find the appropriate officer to go to Villa. It sounded hopeful.
I brought Alex some photographs that Uncle Jerry had taken 30 years ago when Alex stayed with him most of the school year that I came to San Francisco, but it didn't relax the atmosphere. I was trying to sweet talk my way into his heart. I said, "Let's go out, it's a beautiful day." That didn't work either. I couldn't find Xavior Amador's book last night, I'm Not Sick; I Don't need Help, in which he explains the four-step process to engage the ill person in conversation. So, I just blurted out what I came there for: "You have a dental appointment today."
"No, I don't need to go to the dentist; I'm feeling fine." I guess giving him his own pizza last night didn't earn me any points.
"Well, don't look for me to take care of you after you go blind. I can't do it; it's too much work."
"I don't need your care; I just need a home and everything that helps me hold a star. (Even) babies know if they're sick; babies know if they're well. I feel good!"
"Dentists know that the infection will come back."
"Nobody knows the future, Joan."
That was about all I could take. I gave him some chocolate and walked into the hall to call the sheriff's office back. I'd already hung up with the sergeant before heading south on route 13 and he'd directed me to first try on my own, then to call back if I needed help, and I'm the first to admit that I do.

The sergeant said again, that he'd find someone to put in an appearance saying the officer would be right over. I thought I'd better go out to meet him at the entrance and asked the receptionist to ask Danielle, the social worker, to come out for a heads up. What Danielle had to say surprised me.
"I talked to management 2 weeks ago and they said you can't bring the police here."
"Who said that?"
"Karen, the director of social services, and Brian, the clinical director. They said you can't have the police come here to force him to go to the dentist."
I said, "I can't believe they would rather he go blind." I also wondered why she never told me that until now. There's just no regard for the parent.
She said I should talk to the director. They have so many directors at Villa, I didn't know

who she meant. "Kate Jones," she said. I couldn't believe that Danielle was telling me that Jones didn't want the police coming to see Alex, so she went into the director's office and came out to let me know Jones would see me. Somehow I don't think she's on my side. We walked into Jones' office and I said, 'hi' to her secretary as we moved past to Jones' desk.
Meanwhile, I had already made the call back to the sergeant before I even saw Danielle in the hall, and he was dispensing an officer to Villa as we were in Jones' office.

She told me the same thing Danielle had just said, first limiting our conversation time to 10 minutes, she said, because she had a meeting. There wasn't much discussion. There was only what she had to say about it, that she wouldn't let the police in to see Alex, to help me get him to the dentist, she said, because the police would "intimidate" him. The only 2 reasons, she explained, that police could come in to the facility at all, are if a patient had left against medical advice or if there were a fight that the staff couldn't handle. She felt that police presence would intimidate the patients. "It's not police business," she said.
I interjected that the police had made it their business, so it must be police business.
She didn't want to pick up on anything that I said. Sometime during the meeting, Jones did comment out of the blue, "You went to Telecare," but didn't go further. Apparently she wasn't enamored with my calling Telecare Corporate Offices for a complaint against Villa. I had gone over her head. But, they don't make it easy to find out who the head is. I couldn't find her name on their web page. I asked people at Villa first, who I should talk to, and her name never came up. Brian didn't tell me, nor Danielle, nor Yolanda or Bruch.

Villa's Ideology On What is "Police Business

So, Director Jones was refusing to let it happen. And the sheriff was my last resort. She inhibited me from trying to get him to the dentist by using the police because, she said, the sheriff "would intimidate him."

It had taken some work on my part to even arrange for the police to come; four trips to three different police departments whereby each time I had to give a presentation explaining why I needed help. That was emotionally draining. First, I went to the Berkeley Police in December, because they were the ones who were able to get him into my car a few years back to go to a doctor's appointment. Their officer told me over their intercom that "It's not in our jurisdiction. Try San Leandro." So, I went to the Sheriffs' Office in San Leandro and told them I needed help. She wasn't impressed and asked why he was in a mental hospital to begin with, throwing the guilt trip on me. I stopped trying for a while until January, when I remembered that she probably meant the San Leandro Police Department, not the Sheriff's Office. By this time I was getting better at coming right to the point. But the officer in San Leandro had said the same thing as Berkeley's officer: "It's not our jurisdiction." She continued, "It's the Alameda County Sheriff's Office," after picking up my journal to show to her supervisor.
"Oh, dear," I said, "But, I was already told that they couldn't help me." I could see by the way she was flipping the pages of the journal in front of her boss that she really wanted to

help. OK, so maybe I could talk to someone else at the Sheriff's Office, I thought. I went back again later in the week for another plea. The officer gave me their business card saying to call that number on the morning that I need an officer to come to the hospital. She was very accommodating.

Back to the director's office. She didn't want to intimidate Alex, the director said, as we sat around her desk. Apparently they are afraid of Patient's Rights, I could only conclude. "There's no reason for us to do that," she explained. "I wanted to give you our facility's (policy) from a client's rights perspective. It would be against our policy to let him intimidate Alex."
"Why does it sound like he would be intimidating? As I explained to Danielle, the Berkeley officer got him into my car and Alex was glad to do it. Alex wasn't intimidated and the officer wasn't intimidating. The officer said, 'Do it for me,' and Alex felt good about doing it."

Apparently, it wasn't up for discussion. She just wanted to assure me that they would watch for the infection coming back. "Our clients are evaluated on a daily basis and if it gets exacerbated, we will take him." She wasn't planning to discuss the definition of intimidation. She had already said that I could have only 10 minutes of her time and time was about up.

What is she doing as head of a hospital when she doesn't value the lives of her patients? I'm trying to get my son to see the value of getting his abscessed tooth fixed before the infection returns, and she doesn't even see the value. I can understand Alex's reasoning, because he's sick and thinks he's a doctor and has everything under control even though he didn't graduate from high school. But, what's her excuse?

They seemed to be more afraid of Patients' Rights infractions than they are concerned with patients' health. Jones let me know that this is a hospital, and patients are, therefore, observed every day. So, when the infection again shows up, they'll be right there and will whisk him off. I wanted to see what that scenario would look like because I don't want him to have a heart attack from the stress. Firstly, where would they take him? To Eden's ER again, where there is no oral surgeon? for another course of antibiotics to decrease the ability of the antibiotics to work? I wouldn't put it past them to do that. They certainly haven't asked for a conference about it. I imagine they don't want to say what they're going to do because that would mean that they'd have to do what they said. Then again, maybe they aren't used to doing what they say because, for example, even though I had informed Alex's nurse about his dental appointment a whole week ago, and she said that she would put it in the chart, there was no note in the chart about his having an appointment today. So, that's how much one can trust them to do what they say they will do. In any case, this 10 minute meeting was only to let me know there would be no sheriff.

And Why Wasn't The Decision To Nix The Police Told To Me Earlier?

What I didn't understand was that I had informed Danielle at least 2 weeks previously that I wanted to try the police tactic. In fact, when I told her about the nice Berkeley Police Officer story, the one who had been able to get him into my van by saying, "Alex, would you do it for me?" Danielle told me that I'd already told her that story months before. When I saw her in the hall today, I said that I'd already connected with the Sheriff's Office and they were willing to help. It was only then, that she told me she had brought it up to her director, Kate Jones, 2 weeks earlier. I couldn't believe she was telling me this now, after I'd been to the Berkeley Police, the San Leandro Police and the Sheriff's Office twice, to figure out how to put this together, since I first spoke to her about it. I couldn't believe she was telling me two weeks after she spoke to Jones, as if it didn't matter that I would have needed to know then, too, so I didn't have to put myself through this, to say nothing about putting the police through this. "This" being traveling to all those places, explaining the situation to more than half a dozen people, making 4 pleas in person and more over the phone to various officers. It was draining, especially when I had to tell the story at their windows in front of several witnesses:

> Do you have a department in your organization that does good deeds for the community? I saw on the TV news where a police department in the Midwest had reduced their crime rate because the officers would go to peoples' homes and help them with whatever they needed doing. I need a good deed, specifically from a police officer, because my son respects the police uniform.
>
> My son needs to go to the dentist. He doesn't believe he needs to go, but the dentist says he could go blind or even die if the infection goes into the blood. He doesn't understand that because he has schizophrenia and the hospital where he is just raised the dose so high that he doesn't even know I'm his mother. So, he can't understand. He went to the dentist on 15 mg., then the doctor quit, but not before raising the dose to 20. So, he's too overmedicated to know. Yet, the same doctor wrote to the conservator that my son could make his own medical decisions. He wrote that on the lower dose, before he raised it again to 20mg.; then he left Villa. My son is at Villa Fairmont. I don't want him to go blind! I came here because once when I had a similar situation , trying to get him into my van to go to the doctor a few years ago, he wouldn't go, so I called 911 and the Berkeley Police Officer came over and said, "Alex, would you get in your mother's car and go to the doctor, OK? Do it for me! Thank you. I would really appreciate it." He said something like that. The "Do it for me" part was what got Alex right into the van with me so fast I didn't even have time to thank the officer. And he was so proud of himself, saying, "I did something for the policeman!"
>
> My best friend of 55 years is married to a dentist, who concurs with my son's dentist here, telling me it's a very dangerous situation if he doesn't go to the oral surgeon. The antibiotics that he got in September don't take the infection away. It's just dormant, like sleeping. And when it wakes up, it will go into the blood and get carried wherever…" bla, bla, bla.

It was very draining, embarrassing actually—especially the first time that I did it in person, at the very same Alameda County Sheriff's Office. That first particular female officer was not receptive to getting the police involved, so she asked,

"What's he doing in the mental hospital anyway?" It was the way she said it, very incriminatingly, that turned me off to going back there any more, after the San Leandro police officer said it wasn't in their jurisdiction; it was a county thing. But, I went. And the next young lady officer was much more responsive and compassionate and gave me their card, telling me to call the morning of the day he has his appointment.

How The Police Are Perceived By Villa

Jones did not want the police to be perceived in any other way except as para military, i.e., to scare and intimidate. That's the 'police business' category she referred to. Yet, recent TV news programs spoke about police helping the community, not only by keeping it safer by its presence, but by doing good deeds that community members couldn't do for themselves, and the statistics showed fewer homicides and break-ins because of it.

All I know is that I need to get my son to the dentist before he gets hurt. I'm not waiting for the infection to wake up. She said that they would be right on the case when it comes back, as if that's OK, just waiting for it to return, and while they wait, they are willing to take the chance that he goes blind. As his mother, I don't want to take that chance. That's where we differ. She's willing; I'm not. He's suffering enough. He doesn't need to be blind, too! Nor do they need to hurt any other organ either, if it can be prevented. And it would be easy to prevent taking the chance, simply by getting him to the oral surgeon since he's too ill to see the necessity himself. My question is, where on the dentist's letter does it say to wait until the infection returns and his face gets red enough to detect that he's in pain, because he probably won't complain to let them know.

> 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

Whatever other new mood stabilizing medicine that he's getting in the morning has to be stopped, so he can be able to make a more intelligent decision like he did before, when he was only on 1000 Depacote, 20 Zyprexa (right after 3 weeks on 15) and Atenolol . Why is he getting another mood stabilizer, anyway, when he's already getting Depacote, a mood stabilizer? She didn't have an answer. "Yes, I understand it's about the medicine," was all I got out of her.

The Public Good

Peter Drucker writes, "Make a list of 3 new services that have failed and will fail because you and your organization have ignored the public good." (The Practice of Management) And to what does Drucker refer when he speaks of ignoring the public good? It could be the spilling barrels of oil in the ocean killing off whole species of life, or it could be ignoring your own customers' needs to keep them safe while using your product or service. By not taking care of the mentally ill in the proper way, hospitals for mental health have become the problem rather than the solution. The proper way is to consult with the people who know the patient, besides doing the obvious normal research, before giving the patient medicine that's not effective, or that the client was allergic to the first time. The proper way is to dispense medicines that work. By not doing enough research into the cause of mental illnesses, universities and other research institutions are ignoring the public good. The government, by allowing this, and concentrating instead on helping the small percentage of wealthy people to increase their wealth, by giving them loans for free to build their huge enterprises, and enabling the rich to pay less taxes than they should, therefore, leaving health care funding organizations with insufficient monies to spend on inventing medicines that work to cure mental illness and restore lives to normalcy.

By ignoring the public good, America's safety has been jeopardized, as depicted in situations like Oklahoma City and Newtown and many more horrific crimes that could have been prevented, if the treatment of mental illness in America were important enough to politicians and other political servants who decide on the distribution of monies. Politicians need to rethink who should be bailed out and in so doing, give more service to the middle class, the poor and the mentally ill citizens first, by finding the best minds in our schools and giving them the financial incentives to invent the best, most appropriate medicines before the next family is made to suffer the consequences of the distorted thoughts and actions that mental illness brings to the unsuspecting.

Tuesday, January 27th, 2015

Court

Arriving at court by 9:30am, my intention was to give the journal to the judge. I knew that the court clerk had said they had their protocol about giving information to the attorney first, but that juncture had already passed. The Public Defender already had her copy for a few weeks. And then? Nothing. A call over a week ago from County Council Shanna Connor, saying that they're "working on getting Alex to the dentist." The other Public Defender, Peter Van Oosberg was at court today and said he'd heard the message I left last night. He made no other comment, but sent another conservator out to talk to me where I waited in the hall. I'd never spoken to this conservator, so I brought her quickly up to date, telling her I wasn't happy with the hospital director's plan to wait until the abscess returned. I told her it's not acceptable to me and not a humanitarian thing to do.

I said that I want him taken to the dentist *before* the tooth gets infected again, not *after*. They should be treating it as urgent regardless of Patients' Rights, and following the advice of the letter signed by the dentist. That letter didn't advise the hospital to wait, I said. Why put him through another infection when it can be treated more effectively when the tooth isn't infected? Why take the chance that he'll wake up blind if the infection attacks during the night? Then he'll get upset and who knows what he'll do. Who knows what will happen to him! He could have a heart attack! He gets upset when he's in pain. Why wait for the pain when it could be handled now? Jones doesn't want to deal with Patient's Rights advocates. Because of that, she's avoiding dealing with my son's health altogether. My son's health comes before his rights as a patient, because he's mentally ill with schizophrenia, and can't understand, plus he's overdosed with too much medication and can't make good judgments. So she's neglecting his health and taking care of her own issues at his expense. After hearing most of what I had to say she excused herself to get back to court saying she'd let her colleague, Mr. Renzi, know about my concerns.

I guess Public Defender Oosberg expected that I would have disappeared after talking to the conservator, but I was still sitting in the hallway when he came out after the cases were over. Holding up an envelope with an updated journal inside, I asked, "How can I give this information to the judge?"
He looked like he was wondering why I was still there. "Well, you would have to have a hearing." "And how can I make that happen?" I inquired.
"Well, you have to ask for a writ."
"We did that a few times," I said. "I don't think it's going to happen."

Bingo! The judge appeared in the hall. I recognized him from the peak I'd taken through the courtroom door earlier on. Between then and now, I'd been writing a brief note to him on the envelope as I waited…a synopsis of what was going on. The judge had the look that court was adjourned as he turned toward the outside door and said goodbye to the public defender. I popped up to keep talking to Oosberg, hoping that the judge would hear, about how I could get this packet into the judge's hands. The judge finally turned to ask the attorney who I was, and said he could only take it if Peter didn't mind. Peter didn't say that he objected, so, that was that. I think I said, "Bless you!" instead of thank you, and left it at that. He gave me a quick look, so it was worthwhile that I had dressed up a little, having swirled my neck with the Joan Miro printed scarf straight from the Joan Miro Museum in Catalon, that I'd never even taken out of my drawer these several years. I'd worn it as my good luck charm. I needed all the luck I could get. I'd also placed myself strategically in the proper place at the proper time. I don't feel that it was out of order, not any more out of order than the fact that the lawyers hadn't brought the situation to the judge in all this time. The lawyers are taking too long. The dentist doesn't want to be subpoenaed. Only G-d's been working overtime but, even G-d can't hold off the infection forever.

So What's Happening With The Subpoena?

The following is a phone message from Conservator Nicholas Renzi on Tuesday, 1/27/15

that I received in response to a message I left him very late on 1/26/15 after Jones wouldn't allow the sheriff to talk to Alex:

> Hi Joan. This is Nicholas Renzi calling you back from the Public Guardian Office of Alameda County. I got your message in regard to the dental situation for Alex. So, as it turns out, I actually did speak with the social worker, Danielle Vosberg, over at Villa Fairmont, and she mentioned to me that they've been monitoring him every day—vital signs, checking for an infection—and there hasn't been any issues at this time…
>
> I had spoken to her about a possibility of getting a doctor/dentist, of calling a doctor to testify in court, and she said that the only dentists they use are at Highland. The doctor from Highland wouldn't actually come to court to testify. I inquired with Dr. Sharma. Dr. Sharma wouldn't be able to come to court. And so, we've actually exhausted all the possibilities (of) getting anyone to come to court to testify, especially when Villa Fairmont is handling the situation for his dental needs, and they are monitoring him on a daily basis. So, I'm not quite sure what we can do past that. We're trying to get the doctor to come to court and getting another possible dental provider who may be available as well, so we're kind of at a standstill.
>
> You mentioned before that he is more agreeable at a lower dose, to go to a dentist. Maybe you can work with him, if he'd be agreeable at a lower dose, as you mentioned in the past. So, maybe that will help. I'm not sure.
>
> Anyway, so just getting back to you and giving you an update of where we are with that. We're kind of at a standstill. There's no other avenues—the dentist, the medicine.
>
> So, I've communicated all this information to Shanna Connor, at County Council, who's our County Council, who would be able to bring this situation to court, but she is not able to get the dentist to come to court, so that's where we stand.
>
> OK? Thank you.

I was under the impression that a subpoena meant that the person served would be compelled to come to court, as in would *have to* come.

Shanna Connor also returned my call on 1/27/15 after I'd left her a message similar to the one I left for Renzi:

> Hi, Ms. Miro. This is Shanna Connor, calling from the Alameda Office of the County Council. I received your message regarding your son, Alex Anderson, and my office is looking into the various options so I appreciate your help and your concern. Please know that the public guardian is aware of them, and I am aware of them and we're doing our best to serve your son. If you have any other questions give me a call at 510-272-6700.

Wednesday, January 28th, 2015

The recovery meeting was not something that I wanted to be put through again after the first one, but I went anyway. I recognized Dr. Beatty, Gene, a social worker, another nurse who was perhaps Metavina. I didn't recognize the gentleman on my left and no one introduced themselves. I started out on the wrong foot, thanking Beatty for lowering the

Zyprexa, when, of course, that was done by his predecessor. He corrected me amiably enough. I wasn't taking notes, nor did I have a recording device, so I only know what stood out. And what stood out in the conversation was their agreeing that Villa cannot and will not get him to the dentist against his will. They gave me the job to do that. Beatty suggested that the court might be the way to go and asked how the subpoena was progressing. I let them know, by taking out my still cut-up-and-glued, handwritten notes of Renzi's phone message above, and passed the paper to Beatty. The point was that there is no progress on the subpoena. The unknown man to my left, stated why Alex wouldn't go to the dentist: "He was in pain when he went to the dentist before and he's not in pain now." He seemed to understand Alex's reasoning and thought it was OK for Alex to make that conclusion that he didn't need a dentist. As a group, they all extended the best regards to me to find a way to proceed and left it at that. I didn't argue with them because I prefer to think about things first. They're entitled to their point of view, and it was unanimous: they're not going to make him go.

It's been about a week of thinking and what I can't seem to understand is, if he's in their custodial care and they have him conserved, why are they giving *me* the responsibility of taking care of him, both to convince him to go to the dentist and to get him logistically there? I don't work for them, and I'm only one person. My conclusion is that they should at least discharge him home, if they can't help, so I can have more influence than just the hour per day that I'm allowed to visit. In addition to that, their doctors are the ones overdosing Alex with their higher-than-necessary doses of medicines. When the last two doctors reduced one medicine to comply with my request, they secretly added or increased another. Dr. Dovale lowered the Zyprexa from 20 to 15 then raised the Abilify by the same 5 mg. Dr. Beatty lowered the Abilify by 7.5mg. but then added a second bi-polar medicine in the morning. Dr. Nicholas had raised the Zyprexa back to 20 after lowering for just 3 weeks before he left. And Dr. Freeman didn't do anything. So, while they continue to do the damage, they are asking me to get him to touch the ceiling after they've tied his hands to his feet, crippling his ability to think for himself, while they at the same time, insist that he can make his own medical decisions regardless of the doses they give him. Does that about spell it out?

It appears to me that they have the building, the offices and all the other accoutrements that make it look like they are helping patients, but, in fact, they are not helping my son. They are taking the easy way out and giving the responsibility to me. They are relinquishing their responsibility of helping him save himself from going blind or worse, by going against the opinion of the dentist who attested to the fact that he's in a dangerous situation on a letter signed by her, which is in their chart. They then, give the job of convincing Alex to go, back to me, while they continue to overload him with medicines that dis-able him to think straight in order to make the better judgment that he needs to make, and that he did make after 3 weeks on the 15mg. of Zyprexa and the 1000mg. of only Depacote. At the same time they are saying that they are all talking to him to convince him to go, but I have not seen that happen. They are never there when I arrive to take him for an appointment. Nor have they ever even called a meeting, as the Ombudsman, Kim Welty, from Kaiser, suggested: "You might want to put a meeting

together with just the doctor, the social worker, Brenden, yourself and Alex, so that it would look important to Alex to talk about the tooth."

Furthermore, in reference to the comment at the recovery meeting, showing their understanding of Alex's reasoning for not wanting to go: "He was in pain when he went to the dentist before, and he's not in pain now." That statement is actually not true! or shall we say, it may sound true to the sleepy, un-attending ear, but it's an incorrect observation. And here's the proof: When Alex went by ambulance on September 17th, 2014, to the Eden Hospital Emergency Room, the doctor gave him 10 days of an antibiotic which he would have finished on Sept. 26th, given that he took it that first night. That would have cleared up the pain, so that eleven days later, when he went to the dentist on October 7th, he was still not in pain, as he is not in pain now, because the administration of the antibiotic took him out of pain. So, the statement that was made at the recovery table, above, that everyone at the table seemed to be in agreement with, is less than factual. Perhaps their understanding of the situation is not as clear for them, because they don't dwell and obsess on it, as the mother does. Perhaps it's instances like this that poets like Samuel Taylor Coleridge wrote: "A mother is the mother still, the holiest thing alive."

Perhaps, if they had more respect for the parent, and had sat down in a more timely fashion, as Kaiser's Ombudsman suggested, right at the time that Alex willingly did go to the dentist—even though he wasn't in pain—to make a plan to follow up on the referral, and to get him to the oral surgeon right away, all of this wouldn't have happened. Because at that time, when Alex was willing to go to the dentist and did go on his own volition, it would have been more probable that he'd have gone to the follow-up care. Apparently, that wasn't the objective for Villa—to take care of Alex's health. They may have had some meeting between Villa staff because they decided to let Highland do the dental work, but I wasn't invited to any meeting. I only assume that because Danielle told me the very next day after the dental appointment, about their requirement to use Highland. At that time she asked me for the dentist's referral, which I then gave her. But, they didn't proceed to move ahead on his dental need. They let it go, put it on the back burner, and this is what has happened because of their negligence.

But, Telecare Villa Fairmont is the organization that the Alameda County government agency contracts with, to take care of the mentally ill in the county. As Vivian Jackson, past President of NAMI-East Bay used to say, "This is what we have," so we have to work with them. We have to train them, educate them. And that is the point of this journal. Even though Freeman, M.D., may have looked down on a mother's intelligence, placing the blame of mental illness on the mother's shoulders, it is my hope in writing this information for your edification, that that supposition couldn't be further from the case.

The Objective

The objective was never Alex's health. The objective for Villa was to keep him at Villa, so they could do whatever they do to fulfill their own objectives. And he was only

transferred to Villa because of the negligence of Herrick's psychiatrist to do what he said he would do: Confer with the family about where Alex would be discharged to. He left that message on my phone mail, but never got in touch or had a meeting with me. Villa's objectives apparently, as portrayed by their actions, have nothing to do with my son's health. The fact that they've employed 4 different psychiatrists over a 4-month period, itself, where one left and the next one arrived, speaks to their lack of good management. On January 30th I happened to be watching the C-Span channel and heard Henry Kissinger say, "We have to begin with the objective…and follow up with strategy…You get much better policy if there is a discussion and you include the different groups…There needs to be a discussion…a consultation."

Following that program, David Barlow, Former U.S. Attorney for the District of Utah added more information about the need for consultations between groups. He stated certain words that "brought light, not heat to the conversation." I scurried to write them down, but I couldn't get them all: "dignified…calm.manner…inciteful…organized…smart…well.prepared…listened…facilitated… consensus…elevated the discourse…tough…fair…gracious…independent." Although he was talking about the confirmation of Loretta Lynch to be the next U.S. Attorney General, I couldn't help thinking that these words also described how any meeting or discussion should be conducted. And because none of these words could have been used to describe the first recovery meeting that I attended, I was compelled to pick up the pen again. So, a thank you goes out to Dr. Freeman for her being so disrespectful that it motivated me to start writing again after a one-year lull, just to tell this story.

Tuesday, February 03, 2015

As I sat in my van right in front of the door of the John George Pavilion Court Building, the judge came out for some fresh air. My intention was to informally connect with the judge again, to see if there was any progress on the case, especially since there had been no forward movement even after Alex called for another writ hearing over a week ago. Had McGuire, his public defender, presumed he would change his mind for the third time? The public defender usually calls me after Alex calls for a writ. It was Alex who had changed his mind in my direction and now wanted to come home. Why couldn't they put him before the judge while he was in that state of mind? Plus, there has been no more news from anyone about the dentist and that stalemate.

I didn't want to stalk the judge, and I had already noticed that the bailiff didn't invite me into the building and seemed annoyed at my presence outside, so I sat still working on my laptop and pulled the curtain open a few more inches to see him better. I heard the judge ask the bailiff who I was, after which he came over to the van and I spoke first: "Have you had a chance to read the manuscript?" He said something like, "somewhat," and followed that with, "What do you want? It didn't say what you wanted" to happen.
I replied "to take Alex home," because the hospital said they can't get him to the dentist, and they're not going to try and in fact, told me to be in charge of that, I would have said, if he'd hung around after hearing the first 4 words. As he returned to the building, I

heard him say that he didn't understand that from the writing. Maybe I should make that the title of the book: To Take Alex Home. Is that more explanatory than 'Hell'p!? At this point, with Alex knowing that I intend to get him to the dentist if he comes home, he now doesn't want to come home, so I still do need help to make that happen.

Monday February 9th, 2015

Deciding that I needed to find the organization(s) that I might be able to report this situation to, I attended the Alameda County Mental Health Board Meeting today. I use to attend those meetings more than 2 spine surgeries ago—4 years—before it became too painful to even walk to the meeting room. They seemed to like Alex's Song when I sang it to them, because my colleague from NAMI, VP Margot Dashiell, told me they were impressed. I knew they were touched because no one spoke for at least 30 seconds afterwards, until another parent was able to make a comment. And it was after that that Margo introduced me as her colleague. But, today there was a new group. And I was the last of the speakers in the "public" domain of which there were 3, and I should have asked how much time I had before I opened my mouth, because the leader, Rochelle Elias, seemed to think she heard enough even before I got to the point, which was: Who are the accrediting organizations for Telecare Villa Fairmont? because I'd like to send them my journals. I held each year up going back to 2010. The others going back to 1999 are still in my computers. And the first few years are still handwritten. I'd brought the journals to let them know that I'd been keeping a record of the behavior of the mental health system for going on 19 years. And these people were and still are a part of that "system." When Elias started to interrupt me, perhaps because I was beginning to get a bit emotional as I posed the question, "How could the county contract out to an organization like Telecare, where they don't care about our children?" Yea, I think it was about then that she said the meeting was over. It took a few hours to calm down after being told that I was finished. Talking to Margot afterwards, who seemed to understand why I was upset, driving home with music, then over to the Berkeley Marina to do some more writing did the trick. I finally realized why I got so upset toward the end of my minute. It was the same rudeness that was displayed to the parent last October when Freeman, M.D., kept interrupting me with the hiss, for trying to give her information. Even the Mental Health Board didn't want to hear what a parent had to say. Round and round and round it goes…

ACHCS Quality Management Director, Rudy Arrieta—whose associate, Wilma Gaines, presented information about the "Consumer Grievance Process" at the meeting—will get back to me, he said, about whom to speak to in Patients' Rights. He looked surprised when I handed him my ad-specialty pen with my "Joan of Art" phone number on it. He was probably convinced I was a consumer of mental health services since my emotions got the better of me toward the end. I bet he would have been even more surprised that I designed ad specialties for clients like Chevron, General Foods and the Oakland A's, when I arrived in California 30 years ago.

The New World View

Crossing the Divide into the new realities

> Every few hundred years there occurs a sharp transformation. We cross a "divide" Within a few short decades, society rearranges itself—it's world view, it's basic values, its social and political structure, its arts, its key institutions. Fifty years later, there is a new world. The people born after the transformation cannot even imagine the world in which their grandparents lived and into which their own parents were born.

The above is from The Daily Drucker (p. 37) as extracted from:

The New Realities
Post-Capitalist Society
The Age of Discontinuity

I'm hoping this next new world that Peter Drucker is referring to, will be one that caters more to the mentally ill, with medicines consistently being invented that actually help to give people a more normal life, and in doing so reduce their pain and suffering. I see that world spending money on research that values human life and therefore, designs cures for human suffering. It's a world that my Alex already sees, when he's flying out in space "saving all the children," so they can be the best they can be.

As the world has already seen, Germany's reasoning and consequent techniques to get rid of human suffering by killing all those who suffered, didn't work, not only because there are always more people born to take their places, but because it's immoral and therefore, had to be eradicated by those who could and would stand up to immorality. Instead, another way to get rid of suffering is to fix the human condition, so people can enjoy the time they have. It benefits everyone to help, to cure, to fix, to feed, to clothe, to house, because there would be less pain, less killing, less frustration, less stealing, less jealousy and hatred, since people see more clearly when they're not depressed, not afraid, not sick, not hallucinating, not anxious, not hungry and, therefore, can make better decisions to have a happier, more fulfilling life.

May this next new world of transformation—into valuing life and making better decisions in regard to mental health—take place in the near future. It can happen by simply putting more resources into changing mental illness into mental health. Only then can the presently mentally ill get better and become contributing members of society. Then will they be able to participate in their own wellbeing without being accused of hurting the wellbeing of others. We wouldn't need to use the mentally ill as scapegoats for the shootings and other insanities since they wouldn't be the ones doing that. Why? Because those more fortunate and intelligent beings, who are not mentally ill, would have taken the initiative to commit to investing in a tomorrow that will keep all of us safe by helping the less fortunate.

The following are current addendums, applicable to healthcare, disability and civil rights, which are located on the HHS.gov website and relevant to Alex's story:

Addendum to HIPAA
DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

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.

The HIPAA Privacy Rule protects the privacy of patients' health information but is balanced to ensure that appropriate uses and disclosures of the information still may be made when necessary to treat a patient, to protect the nation's public health, and for other critical purposes, such as when a provider seeks to warn or report that persons may be at risk of harm because of a patient. When a health care provider believes in good faith that such a warning is necessary to prevent or lessen a serious and imminent threat to the health or safety of the patient or others, the Privacy Rule allows the provider, consistent with applicable law and standards of ethical conduct, to alert those persons whom the provider believes are reasonably able to prevent or lessen the threat. Further, the provider is presumed to have had a good faith belief when his or her belief is based upon the provider's actual knowledge (i.e., based on the provider's own interaction with the patient) or in reliance on a credible representation by a person with apparent knowledge or authority (i.e., based on a credible report from a family member of the patient or other person). These provisions may be found in the Privacy Rule at 45 CFR § 164.512(j).

Under these provisions, a health care provider may disclose patient information, including information from mental health records, if necessary, to law enforcement, family members of the patient, or any other persons who may reasonably be able to prevent or lessen the risk of harm. For example, if a mental health professional has a patient who has made a credible threat to inflict serious and imminent bodily harm on one or more persons, HIPAA permits the mental health professional to alert the police, a parent or other family member, school administrators or campus police, and others who may be able to intervene to avert harm from the threat.
In addition to professional ethical standards, most states have laws and/or court decisions which address, and in many instances require, disclosure of patient information to prevent or lessen the risk of harm. Providers should consult the laws applicable to their profession in the states where they practice, as well as 42 CFR Part 2 under federal law (governing the disclosure of substance abuse treatment records) to understand their duties and authority in situations where they have information indicating a threat to public safety.

We at the Office for Civil Rights understand that health care providers may at times have information about a patient that indicates a serious and imminent threat to health or safety. At those times, providers play an important role in protecting the safety of their patients and the broader community. I hope this letter is helpful in making clear that the HIPAA Privacy Rule does not prevent providers from sharing this information to fulfill their legal and ethical duties to warn or as otherwise necessary to prevent or lessen the risk of harm, consistent with applicable law and ethical standards.

Leon Rodriguez

Demonstrating the U.S. Commitment to People with Disabilities

December 3, 2013
by Sharon Lewis, Senior Advisor on Disability Policy, U.S. Department of Health and Human Services (HHS); Dr. Nils Daulaire, Assistant Secretary for Global Affairs, HHS; and Leon Rodriguez, Director, Office for Civil Rights, HHS

The Americans with Disabilities Act (ADA), passed more than two decades ago, has greatly improved the quality of life, not only for the more than 50 million people with disabilities here in the United States, but also for the one billion more who are living around the world.

The ADA is the gold standard for the treatment of people with disabilities, serves as a model for other nations, and is the inspiration behind the creation of an international treaty that prohibits discrimination against people with disabilities worldwide.
As President Obama recently said, “Disability rights aren't just civil rights to be enforced here at home; they're universal rights to be recognized and promoted around the world.” We are reminded today, International Day of Persons with Disabilities, that the United States Senate has the opportunity to ratify the Disability Treaty and cement America’s leadership in global disability rights.

The vast majority of us know someone with a disability, and people with disabilities are a critical part of our diverse society. They are our family, friends, neighbors, and colleagues. Over five million are veterans, over seven million are children, and over thirteen million are older adults.

Thanks to U.S. laws and policies, these Americans all have the right to fully participate in their communities, and they are protected from discrimination—but only when they are within the United States’ borders.

By ratifying the Disabilities Treaty, we demonstrate that these protections and standards must extend beyond our shores.

Ratification would help promote accessibility standards internationally, as well as facilitate collaboration, innovation and idea-sharing. This treaty will expand markets for accessible products, technologies and decades of American expertise.
Senator Bob Dole, among others, has been a strong supporter of the treaty, as a disabled veteran. “Now is the time to reaffirm the common goals of equality, access, and inclusion for Americans with disabilities—both when those affected are in the United States and outside of our country’s borders.” It’s time that all people with disabilities, regardless of where they live in the world, are able to live with dignity, make their own choices and participate fully in society. It is time for the United States Senate to ratify the Disabilities Treaty.

November 2014
U.S. Department of Health and Human Services,
Office for Civil Rights
BULLETIN: HIPAA Privacy in Emergency Situations

In light of the Ebola outbreak and other events, the U.S. Department of Health and Human Services (HHS), Office for Civil Rights (OCR), is providing this bulletin to ensure that HIPAA covered entities and their business associates are aware of the ways in which patient information may be shared under the HIPAA Privacy Rule in an emergency situation, and to serve as a reminder that the protections of the Privacy Rule are not set aside during an emergency.

The HIPAA Privacy Rule protects the privacy of patients' health information (protected health information) but is balanced to ensure that appropriate uses and disclosures of the information still may be made when necessary to treat a patient, to protect the nation's public health, and for other critical purposes.

Sharing Patient Information
Treatment Under the Privacy Rule, covered entities may disclose, without a patient's authorization, protected health information about the patient as necessary to treat the patient or to treat a different patient. Treatment includes the coordination or management of health care and related services by one or more health care providers and others, consultation between providers, and the referral of patients for treatment. See 45 CFR §§ 164.502(a)(1)(ii), 164.506(c), and the definition of "treatment" at 164.501.

Public Health Activities
The HIPAA Privacy Rule recognizes the legitimate need for public health authorities and others responsible for ensuring public health and safety to have access to protected health information that is necessary to carry out their public health mission. Therefore, the Privacy Rule permits covered entities to disclose needed protected health information without individual authorization:

• To a public health authority, such as the Centers for Disease Control and Prevention (CDC) or a state or local health department, that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury or disability. This would include, for example, the reporting of disease or injury; reporting vital events, such as births or deaths; and conducting public health surveillance, investigations, or interventions. A "public health authority" is an agency or authority of the United States government, a State, a territory, a political subdivision of a State or territory, or Indian tribe that is responsible for public health matters as part of its official mandate, as well as a person or entity acting under a grant of authority from, or under a contract with, a public health agency. See 45 CFR §§ 164.501 and 164.512(b)(1)(i). For example, a covered entity may disclose to the CDC protected health information on an ongoing basis as needed to report all prior and prospective cases of patients exposed to or suspected or confirmed to have Ebola virus disease.

• At the direction of a public health authority, to a foreign government agency that is acting in collaboration with the public health authority. See 45 CFR 164.512(b)(1)(i).

• To persons at risk of contracting or spreading a disease or condition if other law, such as state law, authorizes the covered entity to notify such persons as necessary to prevent or control the be found at:
http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html

Disclosures to Family, Friends, and Others Involved in an Individual's Care and for Notification
A covered entity may share protected health information with a patient's family members, relatives, friends, or other persons identified by the patient as involved in the

patient's care. A covered entity also may share information about a patient as necessary to identify, locate, and notify family members, guardians, or anyone else responsible for the patient's care, of the patient's location, general condition, or death. This may include, where necessary to notify family members and others, the police, the press, or the public at large. See 45 CFR 164.510(b).

• The covered entity should get verbal permission from individuals or otherwise be able to reasonably infer that the patient does not object, when possible; if the individual is incapacitated or not available, covered entities may share information for these purposes if, in their professional judgment, doing so is in the patient's best interest.

• In addition, a covered entity may share protected health information with disaster relief organizations that, like the American Red Cross, are authorized by law or by their charters to assist in disaster relief efforts, for the purpose of coordinating the notification of family members or other persons involved in the patient's care, of the patient's location, general condition, or death. It is unnecessary to obtain a patient's permission to share the information in this situation if doing so would interfere with the organization's ability to respond to the emergency.

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). Disclosures to the Media or Others Not Involved in the Care of the Patient/Notification Upon request for information about a particular patient by name, a hospital or other health care facility may release limited facility directory information to acknowledge an individual is a patient at the facility

Disclosures to the Media or Others Not Involved in the Care of the Patient/Notification Upon request for information about a particular patient by name, a hospital or other health care facility may release limited facility directory information to acknowledge an individual is a patient at the facility and provide basic information about the patient's condition in general terms (e.g., critical or stable, deceased, or treated and released) if the patient has not objected to or restricted the release of such information or, if the patient is incapacitated, if the disclosure is believed to be in the best interest of the patient and is consistent with any prior expressed preferences of the patient. See 45 CFR 164.510(a).

In general, except in the limited circumstances described elsewhere in this Bulletin, affirmative reporting to the media or the public at large about an identifiable patient, or the disclosure to the public or media of specific information about treatment of an identifiable patient, such as specific tests, test results or details of a patient's illness, may not be done without the patient's written authorization (or the written authorization of a personal representative who is a person legally authorized to make health care decisions for the patient). See 45 CFR 164.508 for the requirements for a HIPAA authorization.

Minimum Necessary
For most disclosures, a covered entity must make reasonable efforts to limit the information disclosed to that which is the "minimum necessary" to accomplish the purpose. (Minimum necessary requirements do not apply to disclosures to health care providers for treatment purposes.)

Covered entities may rely on representations from a public health authority or other public official that the requested information is the minimum necessary for the purpose. For example, a covered entity may rely on representations from the CDC that the protected health information requested by the CDC about all patients exposed to or suspected or confirmed to have Ebola virus disease is the minimum necessary for the public health purpose. Internally, covered entities should continue to apply their role based access policies to limit access to protected health information to only those workforce members who need it to carry out their duties. See 45 CFR §§ 164.502(b), 164.514(d).

Business Associates
A business associate of a covered entity (including a business associate that is a subcontractor) may make disclosures permitted by the Privacy Rule, such as to a public health authority, on behalf of a covered entity or another business associate to the extent authorized by its business associate agreement.

Safeguarding Patient Information
In an emergency situation, covered entities must continue to implement reasonable safeguards to protect patient information against intentional or unintentional impermissible uses and disclosures. Further, covered entities (and their business associates) must apply the administrative, physical, and technical safeguards of the HIPAA Security Rule to electronic protected health information.
Other Information
Limited Waiver The HIPAA Privacy Rule is not suspended during a public health or other emergency; however, the Secretary of HHS may waive certain provisions of the Privacy Rule under the Project Bioshield Act of 2004 (PL 108-276) and section 1135(b)(7) of the Social Security Act. If the President declares an emergency or disaster and the Secretary declares a public health emergency, the Secretary may waive sanctions and penalties against a covered hospital that does not comply with the following
provisions of the HIPAA Privacy Rule:

• the requirements to obtain a patient's agreement to speak with family members or friends involved in the patient's care. See 45 CFR 164.510(b).
• the requirement to honor a request to opt out of the facility directory. See 45 CFR 164.510(a).
• the requirement to distribute a notice of privacy practices. See 45 CFR 164.520.
• the patient's right to request privacy restrictions. See 45 CFR 164.522(a).
• the patient's right to request confidential communications. See 45 CFR 164.522(b).

If the Secretary issues such a waiver, it only applies: (1) in the emergency area and for the

emergency period identified in the public health emergency declaration; (2) to hospitals that have instituted a disaster protocol; and (3) for up to 72 hours from the time the hospital implements its disaster protocol.

When the Presidential or Secretarial declaration terminates, a hospital must then comply with all the requirements of the Privacy Rule for any patient still under its care, even if 72 hours has not elapsed since implementation of its disaster protocol.

HIPAA Applies Only to Covered Entities and Business Associates The HIPAA Privacy Rule applies to disclosures made by employees, volunteers, and other members of a covered entity's or business associate's workforce. Covered entities are health plans, health care clearinghouses, and those health care providers that conduct one or more covered health care transactions electronically, such as transmitting health care claims to a health plan. Business associates generally are persons or entities (other than members of the workforce of a covered entity) that perform functions or activities on behalf of, or provide certain services to, a covered entity that involve creating, receiving, maintaining, or transmitting protected health information. Business associates also include subcontractors that create, receive, maintain, or transmit protected health information on behalf of another business associate.
The Privacy Rule does not apply to disclosures made by entities or other persons who are not covered ations. See 45 CFR 164.522(b).
entities or business associates (although such persons or entities are free to follow the standards on a voluntary basis if desired). There may be other state or federal rules that apply.

Other Resources
For more information on HIPAA and Public Health, please visit:
http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/publichealth/index.html
For more information on HIPAA and Emergency Preparedness and Response, please visit:
http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/emergency/index.html
General information on understanding the HIPAA Privacy Rule may be found at:
http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html