
NAMI EAST BAY NEWSLETTER

A local affiliate of the National Alliance on Mental Illness (NAMI)

March-April 2015

FERC at Five Years

Wednesday, March 25

The Family Education and Resource Center (FERC) is an innovative family/caregiver program in Alameda County. Since opening its doors in September 2009, the center has served 10,586 families who have a loved one with a serious mental health challenge. At our next speaker meeting, Director **Annie Kim** and Lead Family Advocate **Bettye Foster** will share some of what they have learned in the past five years: advocating for your role and inclusion with providers, what families should know during a crisis, and the often overlooked importance of practicing self-care. Conceived and put into being by Alameda County family groups with funds from the Mental Health Services Act (Proposition 63), FERC is unique in the nation.

Meeting starts at 7:30 pm

Albany United Methodist Church

980 Stannage Avenue, Albany

Corner of Stannage and Marin

Meeting is free and open to the public.

Support Meetings

NAMI East Bay offers the following monthly support meetings:

- **Support and Share Group for Families of Adults** is held on the 2nd Wednesday of each month. The next meetings are March 11, April 8, May 13.
- **Support and Share Group for Families of Children, Adolescents, and Young Adults** is held on the 3rd Tuesday of the month: March 17, April 21, May 19.

Support Group Meetings are held at the Albany United Methodist Church, 7-9 pm. Enter through the gates to the right of the door on Stannage Avenue, turn left through the large room, go down the hall, and come up the stairs. Signs will be posted.

All support meetings are free to NAMI members and non-members, offering a chance to talk with others who understand, give emotional support, and share ways they have found to cope.

FERC Family/Caregiver Conference and Anniversary Celebration

The Family Education and Resource Center is excited to announce an all-day conference on **Thursday, April 30**, to recognize the importance and needs of families and caregivers. In addition to break-out sessions covering essential topics, the event will celebrate the amazing five-year journey of an innovative family-centered program. Two nationally recognized keynote speakers, Dr. Penelope Frese and Dr. Fred Frese (www.fredfrese.com), will participate in the conference and join in the celebration. Invitations will be sent out in March, and an RSVP will be required to participate.

BACS Wellness Centers Now Open to New Members

Bay Area Community Services (BACS) has now opened the doors for adult consumers to access its four Wellness Centers in Oakland, Hayward, Pleasanton, and Fremont!

What this means is that anyone who needs mental health support can stop by during regular hours (8:30 am to 6:30 pm, Monday to Friday, and Saturdays and holidays in Oakland and Hayward from 8:30 to 4:30) for groups, classes, individual support, employment support, or just a welcoming place to hang out and participate in a community free of stigma.

Please join BACS Wellness Centers or refer anyone who may benefit from this peer-to-peer support! For more information, please contact BACS at 510-613-0330 or www.bayareacs.org for activities calendars and more.

SPEAKER NOTES

Targeting Sensory Processing Abnormalities in Schizophrenia with Cognitive Training

Summarized by Thomas T. Thomas

Research into the schizophrenia-spectrum disorders is proceeding on many fronts. The speaker at our January 28 meeting, **Bruno Biagianti, MD**, is a Post Doctoral Fellow in the Vinogradov Schizophrenia Laboratory at the University of California - San Francisco, where he coordinates a series of neuroimaging experiments to investigate the effects of cognitive training and oxytocin on key brain regions. He also investigates the use of mobile devices to disseminate cutting-edge treatments for schizophrenia, including cognitive training, automated cognitive behavioral therapy (CBT), computerized neuropsychological assessments, and virtual group therapy, to individuals with schizophrenia who live in community settings around the Bay Area.

Dr. Biagianti trained as a psychiatrist at the University of Milan, Italy, and has worked with patients with schizophrenia. His long-term goal has been to improve their quality of life. He believes that, by treating sensory processing, we can improve their cognition, symptoms, and real-world functioning.

“Schizophrenia is a highly prevalent disorder,” he said, twice as prevalent as Alzheimer’s and five times the incidence of multiple sclerosis. “It’s also a costly disease to treat,” several thousands of dollars more annually than cancer, stroke, or heart disease. The hallmarks of schizophrenia are positive symptoms like delusions and hallucinations; disorganization in thinking and speech; negative symptoms like affect flattening and loss of volition or pleasure; and social or occupational dysfunction. “Medication works quite well on most of these symptoms,” Biagianti said, “and psychotherapy can help with a person’s coping skills, but neither addresses the cognitive impairments that may be present.”

These impairments are common and stable features of the schizophrenia-spectrum disorders, even with individuals who are young, taking medications, and are clinically stable. They include problems with

focusing, sustaining attention, learning and memorizing, retrieving information, and planning.

For the past 100 years, medical science has been deconstructing schizophrenia. From an empirical observation of patient behaviors and experiences (or phenomenology), it’s a mental disorder. From the study of symptoms (psychopathology), it’s a thought and perception disorder. From the viewpoint of cognitive impairments (neuropsychology), it’s a cognitive disorder. And from the viewpoint of neural system imbalances (psychophysiology), schizophrenia is a sensory processing disorder.¹

Several parts of the brain are involved in sensory processing. Say you’re walking down the street and a friend comes up and says, “Hi!” The sensory cortex processes both the auditory signal (“Hi!”) and the visual signal (her face). The prefrontal cortex limits your attention, filtering out extraneous details, so you can focus on her voice and face. And the hippocampus retrieves information, so you can identify her voice and features as a particular person known to you, with associated emotional representation.

“In schizophrenia,” Biagianti said, “every part of this process is disrupted. The system is ‘noisy,’ so you can’t interpret the signals, can’t filter the flow, can’t retrieve the information.” The usual processing time in the brain is 200 milliseconds, but a person with these sensory disturbances may take 600 or 700 milliseconds to make these connections.

Aberrations in neurochemical and neurophysiological processing can cause disturbances in sensory perception and representation, leading to faulty cognitive processes and experiences. Reverberations from these disturbed processes can then rupture an individual’s sense of ownership of an experience, his or her sense of presence, corporeality, self-demarcation, and existential orientation. And that can ultimately lead to psychotic hallucinations and delusions.

Conversely, rehabilitation of sensory processing—in both its speed and its accuracy—should improve brain function and translate into an improved quality of life. Rehabilitation is possible because the

¹ Other ways of looking at this disease are from molecular biology, the study of neurotransmitters and receptors, as a neurochemical disorder, and from the study of genetic polymorphisms and epigenetic modifications as a genetic vulnerability.

brain exhibits “neural plasticity.” That is, it is like a muscle and it responds to exercises.

Targeted training of early sensory processing uses computerized tasks that are carefully controlled and constrained. The subject undergoes a highly intensive training schedule—usually an hour a day, five days a week—for 20 to 40 hours total. The tasks are customized, based on psychological assessment. They are designed never to be too difficult, and therefore frustrate the subject, but never too easy, either. As the subject performs the training, he or she enters a learning curve, and the tasks become progressively harder.

For example, training the auditory system might play two “chirps,” or sweeps up or down, from a low pitch to high, or vice versa. The subject identifies the direction of each chirp on screen with an arrow. As the training progresses, the chirps become shorter and closer together. Then the subject might be presented with four cards, two each associated with a spoken word like “fig” and “mat.” The subject must match the cards to the words he or she hears. As training progresses, the subject is presented with closer-sounding words like “chuck” and “rug,” and more cards are shown with more words to match.

For visual training, the task might show a circle of eight birds all alike, except that one has different plumage. The circle disappears, and the subject must indicate the position of the unique bird. As the training progresses, more birds are shown in different patterns. Another task will show a human face, followed by two more, and the subject is asked to match the emotion shown on the first face with that on either of the second faces. This task can help with the subject’s interpretation of facial expressions and social functioning.

To test whether this training improves cognition in people with schizophrenia, Biagiante’s group ran tests between subjects with chronic schizophrenia—people in their 40s with a diagnosis for more than five years—and a set of healthy controls. The schizophrenia group was randomized to avoid contaminating results with effects of particular medications or other conditions. One group took 50 hours of auditory training; the other, 50 hours of computer games. Those with the training showed significant improvement in global cognition, speed of processing, memory, verbal learning, visual learning, and problem solving. Similar testing with younger people

who had a diagnosis for less than five years showed even greater results.

Neural scans with magnetic resonance imaging (MRI) compared brain activity in the healthy controls with the schizophrenic test subjects both before and after training. After training, their brains showed areas activated in ways comparable with the controls. The improvements are real-world and lasting, because test subjects were followed for 24 months, and their improvements remained constant after the initial 50 hours of training. Biagiante attributed this lasting effect to the subjects being able to function better and exercise their cognitive faculties. Test subjects themselves reported sensing a 30% to 40% improvement in their abilities.

“The training has no negative side effects,” he said. “But it does take time, hours of training—at least an hour each day.” Biagiante also noted that the results apply only to individuals with schizophrenia, schizo-affective disorder, and bipolar with psychosis, but not to other forms of bipolar or other mental disorders like depression.

The cognitive training project is now in its fifth year. In the Bay Area, training started at the San Francisco Veterans Administration Medical Center and is also offered at Prevention and Recovery in Early Psychosis (PREP, <https://askprep.org>) facilities in San Francisco, San Mateo, and Alameda counties; at Putnam Clubhouse in Concord; Lakehurst Hotel, Oakland; and Alameda County Hospital. This training is not commercially available and is used for research purposes only, as it requires a battery of tests to develop an individual’s capabilities and customize the tasks for his or her progression.

Biagiante is now developing a version available for the Apple iPad that can be delivered unsupervised, with weekly check-ins, for people in areas poorly served by mental health clinics. A future direction is use of cognitive training to prevent the onset of psychosis in youths at risk for schizophrenia.

Anyone interested in taking part in further work on cognitive training at UCSF should contact the study coordinator at (415) 221-4810 extension 3077, or contact bruno.biagiante@ucsf.edu.

Past articles in the Speaker Notes series are available online at www.thomasthomas.com under “NAMI East Bay.” Also available is a copy of the brochure “Medications for Mental Illness.”

Musings from the President

About a month ago, a black bunny rabbit appeared in my yard. Cute as could be, it munched on weeds, hid under a salvia bush, twitched its little nose, and was super alert to my presence, scurrying away when I approached to talk bunny talk. One day I noticed an early spring flower was missing, one I had admired the day before. Then I found the bunny sunning itself in my back yard, lying in a large pot destined for summer vegetables. All of a sudden, I had an “aha” experience about the charms of having a rural experience in Oakland. Bunny had become a problem and I had to stop its path of garden destruction. So I became the arch villain of my Beatrix Potter-infused childhood: I became Farmer McGregor.

It's not satisfying nor at all rewarding to become a villain. It's not something that most of us are cut out to do, or be. Yet so many of our NAMI families are vilified by their sons and daughters, children who have been loved and cherished all their lives, yet whose adult perspectives on the world are colored by a psychotic process where reality and fantasy are complicated distinctions. We're the ones who try to set limits and explain boundaries. We're the ones who confront misperceptions and distortions. And most seriously, we're often the ones who have to call the authorities in a 5150 process which brings in the police. Our roles become contaminated early on in the saga of parenting a child with mental illness.

In support groups and conversations, many, many family members share the experience of being verbally abused and characterized as vindictive, unfair, punitive, and unloving mothers and fathers. Oftentimes, they are the recipients of such anger because they are a reliable presence: they are striving to engage and make things better. The commitment they have to their child is palatable. And they are there and present in a confusing world in which a lot of other social contact has diminished, because friends don't stick around someone who lashes out and is unpredictable. It is so poignant to hear perfectly reasonable and lovely people who are valiantly coping with their family angst tell of the emotional pain they endure at the hands of their offspring. It's not fair being labeled the villain in these family sagas.

—Liz Rebensdorf, President, NAMI East Bay

Humane Treatment for the Seriously Mentally Ill: Urge Alameda County to Adopt AB1421

Note: NAMI East Bay's leadership has devoted countless hours over the last couple of years in advocating the passage of AB1421, Laura's Law for Assisted Outpatient Treatment (AOT), in Alameda County. We congratulate our Contra Costa and San Francisco county colleagues who have just recently succeeded in getting pilot programs onto the books. In our efforts, we have spent more than 20 hours in direct dialog with representatives from consumer group, and in the end we agreed to disagree on this subject.

At heart, we don't think it should be controversial to help those who can't help—much less speak for—themselves. And we feel the toolbox of interventions should include one heavily monitored process that doesn't rely on an individual voluntarily asking for help. That said, below is an overview statement, heavily condensed, from the AB1421 advocacy consortium.

AB1421, Laura's Law, passed into California law on January 1, 2003, is designed to help persons who have a serious mental illness (SMI), whose condition is deteriorating, and who will not accept services on a voluntary basis. AB1421 will help ensure they receive adequate, community-based, mental health services.

We need to move from a crisis-driven system of care and recognize these are chronic disorders that need long-term strategies. We need to acknowledge that people in the throes of psychosis may not be competent to make medical decisions for their own care. AOT laws could help to get care to people before they deteriorate and would reduce our reliance on costly and ineffective short-term strategies. AB1421 could also help to break the cycle of homelessness that traps so many.

The law enables a judge to mandate that a person with SMI in deteriorating condition who has repeatedly refused voluntary treatment participate in a comprehensive outpatient program. Under court or-

der, the person will be housed and provided with community-based mental health and social services, usually for a minimum of six months.

Contra Costa, Los Angeles, San Diego, San Francisco, and Orange counties have all adopted AB1421. Unfortunately, Alameda County's Behavior Health Care Services staff are only recommending voluntary services to the Board of Supervisors, not AB1421.

A consortium of parents, mental health professionals, and concerned community members is trying to get Alameda County to adopt AB1421 and, if not in full, to conduct a pilot program to demonstrate the benefits to the clients and the county. To achieve this, the Board of Supervisors must hear from constituents now. We cannot stand by watching people with severe mental illness deteriorate on the street and risk violent behavior when there is a proven alternative. Citizens need to communicate their strong support for action on AB1421 by the Board of Supervisors.

Be the voice of those who do not have one of their own by contacting your Alameda County representative:

- Scott.Haggerty@acgov.org, 510-272-6691
- Richard.Valle@acgov.org, 510-272-6692
- Wilma.Chan@acgov.org, 510-272-6693
- Nate.Miley@acgov.org or district4@acgov.org, 510-272-6694
- keith.carson@acgov.org, 510-272-6695

For more information contact the [Alameda County Advocates for AB1421](#), or visit the website <http://treatmentadvocacycenter.org/lauraslaw>.

Family-to-Family Teacher Training

If you were a participant in one of our 12-week winter Family-to-Family classes and would like to give back by becoming a member of our teaching team, let us know. A weekend training will be held in May.

Join NAMI's Peer-to-Peer Program

The NAMI Peer-to-Peer Education Program is a free 10-session course for adults living with mental health challenges. Held once a week for two hours each, it is taught by trained peer mentors living in

recovery themselves and provides an educational setting focused on recovery that offers respect, understanding, encouragement, and hope. NAMI Alameda County is offering two classes in late March: in Fremont near BART on Wednesdays from 1:30 to 3:30 pm, and in Oakland off Fruitvale Avenue on Saturdays from 1 to 3 pm. Contact kathrynlum@comcast.net (408-422-3831) for more information and to register.

Thank You! Thank You! Thank You!

You readers responded generously to our recent annual fund-raising drive and we are most grateful. We now can redirect our anxieties away from keeping financially afloat and into supporting families and advocating for positive change.

We especially want to acknowledge donations made in honor of Quinton Hackemack, the father of our treasurer Trish.

And an extra big thank you goes to an anonymous donor whose very generous donation will enable us to get a new NAMI East Bay website up and running this spring.

NAMI Coalition Forming to Reform Kaiser's Mental Health System

Last month, Kaiser psychologists, social workers, and therapists held a week-long, statewide strike to protest the understaffing at Kaiser clinics that forces patients to wait too long to get care. It was the largest strike by mental health workers in U.S. history.

As NAMI members and affiliates, we have an opportunity to unite with mental health clinicians and other consumers to repair Kaiser's broken mental health care system. We're forming a statewide coalition of NAMI affiliates united for better mental health care at Kaiser.

We are asking NAMI affiliates and members to (1) write the Department of Managed Health Care about your experiences at Kaiser; and (2) collect stories about poor mental health care at Kaiser.

To participate or for more information contact edherzog@comcast.net.



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Please check your mailing label. If the code "15" is over your name on the right side of the label, your dues are current through 2015. If your mailing label indicates a previous year, or nothing at all, your dues are not current.

We urge you to mail your 2015 dues now. And if you can afford to add a bit more, please do so. Your \$35 NAMI East Bay membership gives you our newsletter six times a year, the quarterly "Connection" from NAMI-California, and the NAMI-National "Advocate." NAMI East Bay is nonprofit [501(c)3] and your dues and contributions are tax deductible.

Family Membership, \$35 per year Open Door Membership, \$3 per year

Make checks payable to "NAMI EAST BAY" and mail to NAMI East Bay, 980 Stannage Avenue, Albany, California 94706

Contact me for Family to Family Education Class

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