

## **Frank Baron talks about his experience with mental health advocacy...**

...Your name gets around and you get called in to various things. It's sort of funny. Sometimes things happen on the same day, which is always difficult. You hate to turn down something. I got call from the L.A. coordinator for [the NAMI program] In Our Own Voice and they want me to speak to this school of psychologists, and then Mental Health Commission is meeting that day. I mean, I wish there wasn't conflicts. I wish there was less of that. And mental health advocacy is a wonderful, wonderful thing. You meet a lot of very interesting people. I love the NAMI conventions. I have gone to probably ten between the CAMI [California Alliance for the Mentally Ill, now NAMI-California] and the California ones. 'Cause of the cost, I don't know if I will go to Washington, D.C. next year. But that, I have enjoyed. But again, your name gets around.

You're giving me a lot of time here, but I was invited by a well-known psychiatrist at the VA to go with him with to Washington, D.C. with other researchers to try to convince congress people and their staffs to provide additional funds for mental health research. And I did that. I was invited to that three years in a row. In that case, I was invited there, they needed somebody who could talk fast because I had three and half minutes flat, and that was it. The doctors made their pitch, I made my pitch. Interestingly enough, the congress people and the staffs were far nicer to me than they were to the doctors because they sort of viewed the doctors as being hat and hand trying to get money for their facilities and themselves. So, they were much nicer to me in that regard. But I was glad I got invited for that.

**READ THE FULL TRANSCRIPT BELOW.**

**Interviewee:** FRANK BARON

**Interviewer:** Katie Cadigan

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**I. Young Adulthood; Becoming Ill; Medication & Support at VA; Involvement with NAMI; Partial Hospitalization Program; Psycho-Social Rehabilitation; On Working**

KC: Tell me how you ended up getting into treatment.

FB: Well, I should say my whole story, or briefly. I grew up in L.A. I graduated from Fairfax High School. I graduated from Cal-Poly San Luis Obispo in 1981 with an engineering degree. I joined the Navy. I was a U.S. Navy officer for three years. I volunteered to spend one year on a little tropical island in the middle of the Indian Ocean for a year. It was during peace time, which is very different than war time. And after I was on this island for a year, my reward was Naples, Italy. I lived two years in downtown Naples, Italy. I wore my uniform on the Neapolitan subway to go to work. It was a lot of fun. I was three years in the Navy [and] I was never on a ship. That's the best way to be in the Navy, believe me.

After the Navy, I wanted to do something else interesting. I joined the Peace Corps. I was a Peace Corps volunteer in Yemen out of all places – two years and three months in Yemen. This was in the '80's, here. It was probably much safer then than it is right now, but I had an interesting time.

I came back to the United States. I was working in Orange County as a civil engineer. I was doing structural calculations for water treatment plants. And one day at work, I started having hallucinations. And I was not using street drugs of any kind. I never used street drugs. And I wasn't abusing alcohol. But unfortunately, there's a biological predisposition in my family for this. I have a brother, my only sibling, with very severe paranoid schizophrenia, who's very sick, who's on the same meds as me at much higher doses and other meds, and he's still a mess. I got lucky with the meds after a long time. As I mentioned, it happened while I was at work. And also, besides my brother, I had a grandmother that died before I was born that was institutionalized most of her life with schizophrenia. So, there definitely was a biological predisposition in my family. So, I got really sick in 1990 and—

KC: You were saying you were at work. What happened?

FB: I was having hallucinations, and I got very paranoid and, at times, very, very depressed. I was hospitalized, like, around nine times before they found medication to help me. I was very, very sick.

KC: In your long course of treatment, what aspects of treatments or specific things have helped the most or been the best?

FB: Well, I'm interested in medication. I'm a pro-medication person. A lot of consumers are not. And in my opinion, medication is a good chunk of it. If you're fortunate enough to find the medication for you, life can be enjoyable, or at least you can have a decent life if

you're lucky enough to find the right meds. So, in my case, after spending so many years on different—as I mentioned, I was hospitalized nine times, you know, [with clinicians] trying Haldol and Navane [antipsychotic medications] and so many other things on me. It wasn't until I went to a new doctor at the VA who told me he has tremendous faith in Clozapine [an antipsychotic medication]. I guess I'm one of the Clozapine miracle stories in this regard. Clozapine has really helped me a great deal.

Also, counseling is important. I did have two psychiatrists, both at the VA. I didn't plan it out this way, but how I ended up at the VA was that when I was working as a civil engineer in Orange County, I worked in this office. I was in a 500-person firm. They had this beautiful John Hancock Insurance policy. I would say what a wonderful insurance policy it was, but inside there was an exclusion clause for mental illness. I had \$25,000 lifetime, and if I'd had cancer or heart disease, they would have paid a million dollars, no questions asked. But in the fine print, \$25,000 lifetime—within a few weeks, I found out—I was an uninsured person, which I never, in million years, thought would happen to me as a civil engineer. So, I didn't plan it out this way, but thank God I was a veteran because I'm able to get free treatment at the West L.A. Veterans Hospital. And I didn't plan it out this way, but I was hospitalized at the VA probably about six times there.

I did have two very good psychiatrists there that helped me. I also had a UCLA psychiatric nurse because I went to the partial hospitalization program at UCLA, and you get to meet a large number of professionals there. And I was very fortunate – there was a nurse with a Master's degree psychiatric nursing, and she also had a small private practice, so because I had Medicare, I was able to get her services as well. So, I had some very good—I got very lucky with some good medication, and I've had two psychiatrists at the VA really do far more for me than they were required to. So, I'm grateful for that. I'm not cured, I'm not perfect, but I'm doing better than the vast majority of people with my illness. My psychiatrist at the VA has said to me I'm doing better than 95% of his other patients.

KC: Are there specific things in how you approach your recovery that you think contribute to why you think you're doing better than 95 [%]? Is it just luck, is it—

FB: No, I—the Clozapine has stopped the paranoia, it's stopped the hallucinations, which, in itself, is an accomplishment. But it's also improved my self-esteem. I've been very active in National Alliance on Mental Illness, NAMI. I've doing a lot of speaking through the NAMI In Our Own Voice speaker's program [a program in which consumers talk about their experiences with mental illness]. I've spoken before [at] Twin Towers Jail with deputies about three times, which is an interesting audience. And I've spoken both at UCLA and USC [in] abnormal psychology classes. I've spoken to a lot of parent groups that are in the NAMI Family to Family thing [a NAMI program]. So I think getting involved with NAMI makes me think maybe I'm accomplishing something in life as opposed to just being bitter. It looks like, in my case, in terms of long-term, I still have not made it back to work as a civil engineer, as I mentioned, before I got sick.

Cognitive deficits in schizophrenia is a very big problem. When I first went into this, I thought I got over the big hill, which was hallucinations and paranoia and clinical depression and everything. And getting over that hill was a tremendous accomplishment. What I did not realize was that beyond that hill, there was another hill I didn't even see, and that's cognitive deficits. This is a very big problem. [Concentration] is a very big problem for a lot of us. This is why I primarily devote my life to, besides

helping my elderly mother and my brother who's very, very sick, I've got involved as much as I can in NAMI to do as much good as I can with what I have. But in my case, my illness probably ended my engineering career. Maybe it's vanity, but every three years, I renew my engineering license. It was very hard to get my civil engineering license. I had to take a very hard test, and if I don't renew every three years, I lose it for good, so I've done it, but I don't if I'll ever make it back to engineering or not. I hope that if someone sees this film 40 years from now, maybe they'll have all these drugs that help people with concentration and negative symptoms with schizophrenia. [Negative symptoms are characterized by an absence or reduction of certain abilities, including producing meaningful speech, expressing or understanding emotion, and maintaining social relationships.] I don't know, but it would be a wonderful thing.

KC: That is the newest frontier for research right now.

A: Yeah. It's a very big—I've met parents that are doctors, that are lawyers, and their kid [is] also like me—many of them say [that their kid] has schizoaffective disorder. You go to a NAMI convention, and there's an enormous number of parents in the audience [whose] kid's on Clozapine. For treatment-resistant schizophrenia, it's a wonderful thing, but again, the issue of the negative symptoms – it's just a very big problem. I hope there is some [medication] in the future, down the line, for this.

KC: When you talk about cognitive deficits, for you, what is it? Some people hear that word and they think that you're stupid, you know. You become—

FB: Well, let's put it this way. I was a working person before I got sick, obviously. I've tried going back to school and work several times. Let's say I take job. Okay, I might be able to make it through eight hours on day one, okay? I'm going to be exhausted, but by day two, I might be able to make it through six hours. But by day three, constant—I'm so mentally exhausted, I might be able to do it two hours, and this is not conducive to full-time work. This is a very big problem. If you imagine yourself – let's say you were very, very busy and you worked fourteen hours straight and you didn't get much sleep one night. You know how that would feel. I'm like that after, like, two and a half hours a day.

KC: So, is it concentration? Is it logic?

FB: Concentration. Yeah, concentration.

KC: Getting back to your early treatment – how did you come to understand the reasons for your illness? What was the process in understanding? Can you talk about it briefly?

FB: Well, my brother got very sick before I did. I may have some mania before I got sick, but I didn't recognized that at that time. I made through the Navy. I made it through the Peace Corps. I made it through college there, but it took a while. Everyone is in denial in the beginning. Denial is not abnormal; it's normal. The question is for how long did the denial last? I've met people who have been hospitalized ten times and they still tell me point blank they don't have a mental illness, okay. My brother has been hospitalized 25 times, you know. He's very, very sick.

So, it wasn't until I got involved at NAMI that I had some sense that what was going on here can happen to anybody. I've met rich people with mental illness. I've met poor people with mental illness. And I've met rich people that end up poor people because of

mental illness, so it really can happen to anybody, and once I realized that, I realized I really would try to do as much mental health advocacy as I could for the rest of my life. I'm committed to this for the rest of my life.

KC: Some people think that because there's a lot of mental illness in a family, it's caused by families. Did you ever have that understanding?

FB: No, I don't blame—and I'm not, by the way—because I'm a veteran—I'm not service-connected, either. I don't get money from the VA. And I don't blame my illness on my parents. I don't blame my illness on things I've done in my life. I just inherited a predisposition for it, and I got unlucky here. But—I lost my train of thought, I'm sorry.

KC: No, that's okay. I want to get back into when you said you had some really good treatment. Are there moments or things people said to you – either doctors or the people who were helping you earlier – things that they said that were really helpful that you hang on to?

FB: Insight [into one's illness] can be taught. You know, I have high level of insight into my illness. Someone invited me to do another NAMI function. They want me to teach a NAMI course at night for consumers, and I'm going for a training [at] the end of this week for that there. I'm sorry. I lost my train of thought.

KC: I wanted to know – was there a moment someone said something to you that made it click or gave you a thing to look forward to?

FB: Yes, yes, now that I look back. I was in the partial hospitalization program at UCLA, which was very, very valuable. I got a lot of good out of that thing. And during one—there was, like, ten of us in this partial hospitalization [program]. You don't sleep at night there. It saves a lot of money. And it's just people after hospitalization. They even have a bus, a little van comes to your house in the morning and takes you to UCLA and even took us back at that time. And during the break, I was talking to a guy around my age, and I mentioned to him, you know, "I went to Cal-Poly San Luis Obispo." He turns to me and says, "I went to Cal Poly San Luis Obispo." And then I said to him, "My major was architectural engineering." And he turns to me and said, "My major was architectural engineering." And neither of us could believe it. We were one year apart – this is why we didn't know each other by face. But the point being, we both were stunned that we both came from the same background. It was a one-year difference, so we didn't know each other. But we had all the same teachers. We were talking about it. I was there for psychosis. He was there for very bad depression. I think it hit me like a lightning bolt that it really can happen to anybody. I think that was one of the biggest moments for me – [that] realization. But again, the counseling that I received from these two psychiatrists and this psychiatric nursing – I learned a lot.

KC: What [did you learn]?

FB: That medication can help; that some people [who] get medication get very, very lucky; that a combination of medication and counseling can improve your chances there. There are some high-profile people. I'm not one of them. Elyn Saks at USC – she has schizophrenia, and she's obviously a law professor. I mean, she's in a different category than me. She's up there, but I'm still doing better than most people are. But it really can happen to anybody. I've written several articles in the L.A. Times – letters to the editor

about this – so I really benefited from that. And again, this doctor – I don't know if I should say the name or not; maybe I shouldn't – at UCLA, but he really—I had an expert in psycho-social rehabilitation, and I owe him a great deal.

KC: Specifically, what things did psycho-social rehabilitation teach you?

FB: This doctor has published a series of modules that consist of workbooks and films, and one of his modules is called the Symptom Management module. And it's very clever and, I think, very, very helpful. The doctor and the patient – the consumer – and the consumer's parents sit down, and they try and think back of all the—they call it prodromal signs – things giving small hints that a person was headed for a major relapse. And they think back over the various relapses that that person has had. And they put it down on a piece of paper. It's different for each person. Obviously, some are very common – for example, not sleeping at night. But it could be a lot of other things – not putting on clean clothes; simple things. When you think back on it, gee, the last two times, three times I was hospitalized, that happened two weeks before or three weeks before. And once you identify for each individual what their specific signs are, you keep track on a daily basis with a chart. And you can see that if you study—if you think about it and your parents help you think about it – gee, I'm starting to repeat some of those symptoms, and if you can get to a doctor in time, before it's full-blown, there's a much better chance of helping the situation, as opposed to not knowing what's going on, and then you have a full-blown manic or psychotic episode. And then it's very, very hard to help that. You're talking about weeks or more in the hospital – it costs a fortune. The symptom management module in particular—there were several other modules. There was Leisure Time, there was Employment. But for me, the Symptom Management was very, very helpful because I realized that if you can see it coming, you can do something about it.

KC: That has been the biggest thing for my brother, as well. What are the symptoms, if you're comfortable saying? What are your warnings?

FB: In my case, a big one, besides sleeping, which is obvious, [is] irritability. I would get very irritable, and I don't think I realized it. I'm grateful; I have not had a relapse in 15 years, you see. I'm told I've been on Clozapine longer than any other patient at the West L.A. Veteran's Hospital. So, I'm grateful that I have not had a relapse for all that period of time. But until I was fortunate [enough] to get on Clozapine – when I was on these other meds that were not really helping me—I was on Navane for a couple years there. And it would work when I was psychotic; it would bring me back down. But then, three months later, I was having another psychotic break. And I'd have depression, and I was taking depression medications. So, I got lucky – we tried, at the very end, Clozapine, and it worked for me. One of my doctors at the VA, who I very much respect, said to me that—'cause again, they typically only try Clozapine at the very, very end after several other drugs have failed because of the problem with the white blood cell count. Clozapine requires frequent blood draws here. But this doctor had said to me, if his daughter had schizophrenia, he would put her, immediately, on Clozapine first around, as opposed to waiting to the very, very end of the situation.

In some ways, I wish I had gotten on it earlier; maybe I would not have had the cognitive deficit problems as much as I do now 'cause these bad psychotic breaks are not good for your brain. And I had probably six – maybe about six or seven – very bad psychotic breaks. And this is also affecting the concentration issue there.

KC: When you look back on your treatment – you talked about some really great—you're really fortunate to have encountered good people – were there any terrible things you were told?

FB: I only had one doctor would be rude to me in my total [time] – really rude to me – was at the VA. I don't want to put down the VA. Again, I had two other doctors that were outstanding at the VA, okay? But it was towards the beginning of my illness, and I told you my insurance had run out from my engineering company, [insurance] for psych. I had no insurance for psych. I went back to the VA, and I got a doctor who's no longer there. And I was very depressed, and maybe the second time that I wanted to get medication, in the hallway, I stopped him in the hallway at VA, and he started screaming at me that I had no right to talk to him outside of the clinic hours, and I should just sit down on the bench, and that's it. No one's ever talked to me like that before, and no one's ever talked to me like that since. I don't blame the VA. He's no longer there. Again, I had two superstars at the VA help me, so I'm not putting down the VA, but that was—particularly because I didn't really know what was going on at that time, and I was very, very depressed. That was a bad experience there.

But in terms of thinking of other things [that were] really bad, one thing I did learn was attempting to go back to work – this has to be very, very well thought out. Or [going back to] school. I tried going back to school. I'm interested in medication, as I mentioned. And I'm not smart enough to be a pharmacist. That takes a very, very hard, six-year degree, but there is a pharmacy technician [degree]. I said, gee, that'll be interesting – I'll help people with medication and I'll work in a pharmacy or something, and I'll help them get their meds. It's called pharmacy technician. You're not a pharmacist, but it's a community college, one-year course. And I did that – and it's true – which was an accomplishment for me. I didn't think I would because I've tried other things – I've tried going getting a Master's degree in business administration. I thought maybe my engineering career is damaged and I couldn't do that. But I made it through this program at a community college for this pharmacy technician program.

Well, the point is I got a job at Rite Aid there. I had to do an internship there, as well. What I did not realize—this was not a good, this was not a wise decision—dealing with the public. And a lot of people that are waiting at a pharmacy, and I was at a very, very busy pharmacy, and these people are sick. The biggest issue was not the meds; it was their insurance not going through, and they took it out on me. And I couldn't do as fast as the other people because of my illness. It was for a minimum wage job, and people were insulting me. It made me feel much worse about myself than better about myself. So, I'm saying it's not simple. Don't think, gee, if you give somebody a job, they'll be happily ever after. This has to be very, very well thought out. And I did not think this. I did not realize the implication.

At this point in my life, I'm really not looking for long-term work. I do a lot of volunteer work. I'm very active at NAMI. That's what I can do at this time. But that was a painful experience. I cannot compete, in a production job, with healthy, young people. I can't do it. You know, I'm 50 years old – turning 50 next month. And I cannot compete against some 19 year-old college student in terms of concentration and speed. So, that was a painful experience for me.

But again, the question is glass half-empty or half-full? I'm luckier than a lot of other people. I know this. I think if not for the Clozapine, at this point in time, I think I'd either be institutionalized or dead – probably the latter at this point, to be honest with you. So, I've been luckier than a lot of people. Think of all those poor countries in the world. They have absolutely no psychiatric hospitals and no medication, and there's nothing. My poor grandmother that died before I was born – just poor lady, never had no meds. I don't think they even had Thorazine [one of the first medications used to treat schizophrenia] in the '30's and '40's, when she was hospitalized, most of her life. So again, I've been luckier than a lot of other people, I know that. But it's not the easiest situation in the world.

KC: I'm really moved by your gratitude 'cause it's something, in our family, that has helped us a lot.

FB: Yeah.

## **II. Mental Health Advocacy & Education; On Becoming Ill at a Young Age; On Taking Medication; Therapy**

KC: But have there been other benefits – surprising benefits – or positive things that have come out [of having the illness]?

FB: Well, if I'd not gotten sick, I probably would have been—I'll be honest with you. I was an average Navy officer. I was very young. I was not that good at managing people. I'd probably do a better job of it now, at this age, but I was in my very early 20's. I was average or below average Navy officer, I was average Peace Corps Volunteer. Civil engineer? I was probably pretty average, too. I always tried the best I could, but I was never an A-student in my life. I was always a strong B-student. So, if I'd not gotten sick, I'd probably still be a civil engineer, and I would have lived in total obscurity. And that would have been it, and I would not have been active in public affairs or in advocacy of any kind. So, again, I am better. Like I said, I've been average most of my life at most things that I've done, but as mental health advocacy, I am above average in mental health advocacy. So, I've found something that, surprisingly, I'm good at. (He laughs) I found something in life that I'm surprisingly good at. So, that's nice, that came out of it, I think. Like I've said, if I'd not gotten sick, you never would have heard of me. I'd just be sitting in my cubicle doing my calculations, and that would have been my whole life.

KC: Can you list all the ways that you have become a public advocate and in the public eye?

FB: I was appointed to the Mental Health Commission of Los Angeles County, which is a big honor 'cause it's a very big county. Each supervisor is only allowed to appoint 3 people, and Supervisor Zev Yaroslavsky appointed me. So, this is a big honor for me. I've been very active in NAMI, particularly the In Our Own Voice speaking program. I've spoken for a wide variety of audiences there. Again, between the Commission and NAMI, I think those are my major efforts.

KC: When you're out in public, what are the biggest things people don't get about mental illness?

FB: Well, depends on the audience. Some audiences are very, very easy. For instance, nursing schools – I've spoken [there] many times. The nursing students, they eat it up.

They love it. Very, very easy audience. Law enforcement is a much tougher audience because these people, on a daily basis, deal with such terrible people, okay. We hand out reviews at the end of each of our speeches, you know. And I didn't think it was going so well with the law enforcement group, but most of them, the vast majority of them, gave us very, very high marks. They said they got something out of it. But I had, for example – you know, this is not typical – but I had a sergeant at the Sheriff's Department stand up and told me he didn't want mental ill people recovering from mental illness in his neighborhood because they're dangerous and he has a 10 year-old son, and these people use drugs. And I thought, gee, oh my God – this was a senior person in the room – I said [to myself] he's poisoning the minds of all the younger deputies. When I got the review forms back, they ignored him. They didn't listen to him. I was very happy in that regard. So, when you're speaking within NAMI's In Our Own Voice program, it's rare to have someone say something really full-blown negative. But some audiences are much more difficult than others.

And one of these Sheriff's deputies came up to me and said—someone that was sympathetic to our situation, he said, "You have to understand – [at] the Sheriff's Academy, we're not trained to be compassionate; we're trained to be tough. They don't train that." But the problem is that in Los Angeles County, Twin Towers Jail is the largest mental institution in the United States of America. There's more mental ill people there than there are beds in any psychiatric hospital anywhere in the United States. So, basically, these young people that have become Sheriff's deputies, I don't think they realized early on that—I don't know if there are 80 percent Sheriff's deputies and 20 percent psychiatric technicians [in the jail]. If they wanted to be psychiatric technicians, they would have gone to become psychiatric technicians. But this is a problem – the law forcing law enforcement into mental health. So, that's an example of it. I'm very happy to do it [present] before them again, but law enforcement is a tougher audience.

KC: If you could change one thing in the mental health system, what do you think it would be?

FB: Well, I'm not a doctor, so I can't think of—I wish they had PET scans right now that worked. They have the experimental [ones]. I wish they could say, right now, "We've done a scan on this person's brain. Let's try this medication, [which] has a higher likelihood than that medication [to work for this person]." I wish they had that right now. But like I said, that's out of my control. I think that's definitely where it's heading.

KC: If you, and you do, encounter people who are just new to the illness, if you were to give them one piece of advice, what would you [tell them]?

FB: Well, you see, I'm 50 years old now, almost 50. I got sick when I was 30, which is late. Most people get very sick [in their] teenage years. My brother, for example, as a young—[at] 16, he was already very, very sick. So, to be honest with you, it was much easier on me than I think it is on a young person. I think if you're 19 years old and you worked real hard in high school and you got into a good college, to have a bad psychotic break in college means you've got to drop out of that quarter or that semester. And as you know, [as] everyone knows, the courses aren't always offered every semester. And now you're off-sync, and then you have another episode two years later, or a year later when you come back. And now all your friends are graduated. I think it's a devastating blow to a young person. They have in L.A. even some agencies that specialize in trying to help young people. It was tough enough on me at age 30 when I got sick, but I had a

run for my money, you know – I was able to make it through college; I was a Navy officer; I was a Peace Corps volunteer; I was an engineer. I had more life experiences, I think, than a lot of these younger people actually have. I had it easier in that regard.

My heart goes out to a young person. I really encourage, as I mentioned, the psycho-social rehabilitation, the symptom management module. I think every person should go through that, number one. Get involved with NAMI. There's a need for young people. They are having NAMI people on college campuses. There's a need for that. Don't give up. The issue of meds in 2010 – it's still the same problem. Some people get very, very lucky with meds, and some people, unfortunately, get very, very unlucky. But there's no choice at this time in that regard. So, I would encourage them to get involved with NAMI and get a lot of good counseling.

KC: One gal we have become good friends with, she always says that for the people that don't want to take the medication – because there's the issue of what [medication] you respond [to] and what you don't – she always says, you know, "If you don't take your medication, you're handing your control of your life over to the mental health system."

FB: I understand what you're saying. Again, see, some people get very, very lucky, and some people, unfortunately, get very, very unlucky. It's not fair. It's not fair. And I wish there was less randomness to the situation.

KC: But there are twofold issues: there's the lucky – there's some people who get lucky – but then they just don't want to take their medication.

FB: There are several reasons people don't want to take medication. Number one – a lot of people don't think they're sick, okay? It's denial. A lot of people don't like to take medication in general – that's number two. But the number three – really the number one issue – is the side effects. And this is not make-believe. Some people have very, very terrible side effects. And some people get very, very lucky and they have absolutely no side effects. You know, it's interesting—the actress, Patty Duke, for example. You may have read her book, [A] *Brilliant Madness*. She had terrible mania for decades. It was not diagnosed by her doctors. And she, as a movie star, could get away with it. She'd make a million bucks on a film, and then she'd blow it all. And she'd hire someone in the parking lot to be her business manager, and they steal all her money, and then she'd make another—anyone else would have ended up homeless in this situation, but she got away with it.

Well, the point is they tried her on lithium. Lithium probably costs about two cents a pill. There's no patent on it because it's a naturally-occurring substance, and in her case, she [a psychiatrist] gave it to her, [and she had] no side effects, no problems. End of story. It stopped the mania, no side effects. And that's the end of her book. I mean, unbelievable. She got very, very fortunate.

A lot of people, for example, both my brother and me—all lithium did for me, for example, was terrible acne on my back. That's about all it did. It did not help me with my symptoms, but there are people out there. Someone like myself is not likely to meet many of them because they're unlikely to go into NAMI. If they have one episode, they put them on lithium, for example, and their symptoms are gone, and then they go to their internist to get lithium. I know one guy who gets lithium from—I don't know if it was Wal-Mart or something by bulk, or something unbelievable – he buys it [for] two cents a pill.

So, there are people like this out there, although I'm unlikely to meet them. They get very, very lucky like that. Then I've met other people with depression so bad that say to me, everyday they get up and they pray, gee God, help me not to commit suicide today. The situation is so—it's very unfair, the situation.

KC: What do you look for in a therapist or somebody providing treatment?

FB: I look to see if they're involved with NAMI at some point. A lot of these people—we're in Los Angeles—a lot of these people have spoken with NAMI. That's a good sign right there that they have sympathy.

KC: Why?

FB: Well, number one, they're not going to blame the parents for the illness. Number one. Number two, they're interested in mental health advocacy. They know the issues involved with insurance and reimbursements, and that's a very good sign that you can find somebody who's involved with NAMI. And again, just because you're very, very smart doesn't mean you have to be unkind. Like I said, I've met some very, very good doctors who are very kind. Also, if they're accessible. I know one doctor who actually, in the back of his business card, he puts his home phone number. Now, I recognize that's not typical. It's a senior doctor, he has a home office, and he puts his number on his business card. Now, that's an exceptional person, and I recognize that. And it is a time that you're dealing with residents, and I recognize that a lot of these young people, these residents, they've been on the fast track their whole life. They're in their mid-20's, and I know they're very, very bright people. If you're suffering with the illness, though, I don't know—not so much the resident isn't qualified, but, look, if you're a late teenager or a college student, you [a client] had to drop out of college and you're assigned a therapist who, their whole life, has never really had a setback and most likely [has] been on the fast track all the way through high school and college and everything, sometimes it hurts to have somebody [like that]. Personally, that would not be my number one choice in many cases, although I have had good residents over the years. But word gets around.

And the partial hospitalization program, I really benefited from that – as opposed to going from one extreme, where you're in the hospital for a full-blown psychotic break, and then going home, your parents may not be able to be there all day long, for example. If you can get somebody in the partial hospitalization program, you see, they will meet other people, like I did, that will help them get insight into their illness. Also, they will get to meet maybe five to ten different mental health professionals – social workers, nurses with Master's degree in psychiatric nursing, occupational therapists – that, in many cases, have small, private practices of their own, and so you can sort of see, gee, once I come out of partial hospitalization, I might be able to really benefit from—I like that person. It's much preferable than going cold to somebody [who you do not know].

### **III. On Stigma; NAMI & Involvement; Advice to Parents with a Child with Mental Illness**

KC: I just lost my thought because I was so into what you were saying. I want to switch gears a little bit. In the course of your illness, how has stigma impacted you?

FB: I've been public about my illness. I'm at a point that—I've been in other documentaries, I've written letters to the editor, I have maybe six or seven letters to the editor published in the Los Angeles Times. So, I'm out of the closet in regards to mental illness here. Had I tried or had the situation been different—remember, I was a civil engineer, which is a very conservative—working for a 500-person firm of 500 civil engineers. Most of these people never took courses in biology in college; they took course in engineering, so they know nothing about this. If I tried to stay within that community, my illness might have really worked against me there.

Also, I'm sort of glad that I got sick after I was a Navy officer, after I was a Peace Corps volunteer because I can guarantee you that my diagnosis would have prevented me from being allowed to do either of those things. So, I got lucky in this regard. I was at a training last year, and I met a very bright woman who was a valedictorian of her high school class, had very bad—she was doing better from bipolar, but the point being is that she said she applied to the Peace Corps and they turn her down, which hurt her real bad. You know, she was in her early 20's and she was an internationalist person, but, you know, you've got to understand the reason—the problem, though, [is if] you're in a third world country, you have an episode, there's no mental hospitals to go to. So, Peace Corps turned her down. So, that gives you an example. I've not suffered as much. I was able to make it through college and Peace Corps and Navy before I got sick. I think I was luckier in that regard.

KC: How did you make the decision to go public?

FB: Well, after I met—I mentioned that other guy, my schoolmate, in the hospital there. We both went to Cal Poly. And I realized that I could do more good in this regard than I could as a civil engineer. There's a lot of people that can do civil engineering. There are not that many people who can do mental health advocacy. So, I realized I wanted to devote the rest of my life to this issue because it really, it affects so many people. It destroyed my grandmother's life, my brother has a pretty crummy life, and I don't feel I got ripped off in life. I had a run for my money. My brother got ripped off in life. It's much more important that I do stuff like this rather than try to go back to civil engineering at this point in time.

KC: Have you had any backlash for being public?

FB: No, no, no, I have not.

KC: What's the experience been like?

FB: Going public? Oh, it's very—your name gets around and you get called in to various things. It's sort of funny – sometimes things happen on the same day, which is always difficult. You hate to turn down something. I got a call from the L.A. coordinator for In Our Own Voice and she wants me to speak to this school of psychologists, and then Mental Health Commission is meeting that day. I mean, I wish there wasn't conflicts. I wish there was less of that. And mental health advocacy is a wonderful, wonderful thing. You meet a lot of very interesting people. I love the NAMI conventions. I have gone to probably ten between CAMI [California Alliance for the Mentally Ill, now NAMI-California] and the California ones. 'Cause of the cost, I don't know if I will go to Washington, D.C. next year. But that, I have enjoyed. But again, your name gets around.

You're giving me a lot of time here, but I was invited by a well-known psychiatrist at the VA to go with him to Washington, D.C. with other researchers to try to convince congress people and their staffs to provide additional funds for mental health research. And I did that. I was invited to that three years in a row. In that case, I was invited there, they needed somebody who could talk fast because I had three and half minutes flat – that was it. The doctors made their pitch, I made my pitch. Interestingly enough, the congress people and the staffs were far nicer to me than they were to the doctors because they sort of viewed the doctors as being hat and hand trying to get money for their facilities and themselves. So, they were much nicer to me in that regard. But I was glad I got invited for that. Your name gets around, and that one, I got invited for 'cause I had to talk fast. You're giving me much more time here than they did.

KC: Well, I'm getting to ask you a lot more questions (FB Laughs). You're such a good, fast talker. And thank you for being able to—I'm really impressed with how you're tracking 'cause I'm bouncing you all over the place.

FB: That's okay.

KC: So, thank you. I want to ask about how your family's been involved and what their role has been?

FB: My brother's too sick to help me. I visit him twice a week at the board and care where he lives. My mom's alive. My mom's 85. My dad passed away 14 years ago. I had a very good father. I was very lucky. But he died. He had heart disease his whole life, but when he was 66, he basically just fell over one day and dropped dead, and he was dead in a matter of minutes. It was a big loss. I wish Dad was here, particularly he would help with my brother's situation. The load's on my mother and myself. My mom's elderly at this point. She's doing pretty good for her [age]. Both my parents – 15, 20 years ago – both my parents were involved with NAMI. My brother got sick first, as I mentioned, and he's been much sicker than me, and the prognosis for him is much poorer than it is for me. But having parents in NAMI is very helpful.

KC: What is NAMI and what do they do?

FB: NAMI is the National Alliance on Mental Illness. It has a quarter million members nationwide. They have activities both at the federal, state, and the local level. For example, the chapter in L.A. – Westside L.A. – might have 50 people; maybe have speakers from UCLA; they invite doctors and psychologists and social workers to speak about what their research is and how it could help. Maybe [at] a typical meeting, maybe 30 people show up. The conventions are very interesting. [At] the statewide convention, once in year – NAMI California – maybe four [or] five hundred people show up, and it's very, very good. At [the] national [convention], if you're fortunate enough to make it to a national [convention], like 3,000 people show up, and basically NAMI just takes over the entire hotel, and it goes on for four or five days. That is worthwhile going to if you can possibly afford it. It's well worth going to a NAMI National convention.

KC: Why?

FB: Well, camaraderie is number one because there's going to be thousands of people in the room that are all in the same boat that you are. Either they have the illness themselves or they got a very, very sick relative. Most people that join NAMI have very sick

relatives. If your kid's mildly ill, they're probably not going to really join NAMI. So, we're all in the same boat in that regard. Plus, they will invite the very pro-NAMI researchers to come – psychiatrists and research biologists, and all those people. You want to hear about what medications coming down the line. Very, very good.

There are people organizing to speak before parents. NAMI has this very big Family to Family program, which is wonderful. A lot of parents, before [they come], they're devastated because of their kid's illness, and after they attend a NAMI Family to Family course, they have dramatic improvement in their insight, you know what I mean? If you're not involved with NAMI, I don't think you're going to make it. They're a lot of people in a board and care [like] my brother is. There's lots of sick people there, and maybe their parents visit once a year, on their birthday, and that's it. They're burned out. You have to be very careful. You maybe not realize it happening, but if you have a very, very sick relative, you may say, "That'll never happen. I'll never give up on my kid," but some people get so sick, and their parents burn out.

NAMI is an excellent way to not burn out. And particularly, attending the annual convention – it moves around the country – if you can possibly afford it, it's worth going to because it might give you enough intestinal fortitude to make it another year with your kid. One thing about NAMI, you're going to meet people that have far bigger problems than you and you're going to meet people who have far less problems than you. It never ceases to amaze me. If I had more time, I could tell you a thing—I've had a difficult time, but I've heard stuff you wouldn't believe. And getting involved with NAMI is a very good thing.

KC: So, advice to parents – other than getting involved with NAMI, what advice would you give to a parent whose child has just gotten sick?

FB: They have to do a tremendous amount. Assuming this is the first time this has happened, they have to do a tremendous amount of learning quickly. Throwing money at the problem may not be the best solution here. A lot of parents – they better join NAMI or other groups fast. I'll give an example. I have a volunteer job that, twice a week, I help a woman. She works for the Mental Health Association, actually, and she has a telephone line and a computer line. People email and call in questions to her. And I help her. I know a little bit about computers, a little bit about internet. I help her with that. She's an older person herself. But she had a—I'm sorry, my train of thought lost here. Repeat.

KC: You were talking about advice to parents and—

FB: Right. I was in her office there, and a father called in. This is the reason I brought [this] up. The father called in – "I want to know what's the best mental hospital in the United States of America" is what he said to me. We have two types of people who call in. Either they call in and they have zero insurance – no money to pay for any therapy of any kind, or we've got the—this guy was on the other end now. Okay, his kid has just gotten sick. He's calling us in. Simple question – "I want to know the best hospital in United States." And I said, "Well, you know," I said to her and I said to him, "Look, I know U.S. News and World Report, once a year they have a ranking of hospitals nationwide for various categories, including psych. I know that UCLA, for example, is, I think, number five. It's the top one on the west coast, and the top four happen to be in Boston – Massachusetts General and Harvard." 'Cause I guess how they rate this—this

is up to U.S. News and World Report, probably based on the amount of research papers they publish and all this stuff. He says, "Thank you. I'm flying there right now." I said, "Whoa, whoa, cowboy, slow down." This man is in a panic mode here. And he thinks he's going to get the kid on a plane and fly to Boston and that's going to solve the problem. Look, they might have very good places, but this has to be thought out. I discourage panic thinking, but for someone who's new to the illness—there actually happens to be in L.A.—I don't know if I should say the name, but there actually is a specific organization that helps people with first breaks. I don't know if I should say it or not. Okay. But there is, specifically for young people, what's happening is that a lot of young people—parents and young people were going to a very well-known rehabilitation place in Santa Monica, but they have a lot of hardcore homeless there that have been mentally for several decades. And it would freak the parents and the kids out to go there and see; there's not the outcome that they want. So, there actually is a separate organization specifically for people with first break.

But this has to be thought out. An excellent book – *The Quiet Room*, by Lori Schiller. She came from a wealthy family, and it was interesting. In terms of covering it up, my experience is the wealthier the family – the first break, the second break – the wealthier the family, the more the effort is made to cover it up. And in her case, her father was number one—it was a very good, thin little book, very good book – *The Quiet Room*. And it tells [that] at first—this is the first action – "Gee, my kid is going to have the stigma of mental illness on them. We've got to cover this up. We've got to go to the hospital and make sure that there aren't records of this." And her father was a wealthy person, and she was at a very exclusive private school. She was at Tufts [University] or something like this in Massachusetts, which I guess is a very good school and all that. But, see, that's a panic reaction there, and that's not good. You're going to have to do a lot of learning very, very fast.

And my opinion is that throwing money blindly at it will not—well, how do you judge which hospital is better than another? If you walk it—do you want to take a tour? Okay, you take a tour. What are you going to judge it on? The furniture, how the nice the furniture is? If you don't know anything about psych anyway—for example, at this point in time in my life, I don't plan on getting readmitted to the VA Hospital. I haven't been re-hospitalized in 15 years. I do not expect to get hospitalized again. But in my case, if I had a problem, I'd go to the VA 'cause in my case, it's going to be free, even though the food is pretty bad. I don't mind saying this on camera. The VA food in the hospital is pretty bad (he laughs). And the furnishing – it's passable, but it's not that great. But if you're going to have some smart doctor try a new med on you, it doesn't really matter. You might be faced with two choices, but one is only marginally better but [a] dramatically more expensive situation.

There's a famous book that—I won't mention the name. Another book, here, was by a parent whose kid was also in Massachusetts, interestingly enough, in Boston. And she writes this whole book describing the whole saga of trying to get her kid treatment and everything. And at the very, very end, her conclusion of the book – and remember, this is person giving advice to parents [in] writing this book – is that she got her kid in the most exclusive board and care in the country. She and her husband have to borrow each year further and further in debt to keep this kid at this most exclusive [board and care]. And that's the end of the book. (sarcastically) Great. You're trying to give advice to parents, and in my opinion, that's not acceptable advice. You say, "I love my kid. I'll do anything for my kid." Okay. But if you're not careful, you can get financially cleaned

out here. I've met people [whose] insurance ran out and the mother has put the house up for new mortgage, and the kid's still not getting better. So, blindly throwing money at it is not going to solve it, in my opinion.

KC: Okay. I wanted to ask Marcia if you've got any questions or topics that we haven't covered.

Marcia Meldrum: I think he's done pretty well.

KC: (laughing) Understatement; you're great.

FB: Thank you.

KC: I can see why they're calling you. They should be calling you up to Sacramento every month. (FB laughs)

#### **IV. Schizoaffective Disorder; OCD & Medication; On Living with Mental Illness; Words of Hope**

KC: I wanted to [ask you], just so we got it, if you could say your name and your diagnosis, and take a breath after that, and then say what the illness is.

FB: My name is Frank Baron. I suffer from schizoaffective disorder. That's my primary problem. I also have a moderate case of obsessive-compulsive disorder, which is not fun either, but I'm living with it.

KC: What is schizoaffective?

FB: It's sort of a combination of both a mood disorder and a thought disorder. Sort of a combination of both bipolar disorder and schizophrenia. Interestingly enough – it's a very severe mental illness – but the prognosis for that is even better than [for] people with full-blown paranoid schizophrenia, which is like my brother, for example. It's a combination of both, and I'm lucky to be on one med, but a lot of people with the illness are on multiple meds – one for the thought disorder, one for the mood disorder.

Obsessive-compulsive disorder takes different forms in different people. In my case, I do a lot of checking of things that most people wouldn't check too much. If I leave an area, I look at the floor to make sure I didn't drop anything behind me. This is a problem. I'm living with it. I tried medication for this, which helped me moderately, which I gained 85 pounds on fast. I lost that weight. I am not going to go back on that med. But those are the two primary problems that I have at this point. But again, I'm grateful I have not had an episode of psychosis or of clinical depression, which is a terrible thing in its own right, [in] 15 years, so I've been very lucky in this regard.

KC: With schizoaffective disorder—well, you described what OCD is like. What is it like to have schizoaffective disorder?

FB: Well, if it's full-blown—and I'm fortunate not to have it full-blown at this point in time. But the thought disorder could be paranoia, hallucinations. The affective part of it, the mood part of it, could be depression, very bad depression involved there. You know, interestingly enough, when I was—there's stigma among the various diagnoses, as well.

Interestingly enough, for years, I was diagnosed with bipolar. There's two types of bipolar – bipolar I and bipolar II. Bipolar I has full-blown psychosis, and bipolar II, just hypomania, not major. But the interesting thing is that in our society, even in psych circles, people with bipolar disorder are sort of viewed as misunderstood geniuses. And people with schizophrenia are viewed as shooting up post offices – that's how it sort of looks.

For years, my diagnosis – and it's not uncommon at all for diagnoses to change – my diagnosis was changed from bipolar disorder to schizoaffective disorder. I was hurt very deeply. I said, "I don't want the first part of it, the 'schizo,' I don't want the schizoaffective. That's schizophrenia." So, I had stigma, myself, against schizophrenia. I didn't see myself in that regard. But interestingly enough, that was probably one of the luckiest breaks that I had because that shifted me into a different group of doctors that tried me on Clozapine, [which], if I had remained under bipolar, they probably would not have tried. Now in theory, all these doctors are crossed-trained, but the reality is that in many university hospitals, for example, one group of doctors is doing mood disorders, and another group of doctors is doing schizophrenia. So even though they all went to medical school, the reality is their viewpoint is different. And if my diagnosis had stayed bipolar disorder, it's much less likely, I think, they would have tried Clozapine on me, which is viewed at the schizophrenia end of the situation. Like I said, at the time, I was devastated that my diagnosis was changed from bipolar to schizophrenia, but looking back on it, that was probably one of the luckiest break I had there.

KC: I had the opposite shift. As depression, there was the perception that I was just not able to adjust to life, but the minute it was bipolar II, it was like, "Oh, it's real now," but also switched into better doctors. One little tidbit – and I don't know if you bumped into this research – but Clozapine does have a history of sometimes tripping OCD-like symptoms.

FB: I have heard this. I'm not well-versed in this issue. I'm too sure what to do about it. Again, my years of [being] very sick with schizophrenia was much worse than my years with OCD, with the obsessive-compulsive disorder. They [also] had what is known as exposure and response prevention. I went to a psychologist for this, for OCD. What it means is that you force yourself to not do the compulsion, and then over time, your anxiety will go down. It might take hours. This was not a fun technique for me. I did not enjoy this. I was going to a psychologist who specialized in this. She was a very bossy person. Maybe for her specialty she had to be, I don't know. But I had a very good doctor recommend to me [that] this is the number one treatment because the drugs—again, the one drug that existed for it caused me to gain 85 pounds, which I've lost. I was huge. I was up to 305 pounds, which I gained over a year or something like that.

So, I don't know what to do about the OCD, really, right now. I really don't want to back to that same psychologist because it was not an enjoyable—I know it's not supposed to be enjoyable, but the anxiety of forcing yourself not to do this and then waiting hours for the anxiety to go down.

You see, this is the thing – OCD is not on the spectrum. Emil Kraepelin, a hundred years ago – the famous psychiatrist – [said] you got all the way from bipolar disorder to schizophrenia. You got clinical depression, major depression, you got bipolar type II, then bipolar type I, then schizoaffective disorder, and then paranoid schizophrenia. And this was identified a hundred years ago as a spectrum. Well, OCD doesn't fall on that.

OCD falls under anxiety disorders, which is a different set of doctors. An anxiety disorders clinic, ranging from people—I don't have a problem flying, for example. A lot of people, they are afraid to fly – you know, stuff like this.

Your point, though – I've heard this before, that Clozapine can cause OCD. I don't know much about that. I know there's no way in hell I'm ever going off Clozapine. I'm taking Clozapine the rest of my life without question, even though I've been on it longer than anybody else at the West L.A. Veteran's Hospital.

I've met some people who have said to me—I've even met a young doctor who said, "Well, gee, you—" [with] Clozapine, the big deal is the blood draw. One percent of the population, if they have this agranulocytosis, which is a white blood cell problem, if you're taking Clozapine and you're [part of] the one percent of the population, it can kill you. But the point is this problem almost always surfaces in the first few months of taking Clozapine. What's comical in my case [is] I've been on it 15 years. When you're first put on it, the first few weeks is once a week – the blood draw – to make sure you're not in this one percent category because if you are, they have to discontinue the Clozapine, put you on something else. I understand that – once a week at the beginning, then once every two weeks for six months. But I've been on it 15 years, and at this point, my doctor's even told me if I had this problem happen to me at this point in time, I'd get into the New England Journal of Medicine without a doubt because I'd be one in a trillion.

But I've got to play the game. Each month, I've got to go to the VA and I've got to get blood drawn, and that's it. I'm taking Clozapine the rest of my life. I'm tired of mental hospitals. I don't want to go back to mental hospitals. The blood draw's an annoyance, but I don't want to go back to the mental hospitals anymore.

KC: My last question – is there anything I haven't asked you that you think is important for the general public to know about living with mental illness?

FB: If you have a relative with mental illness, talk to the well part of the person. Even someone like my brother, who's very impaired – I don't know, maybe 65% of his brain is malfunctioning, but there's still a human being there. There's still a loving person there, even though he's very, very sick. Try to talk to that, as opposed to concentrating solely on the illness.

The biggest thing, typically for young people, when they're first diagnosed – they're really embarrassed this is happening to them. They have to drop out of school. They're afraid to tell their classmates. The parents, as I mentioned – the wealthier the family, the more the effort is made to cover it up. They're afraid to tell their relatives what happened. In my own case, I think my father, only years later [after] my brother got sick did he actually write a letter to the other family members. So, it's unfair to make the person suffer in silence and to be alone. It's unfair. It's a terrible illness. It's nobody's fault that this happened, but there's still a human being in there. Try to talk to the well part of the person as opposed to the sick part. That'd be the only comment I would make to you.

KC: Let me ask John if he has any questions. Sometimes I gesticulate too much.

John: Would you have any words of encouragement or hope for people that have just been diagnosed?

FB: There's definitely hope. You may be very, very lucky and have little problem, but you may not be so lucky, and there is hope. It may take some time. But you're still a human being. It can happen to anybody. Tell your friends that you really care about. They'll be glad to reciprocate. They will not abandon you. Learn about the meds – take your meds – but learn about them as to what they—and it's true, some people do have side effects, so learn about that. There are NAMI classes for peer-to-peer. In fact, at the end of this week, I'm spending four days—they're want to train me to do that. They want me to teach a class at night, once a week for ten weeks. Such things do exist. But again, don't give up and just keep in mind that you may get—again, it seems like one third – there's this issue of the thirds – one third of the people have a total recovery, one third of the people, their prognosis is not so good, and one third is in the middle. I'm sort of in the middle myself. Maybe if some young person's watching, maybe you'll get lucky. You'll be in the top third where you'll recover 100%. Don't give up. It's a complicated situation, and you have to do a lot of – same thing I said to the parents – you have to do a lot of learning very fast.

KC: On the one third, one third, they're starting to revise that because they realized they were only staying in touch with people who were staying in treatment. So, they think the numbers are much larger on the recovery side, especially because of all the stigmatized years 'cause nobody would go back and say, "Hey, I had schizophrenia." They just put that in the closet and moved on because they had the blessing for it.

FB: Yeah. Just in my case, I'm in the middle. I got lucky – the verbal skills have not [been] affected [by] my illness. This is why I get invited to do a lot of speaking, that's why I was invited here. I'm lucky in that regard. I wish I did not have this concentration problem because there would even be more things I could do with mental health. I'd even want to return to my work – I was an engineer – and still be involved in NAMI [at the same time]. So, that's the disappointment, but in my case, my verbal skills have not been affected by the illness. I'm in the middle third, myself.

**END OF INTERVIEW**