



NAMI SYRACUSE

National Alliance on Mental Illness

Newsletter

MARCH/APRIL 2016

Meeting Schedule

NAMI Syracuse - Support & Sharing Meeting
Third Tuesday of each month

AccessCNY

420 East Genesee Street, Syracuse 13202

(parking and entrance in rear of building)

NAMI Syracuse is a not-for-profit, self-help organization of active and concerned families and friends of people who suffer from serious and persistent psychiatric illnesses, most commonly schizophrenia, bipolar disorder (manic depression), and severe depression.

**CARING
EDUCATION**

**SHARING
ADVOCACY**

Events Calendar

| | |
|-----------------|---|
| March 15, 2016 | Support & Sharing Meeting 7:00pm - AccessCNY |
| April 19, 2016 | Support & Sharing Meeting 7:00pm - AccessCNY |
| May 5, 2016 | NAMI Syr. Children's Conference <i>Addressing Challenging Behavior in Children & Youth</i> |
| May 7, 2016 | NAMIWalks/Rochester Village Gate, Rochester, NY |
| May 17, 2016 | Support & Sharing Meeting 7:00pm - AccessCNY |
| May 20-21, 2016 | NAMI Syracuse Garage/Barn Sale <i>(see page 7)</i> |
| June 21, 2016 | Support & Sharing Meeting 7:00pm - AccessCNY |

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MESSAGE FROM THE PRESIDENT

Dear Members:

When Mary told me that it was time for me to write a letter for the newsletter, I moaned. Frankly, I had no idea what to write about. You see, this is my time-I feel quite removed from NAMI and Syracuse and mental illness. I don't even know how close Donald Trump is to being the next Republican presidential candidate!

All my adult life winter has been hard on me. As I age it gets harder. Sometimes you just have to take care of yourself.

I'm writing this from Belize, Central America while looking over the Caribbean Sea. I do yoga every day. I swim. I read and write a good book. I might spend an hour or more just playing Cookie Jam. (I'm not very good. So far my favorite level is 40.) I watch HGTV and dream of redoing my home. Sometimes I feel guilty that I'm not more productive. Most of the time I don't.

Whether a primary caregiver or just having a loved one who struggles with mental illness or personally struggling, it's easy to lose self. We become consumed and allow stress to define who we are. I've talked to family members who haven't taken a vacation for years for fear that something bad might happen while they're away. I've seen and directly experienced the havoc an ill family member can wreak on their caregiver's wellbeing. I know individuals who have allowed their illness to dictate who they are.

Nothing will help you or your loved one more than helping yourself. I have a little saying I wrote that I send to myself every day on my phone. It says: You are in charge of your happiness-yours, and only yours. And there is no one who can make you happy other than you.

As winter draws to an end, please remember who you are, what makes you *you*. Take care of yourself without guilt. Do something just for you! Make it your time.

Now I think I'll go back to playing Cookie Jam.

~Karen

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- Frank Mazzotti.....Treasurer
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- Stephen Glatt, PhD

For the latest happenings at NAMI Syracuse visit us on **Facebook** and LIKE our page.

 [facebook.com/NAMISyracuse](https://www.facebook.com/NAMISyracuse)

Follow us on **twitter**:

 twitter.com/NAMI_Syracuse

Crisis Intervention System - Overview and Vision

The NYS Office of Mental Health recently held a day long meeting to gather input from consumers and families about crisis services in New York State. It was an opportunity to voice what doesn't work and what is helpful during a mental health crisis. The discussions were lively and emotional. A great deal of input into positive changes that can be made in the system of care was gathered from sites across the state. A few of the recommendations made were more emergency housing and respite services, quicker response to crisis by trained teams of mental health professionals, 24/7 crisis lines to assist consumers and families, peer support across all service interventions, assistance to follow up with services and supports after a crisis, more training for first responders and data sharing of advance directives with providers.

Managed care will provide the funds to improve crisis prevention and intervention services to reduce emergency room visits and costly hospitalizations.

Social Security Training at NAMI office

On February 25-26, 2016 a training was held at the NAMI office on “**Myths, Tips, Tricks and How to Make Social Security Work**”. Twenty people attended this in-depth training on SSI and SSDI.

This training will be offered again May 26-27. Families may want to consider attending to find out how to apply for SSI for a family member, what programs are available to promote work and protect benefits.

This training was *free* of charge and was done via skype. We will send out more information as it become available.

Addressing Challenging Behavior in Children & Youth

Thursday, May 5, 2016, 9:00am - 3:00pm

Welch Allyn Room, Rosamond Gifford Zoo, Syracuse

~presenters~

Adrienne Allen MD, Children and Youth Services, Outpatient Clinic, Hutchings Psychiatric Center. Dr. Allen has been an attending psychiatrist in the children's outpatient clinic at HPC since 2004. With her support to the staff and dedication to serving children and families with complex needs, the clinic has grown significantly in the last 12 years.

Assessment, Medications and Treatment Interventions for Self-Destructive and Violent Behavior

Bridget Hier, Ph.D, BCBA Dr. Bridget Hier is an Assistant Professor of School Psychology at the University of Buffalo, where she teaches courses in behavior management, school and family consultation, and academic assessment and intervention.

Promoting Pro-Social Behavior in the Classroom and Home through Positive Behavior Supports

Regina Canuso, MSN, CMHCNS-BC, Coordinator of the Hard to Place/Hard to Serve Unit at the NY State Council on Children and Families has been an advanced practice psychiatric nurse for over 20 years, focusing on children and families in clinical, research and policy positions.

Kathleen Rivers has been the Assistant Coordinator for the Hard to Place/Hard to Serve Unit with the NYS Council on Children and Families for three years. Before moving to the Council, she had worked at NYS Education Department in Special Education for 6 years.

Multi-System Challenges in Serving Complex Children

Panel of Parents sharing

What Has and Has Not Worked for Them

Jennifer Daly is a Family Navigator with the Onondaga County Department of Children and Family Services working with crossover youth in the Juvenile Justice and Child Welfare System.

Jenny Redmond is a Family Care Planner on the Onondaga County ACCESS team.

Kelly Covert is co-owner of Strong Body Whole Heart, a life coaching company.

NAMI Syracuse Children's Conference

Addressing Challenging Behavior in Children & Youth

Thursday, May 5, 2016 * 9:00am - 3:00pm * Welch Allyn Room, Rosamond Gifford Zoo, Syracuse

Please register by Friday, April 29, 2016

- Registration Fee \$40.00
- Become a member of NAMI Syracuse & attend the conference \$70.00
- Sorry, not able to attend; but please accept my tax deductible donation \$_____

NAME: _____

FROM: (Agency, NAMI, School, etc.) _____

ADDRESS: _____

PHONE: _____ E-MAIL: _____

~Registration includes Lunch~

Display Table Requested

Mail registration form along with payment to NAMI Syracuse, 917 Avery Ave., Syracuse, NY 13204 ~or~ visit our website, www.namisyracuse.org, click "Donate" and indicate "conference registration fee" via PayPal

Tel. 315-487-2085 FAX 315-487-2154 e-mail: namisyracuse@namisyracuse.org

NAMI SYRACUSE SPEAKERS BUREAU

by Marla Byrnes

NAMI Syracuse is looking for people willing to talk to community groups. We often receive requests to do trainings for organizations or participate at health fairs. You may feel too timid to do public speaking so “manning” a table at a community function or health fair may be the perfect place to start talking with the community. If you feel comfortable speaking in public, what presentation are you comfortable presenting? Do you want to give a testimony about your own journey with mental illness or your experience helping a family member or how mental illness has affected your family? Are you a person comfortable educating others about schizophrenia, depression, anxiety or bipolar disorder? Would you like to tell the story of how NAMI Syracuse or Family Education classes have been helpful to you?

If you are interested in joining our current speakers, please notify the office, 315-487-2085.

HELP US LEARN HOW TO BETTER DIAGNOSE CHILDREN'S MENTAL HEALTH

Researchers in the Department of Psychiatry at Upstate Medical University are seeking participants in a study funded by the National Institute of Mental Health (NIMH). You may be eligible to participate if you have biological children between the ages of six to 12 years.

Drs. Stephen Glatt and Stephen Faraone are studying new ways of classifying mental health disorders in children in order to change the way that psychiatric disorders are understood and diagnosed. To do this, genetic variation and basic cognitive abilities within families will be analyzed.

“We're taking a fresh approach to the concept of 'gene hunting,’” explains Stephen Glatt, Ph.D, director, Psychiatric Genetic Epidemiology and Neurobiology Laboratory at Upstate Medical University and one of the directors of the

grant. “Instead of assuming that current diagnoses have unique genetic underpinnings, we're looking to redefine the disorders based on genetic variations and more basic cognitive abilities that might generalize across diagnostic boundaries.” Combining genetic data with cognitive performance may provide a better basis for a new diagnostic system that is less subjective than the one currently used.

Upstate is recruiting about 700 families (2800 individuals), examining a broad spectrum of childhood behaviors from children developing with and without mental health concerns. Parents and their children will complete a series of questionnaires and computer-based tasks, and provide a DNA sample for genetic analysis. If parents wish, we can share the results of the Child Behavior Checklist (CBCL) with your child's clinician to help them better understand your child. For more information you can visit our website: <http://www.upstate.edu/childbehavior/> or our Facebook page: <https://www.facebook.com/behaviorstudy>

The study procedure takes up to three hours for the family and each participant is paid \$50. If interested or you are with an organization who would like brochures, contact Pat Forken at 464-5619.

SUPPORTIVE FAMILY TRAINING BEGINS SPRING SESSION IN APRIL

The spring session of Supportive Family Training will begin on Wednesday, April 6. Sheila Le Gacy is completing interviews with prospective students at this time. Although the class is filled, occasionally individuals decide that this is not a good time for them to take the course. Therefore, if someone you know is interested in taking the training, have them contact Sheila or the Assistant Director of the Family Support & Education Center at ACCESS CNY, Patricia Hetrick. (phetrick@accesscny.org)



SUPPORT NAMIWALKS - MAY 7TH

For the second year, NAMI Syracuse is teaming up with NAMI Rochester for the annual NAMIWalks event on Saturday, May 7th at Village Gate in Rochester, NY

You can choose to be a “virtual” walker by simply donating, or you can be an in-person walker and join our team! For those who would like to join the team, we have transportation to and from the walk.

No amount is too little for a donation! As a participating affiliate, NAMI Syracuse will receive a portion of all funds we raise through our teams and our direct sponsorship.

Go to our website, www.namisyra-cuse.org to donate or become a member of our team.

NAMI NATIONAL CONVENTION

This year the NAMI National Convention will be in Denver and is scheduled for July 6 - 9, 2016.

To take advantage of the Super Saver reduced fee of just \$215 for NAMI members, you need to register by March 31.

The program for this year's convention has come together nicely and will address a variety of topics such as decriminalizing mental illness, working with our partners in reducing stigma, veterans and military issues, first episode psychosis programs and much more.

The Sheraton Downtown Denver is holding a discounted room block for NAMI at the special group rate of \$149 per night (plus tax) for a single or double occupancy room.

NAMI National has arranged for airfare discounts on United and Delta airlines for NAMI convention attendees, where they can save up to 10% on their ticket purchase with a special discount code.

For additional information on registering for the convention, making hotel and travel reservations and the program details, visit www.nami.org/convention.

SCIENTISTS MOVE CLOSER TO UNDERSTANDING SCHIZOPHRENIA CAUSE

by *Benedict Carey, NY Times, 1/27/16*

Scientists reported recently that they had taken a significant step toward understanding the cause of schizophrenia, in a landmark study that provides the first rigorously tested insight into the biology behind any common psychiatric disorder.

More than two million Americans have a diagnosis of schizophrenia, which is characterized by delusional thinking and hallucinations. The drugs available to treat it blunt some of its symptoms but do not touch the underlying cause.

The finding, published in the journal **Nature**, will not lead to new treatments soon, experts said, nor to widely available testing for individual risk. But the results provide researchers with their first biological handle on an ancient disorder whose cause has confounded modern science for generations. The finding also helps explain some other mysteries, including why the disorder often begins in adolescence or young adulthood.

"They did a phenomenal job," said David B. Goldstein, a professor of genetics at Columbia University who has been critical of previous large-scale projects focused on the genetics of psychiatric disorders. "This paper gives us a foothold, something we can work on, and that's what we've been looking for now, for a long, long time."

The researchers pieced together the steps by which genes can increase a person's risk of developing schizophrenia. That risk, they found, is tied to a natural process called synaptic pruning, in which the brain sheds weak or redundant connections between neurons as it matures. During adolescence and early adulthood, this activity takes place primarily in the section of the brain where thinking and planning skills are centered, known as the prefrontal cortex. People who carry genes that accelerate or intensify that pruning are at higher risk of developing schizophrenia than those who do not, the new study suggests.

Some researchers had suspected that the pruning must somehow go awry in people with schizophrenia, because previous studies showed that their prefrontal areas tended to have a diminished number of neural connections, compared with those of unaffected people. The new paper not only strongly supports that this is the case, but also describes how the pruning probably goes wrong and why, and identifies the genes responsible: People with schizophrenia have a gene variant that apparently facilitates aggressive "tagging" of connections for pruning, in effect accelerating the process.

Some scientists warned that the history of biological psychiatry stands as a caution against premature optimism. "This work is extremely persuasive," said Dr. Samuel Barondes, a professor of psychiatry at the University of California, San Francisco, "but any step forward is not only rare and unusual, it's just one step in a journey of a thousand miles" to improved treatments.

The study, by scientists from Harvard Medical School, Boston Children's Hospital and the Broad Institute, a research center allied with Harvard and the Massachusetts Institute of Technology, provides a showcase of biomedical investigation at its highest level. The research team began by focusing on a location on the human genome, the MHC, which was most strongly associated with schizophrenia in previous genetic studies. On a bar graph - called a Manhattan plot because it looks like a cluster of skyscrapers - the MHC looms highest.

"The MHC is the Freedom Tower" of the Manhattan plot, said Eric S. Lander, the director of the Broad Institute. "The question was, what's in there?"

The area is a notoriously dark warren in the genome known to contain genes that facilitate the body's immune response, for example, by flagging invading bacteria to be destroyed. That property had given rise to speculation that schizophrenia might be a kind of autoimmune condition, in which the body attacked its own cells.

But the research team, led by Steven McCarroll, an associate professor of genetics at Harvard, and by Aswin Sekar, one of his graduate students, found something different. Using advanced statistical methods, the team found that the MHC locus con-

tained four common variants of a gene called C4, and that those variants produced two kinds of proteins, C4-A and C4-B.

The team analyzed the genomes of more than 64,000 people and found that people with schizophrenia were more likely to have the overactive forms of C4-A than control subjects. "C4-A seemed to be the gene driving risk for schizophrenia," Dr. McCarroll said, "but we had to be sure."

The researchers turned to Beth Stevens, an assistant professor of neurology at Boston Children's Hospital and Harvard, who was an author of a 2007 study showing that the products of MHC genes were involved in synaptic pruning in normal developing brains. But how important was this C4 protein, exactly? Very important, it turned out: Mice bred without the genes that produce C4 showed clear signs that their synaptic pruning had gone awry, Dr. Stevens' lab found.

Taken together, Dr. Stevens said in an interview, "the evidence strongly suggested that too much C4-A leads to inappropriate pruning during this critical phase of development."

In particular, the authors concluded, too much C4-A could mean too much pruning - which would explain not only the thinner prefrontal layers in schizophrenia, but also the reason that the disorder most often shows itself in people's teenage years or early twenties. "The finding connects all these dots, all these disconnected observations about schizophrenia, and makes them make sense," Dr. McCarroll said.

Carrying a gene variant that facilitates aggressive pruning is hardly enough to cause schizophrenia; far too many other factors are at work. Having such a variant, Dr. McCarroll estimates, would increase a person's risk by about 25 percent over the 1 percent base rate of schizophrenia - that is, to 1.25 percent. That is not nearly enough to justify testing in the general population, even if further research confirms the new findings and clarifies the roles of other associated genes.

Yet the equation changes when it comes to young people who are at very high risk of developing the disorder, because they are showing early signs - a sudden slippage in mental acuity and memory, or even internal "voices" that seem oddly real. This ominous period may last a year or more,

and often does not lead to full-blown schizophrenia. The researchers hope that the at-risk genetic profile, once it has been fleshed out more completely, will lead to the discovery of biomarkers that could help clarify a prognosis in these people.

Developing a drug to slow or modulate pruning poses another kind of challenge. If the new study shows anything, it is that synaptic pruning is a delicate, exquisitely timed process, and that it is still poorly understood. The team does not yet know, for example, why C4-A leads to a different rate or kind of pruning than C4-B. Any medication that tampered with that system would be a risky proposition, the authors and outside experts agreed.

"We're all very excited and proud of this work," Dr. Lander said. "But I'm not ready to call it a victory until we have something that can help patients."

SYRACUSE NATIVE USES POETRY TO CHANGE STIGMA SURROUNDING MENTAL ILLNESS

by Gulnaz Khan

Tanisha Wiggins remembers scrounging around her house for spare coins as a 16-year-old. She was careful and secretive; even her mother had no idea anything was out of the ordinary. She walked to the Family Dollar in Syracuse with determination and purchased a bottle of aspirin with change. Wiggins went into her bedroom and swallowed the entire bottle. She lay down on her bed and waited for the pain to go away.

Twelve years later, Wiggins still remembers the taste of the aspirin.

About 9.3 million adults reported having suicidal thoughts in the past year and 1.3 million adults attempted suicide, according to the Centers for Disease Control. As of 2013, it was the 10th-leading cause of death for all ages, an estimated one death every 13 minutes.

Wiggins said she started struggling with depression at a young age, but hid her feelings from her mother out of fear.

"I wanted it to be a secret because I felt like there was something wrong with me," she said.

Instead of talking to family, friends or doctors, she found solace through poetry. Feeling like she couldn't express her emotions verbally, Wiggins said she wrote about them instead.

Wiggins' form of art therapy isn't uncommon, said Arthur Brangman, an art therapist at Hutchings Psychiatric Center in Syracuse.

"Art is a nonverbal form of therapy for individuals who have suffered trauma," Brangman said. "A little escapism and creative thinking goes a long way in helping people."

With one poem, Wiggins' poetry became more than just an emotional outlet. It became her key to getting help.

"I remember one day I wrote a poem for school, and they didn't think what I was writing about was normal," Wiggins said. "I was writing about dying. They said to be so young and write about that stuff was concerning."

Her principal referred her to a counselor, and for the first time, she spoke her feelings aloud instead of writing them on paper.

Her mother never knew she was seeing a counselor until she overdosed on aspirin later that year, Wiggins said. Instead of compassion, her mother responded to the hospitalization with anger.

Wiggins' relationship with her mother has since grown into one of understanding, she said. After she moved out of her house at 17, their relationship improved. Years later, Wiggins' mother disclosed that she tried to kill herself around the same age Tanisha was, she said.

"Her mom (Wiggins' mother's mother) got really upset and told the doctors that she (Wiggins' mother) wasn't going to take any medication. I think she was kind of projecting that on me," Wiggins said.

Wiggins still struggles from time to time with feelings of hopelessness and fleeting thoughts of suicide. She's still learning how to manage her emotions, but, she said, it's much better than when she was younger.

Marla Byrnes, a retired psychiatric nurse and member of the board of directors at the National Alliance on Mental Illness Syracuse, has witnessed this growth firsthand.

Over a decade of working as Wiggins' therapist, they've grown to be friends.

"She's overcome many hardships that would have defeated people, and rightly so. She doesn't let life defeat her. She might get knocked down, but she gets back up," Byrnes said. "For me, that's what spells success in life."

Though Byrnes is a mentor to Wiggins, today Wiggins also inspires a lot of people, Byrnes said. She was a residential counselor at the Salvation Army helping other youth, and has done motivational talks for NAMI about recovery and her poetry.

Wiggins said she takes her responsibility as a role model seriously, especially when it comes to her 8-year-old niece. Knowing that her niece looks up to her motivates her during her toughest moments.

"I can't abandon her. I can't leave this earth on those terms knowing she would wonder, 'Well why did auntie do that?'" Wiggins said. "And when she gets older, if she can't deal with something, I don't want her to be like, 'Well auntie did it, so why can't I?'"

Wiggins graduated in December from Onondaga Community College with a degree in human services, and plans to pursue a career in social work.

Wiggins said she'll continue to speak out about mental illness, and hopes speaking out about her mental health experiences will help reduce the stigma surrounding them.

"When you go to the hospital and they see that you have a mental health diagnosis, they treat you differently than someone with a physical diagnosis," Wiggins said. "It doesn't matter if it's invisible, you still have pain and you still need to be treated with respect. Everyone should feel like they matter."

Even 12 years after her suicide attempt, Wiggins said she can't even look at aspirin without feeling sick. She's glad the attempt was unsuccessful, otherwise she wouldn't be where she is today.

"People used to tell me there is a light at the end of the tunnel and I didn't really believe it," Wiggins said. "But it's not all darkness. Even if it's a dim light, there's still a light."

NAMI Syracuse Garage/Barn Sale

Friday, May 20th, 8am - 3pm
Saturday, May 21st, 8am - 3pm
2503 West Genesee Street, Syracuse

Cleaning out your closet?
Downsizing your house?
Just have too much stuff!

We're looking for items in good condition and suitable for resale. Call 487-2085 to arrange for drop-off.

Do you shop on Amazon?

Did you know that Amazon donates 0.5% of the price of your eligible AmazonSmile purchases to the charitable organization of your choice.

AmazonSmile is the same as Amazon - same products, same prices, same service!

NAMI Syracuse is now registered with AmazonSmile. Support NAMI Syracuse by starting your shopping at www.AmazonSmile.com

Youth Mental Health First Aid

Mental Health First Aid/Youth covers normal adolescent development and common mental health challenges of youth, including anxiety, depression, substance use, disruptive behavior disorders (including ADHD), non-suicidal self-injury, and eating disorders.

This workshop is intended primarily for adults interacting regularly with young people ages 12-18.

Our next classes:

Monday and Tuesday, April 25-26, 12:30 to 4:45 p.m. each day (You must attend both sessions)

Tuesday and Wednesday, May 24-25, 9 a.m. to 1:15 p.m. each day (You must attend both sessions)

Tuesday and Wednesday, June 28-29, 9 a.m. to 1:15 p.m. each day (You must attend both sessions)

Cost: A grant allows us to offer this training for free to any adult who interacts with Syracuse City School District youth. Space is limited. To register, please call CONTACT Community Services, 315-251-1400 x 132.

All Classes are held at Contact Community Services
6311 Court Street Road, East Syracuse 13057

STRESSED OUT! STRESS, MENTAL HEALTH, AND OUR SENSE OF CONTROL

from HealthyPlace.com

"The greatest weapon against stress is our ability to choose one thought over another."
- William James

Ah, stress. The dirty "s" word can disrupt our mental health and well-being. How stressed we feel is related to how much control we feel in our lives. Knowing what stress does to us and identifying where we're feeling out of control gives us the power of choice necessary for decreasing stress and improving mental health.

Stress can get to people physically, emotionally, cognitively, and behaviorally. Knowing that you don't feel well because you're stressed isn't quite helpful in beating stress. Get specific. Pinpoint how you're feeling stress in your life. Getting specific will allow you to choose purposeful actions to counter the negative effects of stress.

To reduce stress's impact and optimize mental health, focus, too, on your own sense of power and control in your life. What's bothering you the most right now? Determining this will allow you to choose your thoughts about what's happening as well as actions you can take to deal with it. When we humans gain a sense of control over ourselves and our lives by identifying choices we have, we can feel so empowered that our sense of stress decreases and mental health increases.

First a howling blizzard woke us,

Then the rain came down to soak us,

And now before the eye can focus -

Crocus.

~Lilja Rogers



A PATIENT CONFESSES: THIS IS WHAT'S IT'S REALLY LIKE TO HAVE SCHIZOPHRENIA

by Anonymous, from Quora.com

If you worked with me or saw me every day, you'd probably think I was a little eccentric-but you might not realize I am mentally ill. You'd notice that sometimes I have an odd way of saying things. Sometimes I get quiet. And sometimes I have bad days when it's better to leave me alone.

I told my boss and a few close coworkers that I am bipolar because it affords me a bit of leeway with some of my slightly off behavior and my occasional need to call in sick. I never, ever tell people that I am schizophrenic, because they assume that (1) I have multiple personalities or (2) someday I will snap and try to attack them with a broken bottle. Both of which are completely ridiculous.

I think and process information very differently than you do. In my office, I am highly valued for my creative approaches to problems and situations and for my ability to detect patterns across large sets of data. My brain processes much more information than the average brain, and it is constantly at work seeking out and forming connections that the average person would never consider. But on some days, it feels as if someone has changed the rules of reality, and I am the only one who notices. Some days, I believe I have important information that other people aren't aware of. Sometimes it is vital that I sit in a certain spot on the train or avoid milk because it's part of an attempt to control my mind. Some days, I see, hear, or believe things that no one else does.

Some days, I feel that every thought in my head is broadcast to the people around me, so I have to be extra careful about what I think because I can't let the people sitting nearby in the coffee shop find out my secrets. On other days, I pick up extra information about people and situations. I might be able to hear voices that explain what the lady behind me in line at the grocery store is really thinking about me. Most times, this extra perception just buzzes quietly in the back of my

brain as I go through my day. Intense episodes happen infrequently.

I started having symptoms when I was 19. Since then, I've had to teach myself to always be the last person to react to things and to mistrust my own judgment and perceptions. Unique situations have to be run through an "Is this real?" test. I have to constantly live with the fear that the universe that I experience may not be the same as the universe that actually exists.

For example, a while ago, I was in a large meeting at work, and a bunch of lightning bugs began to fly around the room. Check 1: Is this possible? Answer: implausible but not impossible. Check 2: Is anyone else in the room reacting or commenting on the situation? Answer: No? Then I'll assume it's not real until I have evidence to the contrary.

I've also had to implement a three-day waiting period when I experience strong, unexpected emotions. For instance, one day, I was suddenly and utterly convinced that my boss hated me and was about to fire me. Check: Find external evidence that proves this belief. Answer: I looked through my e-mail and meeting notes and could not find anything that would have caused him to hate me. And no coworker volunteered any independent verification that there were problems. Response: I had to force myself to put these beliefs on the back burner and reexamine this emotion after three days. By the end of the waiting period, I was able to recognize that everything was fine.

Keep in mind that this process of checking and double-checking your surroundings is not something all schizophrenics are capable of doing, and it doesn't work during bad episodes. After all, you're running the reality test using the same faulty brain and false logic that's telling you, say, that a room is full of lightning bugs. If you're only mildly hallucinating, you can say to yourself, "This is probably not real." If you're experiencing full-on psychosis, you are probably also hearing the people in the room whispering about it behind your back.

Imagine turning on five television sets, full volume, tuned to five different channels, and tell me how easy it is to follow the thread of just one show. On one channel, a show called Reality has a dramatic situa-

tion playing out, and on another TV is a hilarious sitcom. Now try paying attention to the drama, keeping in mind that you absolutely must not laugh or react to any of the jokes in the sitcom. This illustrates the trouble I have paying attention on off days. I'm easily distracted. On my worst days, I have trouble understanding and responding to people. I hear the words, but they don't make any sense. I can't get my brain to interpret them. If I'm feeling particularly overloaded, I just shut down and will barely talk to or respond to others. I take antipsychotic medication, but it's expensive, and it slows me down. Because of the medication, I can't think through complex problems as quickly as I once could, and I sleep several hours more each day and have gained 50 pounds, despite eating well and working out more.

I'm lucky to live with a remarkable, highly patient partner who tells me when I've gone out of bounds in my social behavior or personal appearance. And, thankfully, I have above-average intelligence and self-awareness. They help me recognize that hallucinations and delusions aren't real and analyze what an appropriate reaction should be in most situations. Still, knowing this doesn't make them go away.

WHY YOU SHOULD NEVER USE THE TERM "THE MENTALLY ILL"

by Jeff Grabmeier, MedicalXpress.com
January 26, 2016

Even subtle differences in how you refer to people with mental illness can affect levels of tolerance, a new study has found.

In a first-of-its-kind study, researchers found that participants showed less tolerance toward people who were referred to as "the mentally ill" when compared to those referred to as "people with mental illness."

For example, participants were more likely to agree with the statement "the mentally ill should be isolated from the community" than the almost identical statement "people with mental illnesses should be isolated from the community."

These results were found among college students and non-student adults - and even professional counselors who took part in the study.

The findings suggest that language choice should not be viewed just as an issue of “political correctness,” said Darcy Haag Granello, co-author of the study and professor of educational studies at The Ohio State University.

“This isn’t just about saying the right thing for appearances,” she said. “The language we use has real effects on our levels of tolerance for people with mental illness.”

Granello conducted the study with Todd Gibbs, a graduate student in educational studies at Ohio State. Their results appear in the January 2016 issue of *The Journal of Counseling and Development*.

The push to change how society refers to people with mental illness began in the 1990s when several professional publications proposed the use of what they called “person-first” language when talking about people with disabilities or chronic conditions.

“Person-first language is a way to honor the personhood of an individual by separating their identity from any disability or diagnosis he or she might have,” Gibbs said.

“When you say ‘people with a mental illness,’ you are emphasizing that they aren’t defined solely by their disability. But when you talk about ‘the mentally ill’ the disability is the entire definition of the person,” he said.

Although the use of person-first language was first proposed more than 20 years ago, this is the first study examining how the use of such language could affect tolerance toward people with mental illness, Granello said.

“It is shocking to me that there hasn’t been research on this before. It is such a simple study. But the results show that our intuition about the importance of person-first language was valid.”

The research involved three groups of people: 221 undergraduate students, 211 non-student adults and 269 professional counselors and counselors-in-training who were attending a meeting of the American Counseling Association.

The design of the study was very simple. All participants completed a standard, often-used survey instrument created in 1979 called the Community Attitudes Toward the Mentally Ill.

The CAMI is a 40-item survey designed to measure people’s attitudes toward people with diagnosable mental illness. Participants indicated the degree to which they agreed with the statements on a five-point scale from 1 (strongly disagree) to 5 (strongly agree).

The questionnaires were identical in all ways except one: Half the people received a survey where all references were to “the mentally ill” and half received a survey where all references were to “people with mental illnesses.”

The questionnaires had four subscales looking at different aspects of how people view those with mental illnesses. The four subscales (and sample questions) are:

Authoritarianism: “The mentally ill (or ‘People with mental illness’) need the same kind of control and discipline as a young child.”

Benevolence: “The mentally ill (or ‘People with mental illness’) have for too long been the subject of ridicule.”

Social restrictiveness: “The mentally ill (or ‘People with mental illness’) should be isolated from the rest of the community.”

Community mental health ideology: “Having the mentally ill (or ‘people with mental illness’) living within residential neighborhoods might be good therapy, but the risks to residents are too great.”

Results showed that each of the three groups studied (college students, other adults, counselors) showed less tolerance when their surveys referred to “the mentally ill,” but in slightly different ways.

College students showed less tolerance on the authoritarianism and social restrictiveness scales; other adults showed less tolerance on benevolence and community mental health ideology subscales; and counselors and counselors-in-training showed less tolerance on the authoritarianism and social restrictiveness subscales.

However, because this was an exploratory study, Granello said it is too early to draw conclusions about the differences in how each group responded on the four subscales.

“The important point to take away is that no one, at least in our study, was immune,” Granello said. “All showed some evidence of being affected by the language used to describe people with mental illness.”

One surprising finding was that the counselors - although they showed more tolerance overall than the other two groups - showed the largest difference in tolerance levels depending on the language they read.

“Even counselors who work every day with people who have mental illness can be affected by language. They need to be aware of how language might influence their decision-making when they work with clients,” she said.

Granello said the overall message of the study is that everyone - including the media, policymakers and the general public - needs to change how they refer to people with mental illness.

“I understand why people use the term ‘the mentally ill.’ It is shorter and less cumbersome than saying ‘people with mental illness,’” she said.

“But I think people with mental illness deserve to have us change our language. Even if it is more awkward for us, it helps change our perception, which ultimately may lead us to treat all people with the respect and understanding they deserve.”

ANTIOXIDANT NAC IMPROVES SYMPTOMS OF SCHIZOPHRENIA AND BIPOLAR DISORDER

from Bipolar Network News, Vol. 20, Issue 1, 2016

N-acetylcysteine (NAC) an antioxidant available without a prescription in health food stores, has shown remarkable effectiveness when added to regular treatments for schizophrenia, bipolar disorder, and the substance abuse that often accompanies these illness.

A 2008 article in the journal **Biological Psychiatry (Berk and colleagues)** reported that 2g/day of NAC reduced both positive symptoms of schizophrenia (hallucinations, delusions) and negative symptoms (social withdrawal, difficulty planning and problem-solving.)

NAC also improves symptoms of bipolar disorder. Studies showed that NAC improved bipolar depression, and improved mania as well.

NAC is also effective at reducing habitual behaviors such as substance abuse, which is common in patients with schizophrenia and bipolar disorder. Studies have shown that NAC can reduce patients’ use of marijuana, cocaine, alcohol, and nicotine. It

is relatively safe with minimal side effects, and fights oxidative stress, which is also common in severe mental illness.

NAC comes in 500mg or 600mg capsules. Dosing typically begins with one capsule twice a day for a week, followed by two tablets twice a day thereafter. As with any recommendations in the **Bipolar Network News**, these should not be acted on without guidance from a treating physician.

~article edited by Sheila Le Gacy

MARIJUANA USE WORSENS PTSD SYMPTOMS IN VETERANS

Among war vets who completed a treatment program for post-traumatic stress disorder, those who continued or began using marijuana after treatment had more severe PTSD symptoms, were more violent, and used drugs and alcohol more often. Those who stopped using marijuana or never used it had the lowest levels of PTSD symptoms in the study.

Evidence of the adverse effects of heavy marijuana use are robust and consistent.

Some of these include:

1. A doubling of the risk of psychosis compared to non-users.
2. An increased risk of bipolar disorder onset.
3. A worse course of bipolar disorder.
4. An increased risk of schizophrenia.
5. Memory deficits that remain even after marijuana use has ceased.
6. Loss of motivation (exactly what someone with depression doesn't need.)
7. Anatomical changes in brain structures.
8. A worse course of PTSD and increased violence in those with PTSD.

Bottom line: Those who say marijuana is benign may be ill-informed. People with mood disorders, proneness to paranoia, or PTSD should stay away from marijuana.

~article edited by Sheila Le Gacy

A CRISIS IN CAREGIVING

from NAMI

There are startling inadequacies in the U.S. health care system in meeting the needs of families who manage moderate-to-serious mental illness.

Mental illness doesn't just strike an individual. It strikes a family.

Family caregivers are often isolated by the stigma of mental illness. According to a National Alliance for Caregiving report developed in collaboration with NAMI, **On Pins and Needles: Caregivers of Adults with Mental Illness**, more than 8 million family caregivers of people with mental illness face serious gaps in getting needed support. The report revealed that caregivers experienced the following:

- High emotional stress and anxiety about their loved ones.
- Lack of involvement by providers in health care decisions.
- Poor access to care and community health services.

This crisis in caregiving happens to families addressing mental illness when the responsibility of care falls solely on them. Without adequate support, services or information, that demanding role often affects the entire family's wellbeing.

Everyday caregivers wait on pins and needles for another call that turns their life upside down, and for many of us the endless stress and uncertainty leads to depression and anxiety.

We can't ignore the vital role that a caregiver often has in the recovery of a person living with mental illness. NAMI is taking a stand to demand that mental health reform legislation addresses the needs of family caregivers and ensuring that vital information and support is available.

Please join with those dedicated to improving the lives of people with mental illness. If you're not already a member, please join. If you are a member, please be an active and vocal member.

HOW STAR WARS HELPED MY MENTAL ILLNESS

January 15, 2016

WARNING: STAR WARS SPOILERS

I am a huge Star Wars fan. The movies mean so much to me. The entire first time I saw "The Force Awakens" I cried tears of joy. Literally. The whole movie. I had to wait in my seat five minutes after it ended to gather myself together to be presentable enough to leave the theater. True story. But the second time (two hours after I saw it the first time, of course) was a different story. I found myself completely relating to the sinister antagonist, Kylo Ren. Let me back up. I suffer from bipolar disorder with some borderline personality disorder thrown in for fun. This causes me to be easily agitated, have terrible mood swings, angry outbursts and between those a persistent depressed mood. It's normal to get irked by things in life; someone stole your reserved parking spot, you got a stain on your new shirt; normal stuff. And most people react to it with a few angry words, maybe cheeks a little flushed, but they go about their day. Not me. Something as slight as someone tapping their foot next to me feels like nails on a chalkboard. A stain on my shirt would lead to screaming, tears and lots of negative self-talk blaming myself for the stain.

Irritability is a symptom experienced by many people with mental illnesses. Things that other people would be able to just brush off ravish our minds and take over completely. You can't just "let it go". It's pretty clear to see that in the movie when Kylo Ren gets some bad news and instead of just acknowledging it and moving on, he lashes out on his surroundings with his lightsaber in a fit of rage. When things don't go quite the way I planned or I'm angry at myself, I take to punching the walls until my knuckles are bruised and my fists bleed. I saw myself in Kylo Ren's angry, violent outbursts of taking his lightsaber and destroying most likely very expensive space equipment. When I feel that internal rage I know to keep myself in a safe space where I can't hurt anyone or thing, but myself.

(continued on page 11)

I don't want to do it, but I feel like I can't stop. I'm sure he doesn't want to destroy this specialized equipment. He's in charge of the Star-destroyer and Starkiller Base, why would he want to break stuff on them? He probably feels like he can't stop either. It's embarrassing too. In the movie some Stormtroopers walk by during one of his fits and they run away. It feels so childish to have these adult temper tantrums, but sometimes I feel so out of control I just can't stop it.

What really made my spine shiver with relatability was when Kylo Ren was facing his estranged father, Han Solo. He says "I'm being torn apart" and "I just want the pain to end." Wow. Just wow. This is going to get a little uncomfortable for some people, but I struggle with suicidal thoughts a lot. I've had several suicide attempts in the past and was recently hospitalized for trying to hang myself. Those words spoke such truth to me. "Being torn apart" is exactly how I feel. This duality of the desire to live, but wanting the pain to end. This split between absolute self-hatred and loving myself for who I am. The belief that the world is a better place without me and the light of hope knowing that isn't true. And the words "I just want the pain to end" have been spoken by every single person who has ever thought of suicide. The feelings of I don't want to die, but I would do anything to make this pain end. Many people turn to unhealthy means to make the pain go away, at least temporarily. For some it's alcohol, drugs and others like me self-injury. We know what we are doing is bad for us, but it dulls that pain even for a minute which feels like bliss.

Shame is a huge part of mental illness. Many of us feel like the disease has destroyed us, taken over, turned us into someone we're not. Some of us feel like we are wearing a mask, that our true self is not something anyone wants to see; that we must cover up. For some that mask is to look happy all of the time, like everything is OK. While Kylo Ren's mask certainly isn't to look happy on the outside, it does cover his true self. Behind closed doors he struggles with the light and the dark, the good in him

and the evil. But he cannot show this weakness, so he wears a mask - helmet. We must pretend like everything is OK on the outside while we struggle inside.

Part of my bipolar disorder is depression. It makes me want to isolate myself from the world. In the movie Ben Solo, - Kylo Ren - has turned his back on his family. It is clear that his parents Han and Leia love him and forgive him for his wrongs; they just want him to come home. But sometimes that isn't enough. With depression, people can love you and try so hard to bring you out of it and then not understand why it isn't working.

Depression lies to you, convinces you that people don't actually love you. Even though people might reach out, it forces you to shake off their invitations and close yourself off alone. You don't want to be around anybody. I don't think Kylo Ren had many friends in the movie. General Hux seemed like a jerk and Supreme Leader Snoke probably wasn't a genuine pal - as Han says, "He's only using you for your power." Letting people in is a huge struggle.

Depression lies to you even more by saying you'll never get better. Kylo Ren says it is "too late" for him to change in the pivotal scene with his father. I often feel like I have struggled for so long, tried so many medications and therapies that it is too late for me to change too. That there is no hope for me to get better.

Sometimes mental illness makes you do things you never wanted to do. A hallmark of bipolar disorder is mania and hypomania. Many people report doing high risk things like flying to another country or reckless sexual encounters. Those who suffer from psychosis do things their rational mind would never consider doing. The consequences of these actions can be permanent, like jail time. People's lives have been ruined by the guilt and regret of their actions during an episode even years later.

With a mental illness sometimes you feel what you are doing isn't coming from you. You're not in the driver's seat. I don't mean to rationalize murder, but given that he still has light in him as he says, Kylo Ren will probably feel pretty bad about killing his father at some point in the future movies. Mental illness takes over your mind, making you do things you never

thought you would do, but afterwards your rational mind is left to pick up the pieces.

So, after seeing the movie again I felt completely distraught. How could I identify so closely with the bad guy? And it would be one thing if he was redeemed in the end, but he most definitely is not. It felt like a reverse inspiration, instead of giving me hope it took some away. I thought if he remains evil and unchanged what hope is there for me? I tried to rationalize like maybe Han Solo was a crappy dad who deserved to die. Maybe he didn't mean to kill a village full of innocent people. I did find some hope in the realization that we have two more movies for him to be redeemed, and I think he will be.

However; I did find hope and inspiration in the fact that I am not alone in feeling the way that I do. Others, even if a fictional character, struggle with the same things I do. It felt so good to see my struggle so eloquently displayed in my new favorite movie (I've only seen it seven times in two weeks). One of the hardest parts of mental illness is feeling completely alone. Feeling like you are the only person in the world who feels this way. For me sharing my struggles with others and hearing about theirs has been monumental in my recovery. I hope seeing these struggles on the big screen gives hope to others fighting mental illness too. May the force be with you - but in a good way, not the freezing people and reading their minds way.

~from NAMI Now, Personal Stories, 1/16

**Hutchings Psychiatric Center
Family & Community
Education Schedule**

**Tuesday, April 12, 2016
10:00am-12:00 noon**

**Overview of Medicaid
Managed Care**

**Presenter: Cindy Hill,
Director of Healthcare Finances,
Hutchings Psychiatric Center**

***Free and open to the public. Room
102, 545 Cedar St., Syr., NY. To regis-
ter call, 426-6873 or 426-6870***

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What are the benefits of NAMI membership?

- Membership at all three levels of the organization: NAMI National, NAMI-NYS & NAMI Syracuse
- Eligibility to vote in all NAMI elections
- A subscription to The Advocate, NAMI national's quarterly magazine, as well as access to optional subscriptions to specialty newsletters and information at the national, state and local levels
- Discounts on publications, promotional items, and registration at NAMI's annual convention, state and local conferences
- Access to exclusive members-only material on NAMI National's website

Reminder:

If you are receiving this newsletter but are not a member, please consider joining NAMI.

If you are a member, please check to be sure your dues are up to date.

Please join or renew today.

There is strength in numbers!

The NAMI Syracuse Support & Sharing Meeting facilitated by Sheila Le Gacy is held on the 3rd Tuesday of each month at 7:00pm at ACCESS-CNY, 420 East Genesee Street, Syracuse. (Between South Townsend St. and South State St., next to the Onondaga County Sheriff's Department. Parking and entrance in the rear of the building.)