SPEAKER NOTES

“In Our Own Voice”—Personal Stories of Experience with Bipolar Disorder

Summarized by Thomas T. Thomas

At our November 15 meeting we heard from two young speakers, **Krista Radojevich** and **Robert Villanueva,** who shared their experiences with bipolar disorder. “In Our Own Voice” is a program developed by the National Alliance on Mental Illness (NAMI) to put real names and faces on mental illness. By showing that people with brain disorders can come in all ages, from all ethnic groups and areas of society, the program fights the stigma associated with bipolar disorder, depression, schizophrenia, and other disorders. Radojevich and Villanueva are from the new Tri-Valley NAMI affiliate and have presented at several NAMI conferences, where audiences found their stories uplifting and full of hope. They are not only active speakers in the program but also trainers who have helped others participate in the program as speakers from as far away as St. Louis and New Mexico.

To begin with, they played a brief video, also developed by NAMI, in which people with various brain disorders describe the sequence of recovery: Dark Days; Acceptance; Treatment; Coping Skills; and Successes, Hopes, and Dreams. After playing a relevant segment, the two shared their own experiences from that period.


KRISTA RADOJEVICH AND ROBERT VILLANUEVA

Dark Days

Krista Radojevich said she was raised in Pleasanton, California, studied at University of California - Davis, and took a BS degree in Exercise Physiology. In March 2001 she had been under a lot of stress—planning her wedding, receiving a job promotion—when things started going wrong. “Tornadoes,” she called the experience of what was going on in her brain. Her mind would race so fast her body couldn’t catch up. She would go entirely without sleep for weeks. Then she started saying things to people she herself didn’t understand. She was feeling paranoid and couldn’t calm down.

Even though her father had been diagnosed with bipolar disorder, Krista did not recognize the symptoms in herself. She did not identify with the disease or begin to educate herself. She received medication on an outpatient basis and slowly started to feel better. And then she gradually stopped taking the medication.

Her symptoms came back and were much worse: lack of sleep, anxiety, and paranoid delusions. Because the medication she took was the same as her father’s, she believed it was not hers and that people were using it to poison her. She was brought to the emergency room on tranquilizers and sent to a psychiatric facility. Krista could not understand why she was there, feared she had hurt someone and, because she was locked up, felt she had to leave right away. She became manic and shrill, rushing with adrenaline, so that it took three or four nurses to put her into the "quiet room." There she had no water, feared she would die of dehydration, and was anything but quiet.

For Robert Villanueva, the dark days were filled with isolation and fear, "as if a door had closed." He has since recognized that his problems started when he was a child. His mother had been what was called in those days "manic depressive" and would self-medicate with alcohol and drugs. "As children, we were always walking on eggshells," he said. "Children are greatly affected by mental illness."

But he found refuge in school and work. At 21, he thought he had left his mother's world behind. He was a wrestling coach, had bought a house, started a family, and had a stepdaughter. His life was good. Then he started missing work. He was also missing sleep, needing only two or three hours at night, and would take on several jobs as once because he had so much energy. Then his body would crash. He saw a doctor, but his situation continued its downward spiral. Robert lost his family, had to move out and sell the house. On a manic whim, he opened a business that he was not prepared to pursue and eventually lost it.

Robert had a deal with his doctor that if he ever got suicidal he would come see the man before taking his own life. Robert made an appointment, but it was for two days away; he spent the time locked in his room. When he finally saw the doctor, he said, "If we don't do something about this, I'm going to drive to the Bay Bridge and jump off." That got through to the doctor, and Robert was sent to a mental facility. From there, Robert would go on and off his medications, living with friends or arranging to show up just in time for dinner. "I lived out of a spare change basket," he said.

Acceptance

"For me, acceptance took a while," Krista said. "It did not come overnight." With her illness, she felt alone, weird, different, never sure of why she was there. "Because of the stigma, I never felt confident about sharing, not even with my closest friends. But it was more hurtful to keep it all inside."

She needed more than medication; she needed to learn about her illness. "Bipolar disorder is a disease like diabetes, except that it's in your brain," she said. "And it's totally treatable. You have to be able to accept yourself as having a brain disorder."

Krista found comfort and inspiration in Kay Redfield Jamison's books *An Unquiet Mind: A Memoir of Moods and Madness* and *Touched with Fire: Manic-Depressive Illness and the Artistic Temperament,* both accounts of the author's experiences with bipolar disorder.

"When I left the hospital," Krista said, "the nurse said the goal was not to come back. She gave me a list of support groups, but I didn't really want to go. I finally did go to a group in Berkeley." The people there were from all walks of life, she found, and all had a mental illness. Krista said she was not alone anymore. Some of the things she heard were horrible—but also familiar. She could listen and start to accept her condition.

Robert said that as a wrestling coach he had learned to be stubborn. "You get hurt, you tape it up, and you get back in there," he said. "But with a mental illness, you can't tape it up."

To educate himself, Robert went to his local Barnes & Noble store, where he could sit on the sofas, drink the coffee, and read about his illness. He also found the works of Kay Redfield Jamison useful.

Robert admitted he would go off his medication when he was feeling good. "I was seduced by the highs," he said. "Then I would go all out, meet everybody, be on top of my game. But nobody saw the depression side of me."

From his reading, he learned to study his family history and discovered that all the men had died young. The oldest was 42, and Robert himself was approaching 35. "I came to a realization," he said. He started going to support groups but didn't talk for two or three meetings. He just sat and listened to other people's stories. As with Krista, the shared experiences helped him understand his illness.

Two million people in the U.S. have been diagnosed with bipolar disorder, 19 million with major depression. One of the audience members acknowledged having the illness and said it was easy to tell people about the depression, but she had trouble admitting to being bipolar. Krista Radojevich responded: "That's the stigma. Which one is more socially acceptable? Depressed people are not going to hurt you. But manic behavior tends to frighten people."

Treatment

"These illnesses are biologically based brain disorders," Krista said. "They are extremely treatable. People can get better." She said that medication is an important part of treatment, but that you cannot disregard therapy. Early intervention and treatment are better for a number of reasons. First, there's a better chance of recovery and, second, the person has less time and opportunity to damage his or her own physical person, family relationships, career prospects, and other parts of life.

"It took me a long time to get to the right cocktail of medications," she said. "I was on mood stabilizers, atypical antipsychotics, SSRIs[1]… You name it and I've probably been on it in the last three or four years. They're all there in my pill box." She acknowledged that many drugs have side effects, especially weight gain. In her case, she said, 60 percent of the medications seem to work, and 40 percent don't. She goes to a psychologist once a week to describe her current personal situation and get her medications adjusted. Krista said that, in the current system of behavioral health care, where the consumer sees one therapist for one task, another for something else, the consumer must become an advocate for his or her own health.

Robert said that, because of the stigma and his own independent nature, it took him a long time to become honest with himself and the doctors in order for treatment to work. Over the years he has taken 14 different medications, including antidepressants, antipsychotics, and antiseizure drugs. He ultimately made a deal with his therapist that he would show up once a week, regardless of how he was

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[1] SSRI stands for Selective Serotonin Reuptake Inhibitor, a class of medication that controls serotonin levels in the brain.

feeling—even in deep depression, when he felt most isolated, with his brain slowed down, when he wasn't bathing and didn't want to go out in public. Once, when he did miss an appointment, the therapist wouldn't see him for three months.

In time, Robert learned how to bring himself down when he was becoming hyperactive, and how to motivate himself when he only wanted to stay in bed. He had no family to support him in this, so he had to draw support from his weekly group meetings.

Coping Skills

"I have lots of coping skills," Krista said. "The latest is journaling. I write things down to get them out of my head. And of course I exercise, with a Spinning® class for indoor cycling, yoga, and Pilates. Now I can relax, and I couldn't relax before, because I would become too jittery."

She said her biggest coping skill was her Wednesday night support group, which she started in her area. "The common thread is that we want to help educate each other. I feel like I have a purpose, to give back to these people."

Robert said his biggest coping skill was saying no. "With all that energy, you can go everywhere, help everyone, build a fence, join a party… But sometimes I have to stay home and take it easy. My red flag is when I want to keep going past the end of the day, and when I become obsessive-compulsive, like needing to line up the edges of all the brochures."

He said that a form of coping was also being okay with taking his medications, and the support group keeps him dialed-in. Participating with In Our Own Voice and training others for the program was another way to cope.

Successes, Hopes, and Dreams

"I get a thrill out of helping people, as NAMI helped me," said Krista Radojevich. "People with mental illness can recover. It's a physical disease. It just happens that the organ affected is the brain." She said that her success was looking at all the small successes in her life: getting out of bed, brushing her teeth, going to work, continuing with her life, staying on track with her recovery. "I am not bipolar," she said. "I just have that sickness. Stigma is what keeps people from getting the help they need."

She announced that soon she was going to be profiled in the East Bay's local *Diablo Magazine* in its "Threads of Hope" section for her volunteer work in the community and the In Our Own Voice program.

Robert Villanueva said that his success came three years ago, when he got out of bed after staying there for two months with depression and then making the bed. "I still make my bed every day." he said.

He still goes to his support group, too, and is proud to be training others for In Our Own Voice. "Every time I do one of these presentations, I learn something."

His hope is that "the next generation of my family can grow up and be okay with mental illness."