NAMI EAST BAY NEWSLETTER

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

January-February 2017

Psychiatrist with Berkeley Mental Health

Wednesday, January 25

A recent addition to the staff of psychiatrists at Berkeley Mental Health is **Dr. Rebecca Carrillo**. Her practice includes paying attention to the whole person, including the mental, emotional, and physical health of her patients. She is currently reviewing research on negative symptoms, such as low motivation, lack of interest in everyday affairs, and social withdrawal, that are commonly experienced by people living with serious mental illness. Dr. Carrillo believes in the benefits of family support and appreciates the opportunity to communicate with family members at our January 25 meeting.

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.

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 January 11, February 8, and March 8.
- **Support and Share Group for Families of Children, Adolescents, and Young Adults** is held on the 3rd Tuesday of the month: January 17, February 21, and March 21.

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.

PREP Group for Families of Young Adults

PREP Alameda is delighted to announce a new group for family members of young adults under the age of 30 who experience psychosis. This drop-in group is a blend of support and topic discussion, and is open to all community family members who may be interested in participating.

The group meets at the beautiful BACS Towne House, located at 629 Oakland Avenue, Oakland, on the fourth Tuesday of each month. Winter 2017 dates are December 27, January 24, February 28, and March 28. Meetings begin at 6:00 and go to 7:30. For more information contact the family group facilitator, Stella Allison, Coordinator of Peer and Family Support Services at PREP Alameda, 510-590-0570.

The PREP (Prevention and Recovery in Early Psychosis) program offers treatment for youth age 16 to 24 within two years of their first experience of psychosis. They may be enrolled for up to two years and have access to individual therapy, medication management if desired, cognitive behavioral therapy, peer support, peer led group participation, vocational and educational coaching and support, and individual family support and family support group participation. For information, go to askprep.org; to make a referral for yourself or a family member call 1-888-535-7737.

Short But Good Stuff

Donations: Thank you so much for the generous donations we have received from our paper and online readers. We are still gratefully accepting donations at NAMI East Bay, 980 Stannage Ave, Albany 94706. We truly appreciate your support.

Family to Family Class: We still have a few spots left in our 12-week class, starting January 19. Contact the office to register; we do not accept drop-ins.

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SPEAKER NOTES

Current Research on Emotions and Mental Health

Summarized by Thomas T. Thomas

Ann Kring, PhD, is a professor and chair of the Department of Psychology at the University of California, Berkeley, and a member of its Institute for Personality and Social Research. She received a BS in psychology from Ball State University and her MA and PhD in clinical psychology from the State University of New York at Stony Brook. Dr. Kring is past president of the Society for Research in Psychopathology and president-elect of the Society for Affective Science. She has received many awards for her research work, is the author of eight books and several scholarly papers, and has served on the editorial boards of top journals in the field.

Her current research focus is on emotion and mental health, with a specific interest in the emotional features of schizophrenia, including the negative symptoms, decision making, and the linkage between social life, cognition, and emotion. She also studies the ways in which people differ from one another in emotion and expressive behavior and the linkages between social context and emotion.[1]

To start, Dr. Kring identified symptoms of schizophrenia. Positive symptoms—not a value judgment but an excess of something other people don't usually have—are hallucinations and delusions, as well as disorganized thinking and behavior. Negative symptoms include blunted affect (lack of visible emotion), anhedonia (lack of pleasure), avolition (lack of motivation), asociality (lack of engagement), and alogia (lack of speech). "We need better assessments and treatments for the negative symptoms," she said, "which are the hardest to treat." She added that current medications don't do much for these symptoms.

Her work on emotion has dealt mostly with blunted affect and anhedonia. "These symptoms represent difficulty in feeling and expressing emotion," she said.

Many families with a mentally ill relative can attest that it's difficult to engage and interact with someone who does not show emotion. That's because we use facial expressions and gestures in talking with people to know when we're connecting with them. A person who shows no emotion, has poor eye contact, and speaks in a monotone—all signs of blunted affect—seems difficult to reach.

Anhedonia, no longer enjoying things that once gave a person pleasure, appears to lead to reduced willingness on the person's part to engage in activities and try new things.

In researching these emotions, Dr. Kring and her team brought people both with and without schizophrenia into the lab, showed them film clips of funny things like comic movie scenes and disgusting or fear-inducing things like dental procedures, and then videoed their reactions. The team also attached electrodes to their cheekbones and brows to get minute measurements of the nerves and muscles that create smiles and frowns. And they measured physiological effects like heart rate and skin response, as well as performing brain studies. Outside the lab, subjects were issued pagers or smartphones and contacted irregularly to find out what they were feeling right at the moment and to record their level of happiness or sadness on a five-point scale.

In four separate studies of outward expression, people with schizophrenia watching the film clips registered fewer expressions than the general population. But when asked what they were feeling at the time, people with schizophrenia said they were experiencing strong feelings, particularly negative emotions like sadness, disgust, and fear.

"We have long assumed people who don't show emotion are experiencing an emotional void," she said. "But that is not the case. If we use facial expression to judge response in other people, we may be wrong about how they are feeling."

These findings raise a paradox, Dr. Kring said. If someone says they feel happy even when they don't show it outwardly, why don't they pursue the things that make them happy? To understand the answer, she made a distinction between "anticipatory pleasure"—or looking forward to something in the future—and "consummatory pleasure"—or savoring it in the moment.

In the studies, when people with schizophrenia were presented with a pleasurable experience "in the

[1] To follow Dr. Kring's research work, see http://socrates.berkeley.edu/~akring/.
To contact her, email kring@berkeley.edu.

moment" they felt no deficit. But anticipation was a problem. When asked how much they would enjoy something, people with schizophrenia did not predict as much pleasure as those without the illness. This suggests that people with lowered anticipation will be less likely to go and do something.

Another way to look at this, Dr. Kring said, is that people with schizophrenia had an anticipatory reaction that was about equal to their consummatory experience; so their prediction of the future was accurate. People without the illness often overestimate how good something will be in the future and then have a lower actual experience. This correlates with findings from psychology and the social sciences, that increased expectation of a positive result is a survival mechanism. It drives people toward pursuing a goal and compels them to act, while negative expectations about how bad things might be warn people off trying something dangerous. But Dr. Kring noted her team has not fully studied negative expectations among people with schizophrenia. She also noted that people suffering from delusions may have heightened anticipations, in common with bipolar disorder and mania.

The brain studies Dr. Kring's team performed used functional MRI scans, measuring blood flow in the brain to show the firing of neurons in the amygdala and in areas associated with emotion and feelings. The team showed each subject a picture for five seconds of something either pleasant, like puppies, or unsettling, like a dental procedure. Scans taken in the moment of experiencing the picture indicated no differences between people with and without the illness, suggesting they were feeling the same things. After a 12.5-second lapse, however, the brains of people with schizophrenia were no longer activated, while those without the illness remained active with the emotion. "This suggests that, for people with schizophrenia, it's 'out of sight, out of mind,' " Dr. Kring said. "Imagining the future and holding onto your feelings happens inside your head."

The emotional symptoms of schizophrenia are harder to treat, she said, and current medications don't make a dent in them. One of her team's goals is an emotional rating scale for assessment interviews. They are also working on possible treatments.

One promising approach is a meditation-based treatment. In one of their studies, 31 people, all in their twenties, met in a group once a week for six weeks and practiced meditating for ninety minutes. Their focus was on "loving kindness," where one tries to experience positive feelings toward oneself and others. Measures taken before and after the sessions showed that subjects' anhedonia and blunted affect were reduced, and feelings of pleasure and savoring were increased. Some of these measures lasted as long as three months. Dr. Kring said six weeks were not long enough to achieve a sustained effect, and the subjects would need booster sessions. Also, the test should now be run with a control group.

Meditation is not the only way to treat these symptoms, she said, and current work with cognitive behavioral therapy (CBT), especially in the United Kingdom, is making progress. "These treatments show that schizophrenia is *not* a neurodegenerative disease, like Alzheimer's and Parkinson's."

What can families do with this information? First, don't assume because a relative doesn't show emotion that he or she is not feeling things. Expression does not equal feelings. Second, understand that people with schizophrenia have trouble looking forward, and you can provide them with a positive "scaffolding" to understand and anticipate an event. Third, you can help the person savor an event and their feelings during it by having conversations about feelings and providing language to talk about them.

At the end of her comments, Dr. Kring introduced Debra Wilson, a filmmaker working on a documentary called *A State of Mind*. It's based on two of the team's schizophrenic subjects who have found each other and are making a life for themselves in the Bay Area. She showed an eight-minute sample cut from the film. At the end, Dr. Kring said, "You are living this life with your relatives."

Q. What about using Acceptance and Commitment Therapy (ACT) to treat schizophrenia?

This therapy is generally used for treating depression by accepting your feelings without judgment and then committing to goals. It might apply to some of the delusions and hallucinations of schizophrenia, like hearing voices, in terms of not judging the truth of beliefs, because you can't talk people out of what they believe.

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

Musings from the President

Anyone who has been caught up with the new streaming Netflix drama *The Crown* will understand my distress call: "I need a Tommy!" This series relates the early life of the current Queen Elizabeth, who is suddenly thrust into being the English monarch when her father dies. It's a truly wonderful program, peopled by familiar faces and names. Tommy is the private secretary she inherits from her father's rule—very English and proper. He tells her what needs to be done and how to do it, with a bit of history thrown in.

Is it much of a stretch to imagine how helpful that kind of person would have been when we've gone through our crisis periods with our relatives? The process of becoming a queen brings with it certain issues that none of us will ever face, but the emotionally laden situation of dealing with a relative in psychiatric crisis is daunting and scary … and unique in of itself.

What does one do when, for the first time, your son starts talking about himself in the third person or discusses killing himself? What about the second or third time, and the behaviors have escalated, and there are holes in the wall, and you're truly scared for yourself?

We all need a Tommy-type person by our side to help us get through a crisis, but instead most of us have faced these kinds of situations by ourselves, not knowing nor understanding what was happening in front of our eyes. Our unique relationship and history with our relative have informed much of our interactions, but it has been my experience that I was not dealing with the relative I knew: he had become someone else in the throes of psychosis.

But … we all survived these episodes, and we continue to do so, although not happily nor confidently. We've learned what things to say and do. We've learned what works best to de-escalate situations. We're more familiar with the resources, however limited. And we know what happens if we have to call for help.

Still, it would be nice to have a Tommy by our side.

—Liz Rebensdorf, President, NAMI East Bay

Pyroluria Disorder

By Ed Herzog, NAMI East Bay Board Member

Note: *The following article is offered as part of our mission to explore alternative perspectives on mental illness. This does not imply endorsement of the theory that there may be an easy fix for everybody via a nutritional antidote to mental illness. Since there are perhaps more theories out there than research facts at this time, it is useful to be exposed to non-mainstream ideas. We encourage you to do your own research and consult with professionals.*

We recently discovered that a family member tests positive for a genetic metabolic imbalance called Pyrrole or Pyroluria Disorder. Why is this important? Well, it turns out this condition is found in more than half of those suffering with schizophrenia. It is diagnosed by a simple and inexpensive laboratory test that measures the level of pyrroles in the urine. Results from 10-20 mcg/dL of pyrroles are considered borderline. Above 20 mcg/dL is considered positive for pyroluria. Our family member recorded 23 on the test.

Why is this important? Pyrrole is a normal breakdown product of hemoglobin, the molecule that carries oxygen in your blood. When pyrrole is excreted from the body, it binds with two nutrients that are essential to mental health: zinc and B6. Individuals with this genetic glitch will become deficient in zinc and B6.

The combined effect of B6 and zinc deficiency can be harmful for brain function as well as the immune system. B6 is required for the synthesis of three critically important neurotransmitters: serotonin, dopamine, and GABA, the same neurotransmitters that are regulated by the antipsychotic drugs our loved ones are prescribed to ease some of the symptoms associated with their mental issues.

Some of the symptoms correlated with elevated pyrrole are poor stress control, high irritability and temper, history of underachievement, little or no dream recall, auto immune disorders, severe anxiety and/or depression, psychosis, fearfulness, difficulty in handling stressful situations, obsessions with negative thoughts, extreme mood swings, history of dyslexia, and severe inner tension. Conditions associated with Pyrrole Disorder include ADD/ADHD, Asperger's syndrome, autism, bi-polar disorder, depression, manic depression, obsessive-compulsive disorder, schizophrenia, and substance abuse.

Pyrrole Disorder is often found in children who have behavioral dysregulation, attentional problems, and learning disabilities. Their suffering can be exacerbated when a child has a growth spurt because growing increases the body's demand for zinc and B6. However, with appropriate supplementation, mostly zinc and B-6, people can improve rapidly.

Many psychiatrists and medical doctors do not yet know of this genetic glitch and its impact on mental health; so it is very important to work with a medical practitioner who is familiar with the disorder and who can test for pyrrole and develop a supplemental protocol. Our doctor is Marcey Shapiro, MD, in Albany, California. She uses DHA Laboratory (www.pyroluriatesting.com), which charges $80 for the urine test. The collection process must be done correctly, because pyrolle is light sensitive, and DHA can give you instructions.

This condition is hereditary and tends to run in families at a higher rate; so I would recommend family members be tested as well. Most cases of pure Pyrrole Disorder with no concurrent disorder can be resolved in 3 to 12 weeks. It is a little too early to tell how this is affecting our family member, but we are already noticing improvements. Will let you know.

21st Century Cures Act Passed and Signed

The 21st Century Cures Act (HR 34) includes key pieces of the Helping Families in Mental Health Crisis Act of 2016 (HR 2646), the Mental Health Reform Act of 2016 (S 2680), and the Mental Health and Safe Communities Act of 2015 (S 2002). The Cures Act is a $6 billion bipartisan legislation that will improve integration and program coordination across federal agencies that serve people with mental illness and remove unfair barriers to mental health care. It will also address the needs of people with mental illness who become entangled in the criminal justice system.

The act also:

- Combats suicide in our schools and communities so precious lives are saved.
- Increases the mental health workforce, so more trained professionals can help.
- Strengthens the enforcement of the mental health parity law, so health plans are held accountable for the coverage people paid for.
- Invests in early intervention, so people get the right mental health care at the right time.
- Invests resources to keep people with mental illness out of jails and in treatment.
- Supports Evidence Based Practices, such as Assisted Outpatient Treatment.
- Requests clarification of confidentiality in dealing with families.
- Increases funding for disease research.
- Promotes workforce development and integrated care.

NAMI reviews the mental health provisions of HR 34 at http://www.nami.org/Blogs/NAMI-Blog/December-2016/, "Signed, Sealed, Delivered."

Possible Changes in Obamacare

With the new political climate upon us, we need to be prepared for possible changes that will affect the current medical coverage of 20 million Americans. As it stands right now, treatment for mental health and substance abuse issues has been considered one of ten essential benefits, and covered individuals have benefited from the mandate to treat psychiatric and non-psychiatric disorders equally. We have heard that there will be no exclusion for pre-existing illnesses, which affect so many of our relatives who become ill before age 25. But, that is based on having had continuous coverage for 18 months, and our folks' employment and benefit path may have lapses. If states end up receiving a lump sum for Medicaid, that will roll back the expansion drive of Obamacare, which will hurt our relatives disproportionately. See the opinion piece in *The New York Times,* December 12 (www.nytimes.com/column/richard-a-friedman).

More Short But Good Stuff

Accessibility: If you cannot climb the stairs to our second floor office for a support group, let us know beforehand; we'll try to arrange space downstairs.
SSI Change: Public benefits will see a very small increase (0.03%) in January 1. Let us know if you want a copy of the rate sheet.
Family Night: The next Family Night is Monday, February 20 at 6 pm. We provide pizza, conversation, and games depending on how folks want to spend the time. Format is casual. It is necessary to RSVP (510-524-1250) or email us.

NAMI East Bay
National Alliance on Mental Illness

980 Stannage Avenue
Albany, California, 94706
Time Value

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Are your dues paid for 2017?
(Check Mailing Label)
Your Support Matters
Renew Now!

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

☐ **Contact me for Family to Family Education Class**

Name: _____ **Phone No.:** _____

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