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# NAMI EAST BAY NEWSLETTER

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

March-April 2017

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## Triple Treat with Guy Qvistgaard Wednesday, March 22

We are thrilled to have **Guy Qvistgaard** as our March speaker. He essentially wears multiple hats and we're asking him to share with us his insights into his three relevant-to-us roles. He has been on the Board of Directors of our state organization, NAMI California, and is currently serving as its President. For seven years, he was Chief Administrative Officer of John George Pavilion Psychiatric Hospital, and since last November he has been Chief Operating Officer of the Kaiser Permanente Antioch Medical Center. With his 15 years of experience in hospital operations and 32 years in the behavioral health arena, he is considered an expert in the field of acute psychiatric care administration. Plus, he's just an awfully nice person who has always been accessible to families. Join us for an interesting evening.

### Speaker 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.**

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## 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 8, April 12, and May 10.
- **Support and Share Group for Families of Children, Adolescents, and Young Adults** is held on the 3rd Tuesday of the month: March 21, April 18, and May 16.
- **Hearing Voices Group for Family Members** is held the 3rd Thursdays of each month at the office, 6:30-8 pm: March 23, April 20, May 18.

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.

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## New Housing Resource

We have just learned that help is available for families looking for a board-and-care for their relative. David McGuinness has a placement service available free for families. He can be reached by phone (510-540-7045) or email ([DavesPlacementServices@gmail.com](mailto:DavesPlacementServices@gmail.com)). Thanks to Katy Polony for sharing this information.

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## For Contra Costa County Readers

California state monies are funneled through counties for services. Although we of course complain that there's never enough, no matter where we live, the blunt truth is that most services are county-specific. Our name suggests that we address concerns across the East Bay, which we do; indeed, half our board members live in Contra Costa County. That said, it's difficult enough to learn and understand the processes of one county administration, much less two. NAMI East Bay definitely has a presence within Alameda County Behavioral Health Care Services. But, located in Albany on the Freeway 80 corridor, we are closer to many West CCC residents than to Concord resources and we welcome your participation. So, please come to our meetings where topics are general and feel free to contact us on any issue, but use NAMI Contra Costa County as a resource for actual services (925-942-0767, email [info@namicontracosta.org](mailto:info@namicontracosta.org), website <http://www.namicontracosta.org>).

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The NAMI EAST BAY NEWSLETTER is published bi-monthly, beginning in January, by NAMI East Bay, 980 Stannage Ave., Albany, CA 94706.

Telephone: 510-524-1250 - Email: [namicastbay@earthlink.net](mailto:namicastbay@earthlink.net) - Website [www.namicastbay.org](http://www.namicastbay.org)

Editor: Liz Rebensdorf

Mailing: Irene Moran

Format: Tom Thomas

Publicity: Stella Allison

### SPEAKER NOTES

# Report from the Board<sup>1</sup>

*Summarized by Thomas T. Thomas*

At our January 25 speaker meeting we heard from three of our NAMI East Bay members who described their recent activities. Board member **Ed Herzog** told of his experiences with the Hearing Voices Network. President **Liz Rebensdorf** talked about two initiatives in Alameda County designed to address the problem of housing for the mentally ill. And one of the founders of the NAMI affiliate on the UC Berkeley campus, **Michael Godoy**, discussed his new position as a program manager at the University of California San Francisco, working on scalable mental health therapeutics.

### Hearing Voices Network

Ed Herzog said he became interested in the voice-hearing experience five or six years ago when his son began hearing them, and Herzog didn't know what to tell him. His son was 30 years old at the time, under stress with a new baby, working the night shift, and not getting much sleep. Herzog has since learned that the experience can occur at any age, and children often hear voices and have imaginary friends.

Mental health professionals told him the experience was "very dangerous" and was a symptom of schizophrenia. They told him to fear the voices and to monitor the experience closely. The only treatments available were medication—which didn't stop the voices—or hospitalization if things got rough.

The voices came to dominate his son's life, because he didn't know how to cope with them. For him they were real. Even when Herzog took his son out into the empty street and demanded he show who was speaking, the experience remained real.

In frustration, Herzog looked on the internet and discovered the Hearing Voices Movement. He found it was popular in Europe—England has more than 200 such groups—but virtually unknown in this country. The founder of the movement was Dr. Marius Romme, a Dutch psychiatrist. The chief proponent and developer of the network in England is Ron

Coleman of [Working to Recovery](#). Coleman has lived experience of the phenomenon and still hears voices, even while he is lecturing and conducting training sessions.

Learning about all this, Herzog got together with other family members and people who have the lived experience of hearing voices, having visions, receiving special messages, and holding strange beliefs. They created the Bay Area Hearing Voices Network ([www.bayareahearingvoices.org](http://www.bayareahearingvoices.org)). The group organized a training session under the NAMI East Bay auspices and brought in Coleman. They were surprised when 120 people showed up and paid \$40 for the session.

"Millions of people hear voices and never come in contact with a mental health professional," Herzog said. He cited the common experience of hearing someone call your name in the middle of the night, or hearing the voice of a loved one who has passed away. When Coleman asked people at the training session about such experiences, soon every hand was raised.

The goal of the network is to reframe the voice-hearing experience, to use the voices and the content of what they say as a way to understand the person. Herzog learned to approach his son with an attitude of curiosity, rather than with fear and anxiety, and rather than trying to reassure him. "Reason and logic don't work," he said. Herzog learned that his son usually heard a woman's voice, which was mean, and a man's voice, which was kinder, and both voices told him what to do. Talks with his son have become "a window into his subconscious."

"The troubles are not over," Herzog said. "But this has given us a language. It has allowed me to be with my son—not pushing him away and labeling him. I also learned that I had to change. I have no control over him, but I can change my own attitude."

The Bay Area Hearing Voices Network has two meeting sites:

- **East Bay** at North Berkeley Senior Center, 1901 Hearst Avenue, every Monday, 6 to 8 pm.
- **San Francisco** at Conard Café, 160 Ninth Street, second and fourth Wednesdays, 6 to 7:30 pm.

The meetings are free and conducted on a drop-in basis. Family members are welcome to come with their loved one to a first meeting, but the program is moderated by peers and meant for people with lived

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<sup>1</sup> The speaker originally scheduled for January 25, Dr. Rebecca Carrillo of Berkeley Mental Health, had to cancel because of a family emergency.

experience. It is a place where they can meet with others, learn coping strategies, and hope at some point to manage the experience. To contact the group, email [bayareahearingvoices@gmail.com](mailto:bayareahearingvoices@gmail.com).

### **Housing in Alameda County**

Liz Rebensdorf has been part of two committees in Alameda County to address the dreadful shortage of housing for people with mental illness.

The Shared Housing Collaborative is an informal group that meets monthly and is hoping to become allied with the East Bay Housing Consortium to develop funding and a model for housing in the Bay Area. Two of their members have visited the Cesar Chavez residence in Davis, which provides supported housing for people both with and without a mental illness and provides a social worker on site.

The collaborative is also looking at senior housing as a possible model for people with mental illness. In the senior sector, people start with relative independence and little need for assistance and support but gradually require more and more help as they age. The mental health model would be the reverse of this, with people starting out needing lots of help and then gradually requiring less and less as they gain more skills and confidence.

But, Rebensdorf warned, nothing this group develops is likely to be an immediate benefit for NAMI East Bay family members. “Once you take federal money in these projects,” she said, “your program is open to all and positions are filled on a lottery basis.”

The other group she’s involved with is working with the county housing director in looking at board-and-care facilities. These owners are both aging out and terminating the provision of housing for people with mental illness—who can sometimes be challenging—sometimes in favor of those with developmental disabilities. Also, she noted, licensing of board-and-cares usually has less to do with treatment of mental illness and more with adhering to building codes. Consequently, the county is now looking at unlicensed room-and-board facilities, exploring a supportive referral model, called the Independent Living Association, which has been found successful in several California counties.

Rebensdorf also recognized NAMI East Bay Vice President Margot Dashiell for her work in getting an Innovations grant to fund an 18-month pilot program to increase social activities at the Lakehurst Project, a single-room-occupancy hotel in Oakland.

### **Scalable Mental Health Therapeutics**

Michael Godoy is a program manager in Kim Norman’s Young Adult and Family Center at UC San Francisco. He is working on a number of software applications and websites that will be offered for free to help people around the world deal with mental health issues. These include:

- **Help Chat**, an iOS application for mobile devices like iPhones and iPads that will provide an anonymous peer support group for the user. On demand, the app will offer someone with whom the user can talk to and express feelings and ideas. This is helpful when a person feels unwell and needs to talk.
- **You.org** is a website in development for release this summer. It provides an online portal to support programs and services. The user begins with a Self-Interview Section, where he or she discusses concerns and notes symptoms. For example, if the person shows indications of anxiety, the site refers the user to the page called “Breathing Room,” which helps people monitor breathing as a way to regain control. Or it might direct the person to a Journalism application, which helps them to express their thoughts through writing.
- **Online Courses** are in development to help people deal with specific issues. These are videos of simulated therapy, developed with a clinician, that include an assignment, discussion, and a group session. The first course is called “Women Warriors” and deals with women who come back from combat situations with post-traumatic stress syndrome. The training helps them reframe and take control of the narrative of war. The second course is “Next Mission,” a coed video on post-traumatic growth. Finally, there is “The Fourth R,” which follows up reading, writing, and arithmetic with “resiliency,” which many young adults have said they need, because success is being able to persevere through adversity.

“Technology is going to solve all of humankind’s problems,” Godoy said. “Applied to mental health, the new technologies have great power.”

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

### Musings from the President

This month I was going to write a benign column about the use of language and how we subtly communicate so much via the words we choose. But, today, listening to the radio on my way to a meeting, I got mad ... really mad. And, what I'm going to say may be offensive and, sorry ... that's too bad. I'm an old lady with nothing to lose and I have this particular venue to say what I want to say, and, if it's too bothersome, fire me.

I am mad—and worried. As of today, folks entering the USA from Muslim-predominant countries which do not have business dealings with the President will be detained and not allowed entry. If the current administration looks closely at the data, it will find that many dastardly deeds have been done by white Christian individuals who have been diagnosed with mental illness. These are home-grown terrorists and what is the government going to do about them? They can't be deported and heaven help us if we would start providing early effective treatment. My tendency to do catastrophic thinking is in full bloom, and I shudder to think of what steps this current administration could take in light of this realization ... which is not to say that this treatment of Muslims isn't abhorrent in of itself.

I'm mad that the use of science and reason is being denigrated as elitist, with "alternative facts" being more acceptable. I worry about the eventual repercussions this will have on the essential research being done—research which will enable us to better understand the complexities of climate change ... and mental illness.

I'm mad that the Affordable Care Act is being attacked—in a vacuum of nothing better on the table. Many of our relatives have benefitted from some of its provisions. As with any large systemic process, there are issues which need to be improved, but even with its faults, it has been a lifesaver for many of our loved ones.

I'm mad that on this lovely Saturday morning, six family members will again give up another four or five hours to try to develop a feasible model for housing for individuals with mental illness—sons and daughters we have been housing and managing and loving and, most of all, worrying about. We know we won't be here forever ... what will happen then to our loved ones who have challenges with

coping and daily living? The internal and external challenges our progeny face in our absence are catastrophic.

I'm mad that in Alameda County it took at least three years to get Laura's Law or Assisted Outpatient Treatment (an evidence-based practice) to be passed by the Board of Supervisors in the guise of a five-person pilot program. It's working, as it has in nearby counties, but it took us too many years to counter the hysteria generated by folks who thought it would take away their rights—which it hasn't.

I'm mad when I hear a high functioning consumer refer to serious mental illness as a "mental health condition."

I guess that underneath this all, I'm mad that my son, a wonderful human being, is shackled by the demons of mental illness—and that so many other incredible families are coping and worrying and loving and caring as I am. We're all in this together.

—Liz Rebensdorf, President, NAMI East Bay

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### Update on Assisted Outpatient Treatment in Alameda County

Last July, AB 1421 was passed by the Alameda County Board of Supervisors, and this pilot program, also known as Laura's Law and Assisted Outpatient Treatment (AOT), is getting off the ground. (To review the specifics of the law, please visit our website [www.namieastbay.org](http://www.namieastbay.org), go to "Public Policy" and scroll down).

Our neighboring counties, San Francisco and Contra Costa, have had their programs in place a bit longer and were geared for more participants. Positive results were described for San Francisco in a January 24 article in the *Chronicle*. Taking effect in November 2014, of the 108 referrals in San Francisco, 60% accepted voluntary services, 40% didn't meet criteria, and only three had to be ordered by a judge to receive treatment. These findings are similar to what has been found statewide.

The Alameda County pilot program is only for five individuals and those slots have already been filled. In this county, the AOT process is complemented by four In Home Outreach Teams (IHOTs) and a voluntary Community Conservatorship process, which stresses community-based treatment with family involvement and intensive case management

services. Only one conservatorship slot has been filled. All three programs have a Family Advisory Board as well as a Peer Advisory Board.

Several members of the Family Board commented on the new programs. One said, "AOT is delivering the kind of intensive case management that is promised under the law. It is a level of service that I believe can be game-changing. ... There were procedural kinks that had to be worked out and steps along the way to implementation where the law needs to be interpreted. ... I believe that those involved are very invested in its success. ... Very pleased and appreciative of the care and commitment of the TeleCare treatment team ... [which] has been able to accomplish in a few weeks certain things that his former [service team] could not accomplish in four years. ... Feel I have a partner supporting me and my son." Another, "I'm impressed at their dedication and commitment to developing a successful pilot."

These positive remarks are included here because they're so upbeat, but they don't acknowledge the amount of challenge and stress these particular writers endured as they led the advocacy effort in the county to get Laura's Law put in place. Despite ominous warnings from those opposed to AOT, we're not seeing a sweep of consumers off the street into forced compliance with treatment. It's being handled professionally, with sensitivity and full use of due process. We'd like to have this law extended in the county, and it sounds as if it is getting off to a strong persuasive start.

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### Dignifying Madness

We were invited to participate in a symposium held last week at the University of California Berkeley School of Law titled "Dignifying Madness: Civil Commitment, Disability Rights and Mass Incarceration." Essentially, the intent was to take a new look at the LPS laws which have informed the whole California commitment process since the 1960s.

As we know, the prisons have become the largest psychiatric institutions in the country. The 5150 process is a difficult one with police involvement, and many of our families truly hesitate to call 911 because of the law enforcement issue. No decisions

came out of the four-hour symposium, but the conversation has begun and will continue. The involvement of academicians in law and social work, psychiatrists and legislators plus family and consumer representatives is promising.

If you'd like to be kept informed about this process, let us know. We would also like to know of places in this country where the commitment process is kinder and more gentle.

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### Short Takes

- We want to thank our readers for their very generous response to our annual fundraising request. Your support is so meaningful. We're hoping to have sufficient funds to bring in a part-time office manager who can bring some efficiency and consistency to our volunteer-led office.
- We are sorry to report that the twice-monthly Saturday Oakland Connections group for consumers has been cancelled. Thank you so much to Chris Hunter for going through the training and offering this opportunity to peers.
- On several recent occasions our attempts to respond to an office caller have been frustrated by the automatic response that the caller's message box was full and was not accepting new messages. Since we don't have an office staff, we do recommend that Alameda County residents call the Family Education and Resource Center (FERC) during business hours at 888-896-3372. (Also, see the note on page 1 about Contra Costa County callers.)
- Regarding FERC, their website at [www.askferc.org](http://www.askferc.org) contains invaluable and extensive information on such matters as medication, incarceration, crises, benefits, and practical tips. It's an incredible resource. **Note:** The FERC office will soon be moving into a site near Lake Merritt in Oakland
- The spousal support group is taking a break. We'll let you know when or if it resurfaces.



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## NAMI EAST BAY 2017 MEMBERSHIP

Please check your mailing label. If the code "17" is over your name on the right side of the label, your dues are current through 2017. If your mailing label indicates a previous year, or nothing at all, your dues are not current.

We urge you to mail your 2017 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

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