



# NAMI SYRACUSE

National Alliance on Mental Illness

## Newsletter

SEPTEMBER/OCTOBER 2015

### Meeting Schedule

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

**ACCESS-CNY**

**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*

- September 13, 2015 **NAMI Syracuse Fall Fundraiser**  
**Harvest Hopela**, 4pm-7pm  
2260 Lamson Rd., Phoenix, NY  
*(see page 3 for details)*
- September 15, 2015 **Support & Sharing Meeting**  
7:00pm - AccessCNY
- October 8, 2015 NAMI Syracuse Educational Conference  
**Supports & Strategies for Recovery**  
Empire Room, NYS Fairgrounds  
*(see page 3 for details)*
- October 20, 2015 **Support & Sharing Meeting**  
7:00pm - AccessCNY
- November 17, 2015 **Support & Sharing Meeting**  
7:00pm - AccessCNY

Because of NAMI Syracuse's busy fall schedule, the 1st Tuesday of the month Information and Education Meetings will be postponed until after the first of the year.

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**MESSAGE FROM THE PRESIDENT**

Dear fellow members,

Thanks to the efforts of many people, some very good things are happening at NAMI Syracuse. Therefore, this is a letter of thanks.

As many of you know, we were in desperate need of an updated computer system. Thanks to generous donations by board members August Cornell and Sherie Ramsgard (www.wholementalwellness.com) NAMI Syracuse now has two very functional computers up and running. August, who owns www.Framefixers.com donated both hardware and the expertise of Bob Heman. Bob Heman is the Owner/Operator of RPH Consulting who does expert IT work. Sherie's husband, Andy Ramsgard of Ramsgard Architectural Design P.C., Inc., www.ramsgard.com, donated hardware.

This frees up the generous donation made by the Knights of Columbus, Council 3717, to purchase AV equipment for our educational conferences. Thank you Frank Mazzotti for your hand in making this happen.

As I hope all of you are aware we are having a fall fundraiser **Harvest Hopela** on September 13. This wonderful party will happen due to the efforts of the ever-working Marla Byrnes, and the generous offering of a magnificent "Party House" in Phoenix by Dr. Paula Zebrowski and Pam Fortino. Marie Maher has donated her time and expertise to do the catering. Thanks also goes out to David Gettis of Bryce Cullen Publishing www.brycecullen.com for designing our logo and donating the invitations for this great event. Thanks to Ann Canastra for a donation to help with the expenses of the Hopela. And thanks to all the many many people and businesses who have already donated auction items. There will be a plethora of must haves to bid on.

I want to thank Judy Bliss-Ridgway and Joe Ridgway for hosting yet another successful and tasty summer picnic, and Steve Glatt for bringing his wife Karrie and her amazing carrot cake!

I want to thank Liz Droge-Young for the wonderful job she's doing on our website and social media, along with Brook Gleason of SalesIT (info@salesitconsulting.com). And thanks to new board member, Karen Beck, who might create for us that long wanted e-newsletter! Stay tuned!

Also many thanks to the Community Folk Art Center, www.communityfolkart-center.org, for hosting our **See Me Too!** art and poetry show, and to Reyna Stagnaro and Putter Cox of Dove Creek Band and Steve Rosenthal for providing music for the opening reception.

On another very exciting note, it's more than a rumor that Upstate is looking for bids from architects "for the renovation of two units in University Hospital: 4B inpatient Behavioral Health unit and conversion of an existing unit on 7W to an Adolescent Behavioral Health unit." I believe this is a direct result from our efforts with working with Assemblyman Bill Magnarelli and Congressman John Katko. This committee and task force would not exist if it weren't for Sheila Le Gacy. Thanks Sheila!

On a sad note I want to send my condolences to Peg Gentile. Her son Michael recently passed away. Without Peg and Joe Gentile, NAMI Syracuse might not exist.

As always, I am truly grateful for all the work of all our board members and our NAMI Syracuse members. And even though I have yet to directly thank our vice president Spence Plavocos, and board members: Carol Brady, Sandra Carter, Kris Neagle, Susan Zdanowicz, Steffany Rose or Mantosh Dewan, I am doing so now! Oh, yeah-and thanks to myself! NAMI is, and has always been, a group of caring individuals who want to help those struggling with mental illness live the life that they deserve. Please know each and every one of you is crucial to this task.

Thank you.  
Karen Winters Schwartz, President

**NAMI Syracuse Officers**

- Karen Winters Schwartz.....President
- Spencer Plavocos.....Vice-President
- Frank Mazzotti.....Treasurer
- Marla Byrnes .....Recording Secretary

**Board of Directors**

- Karen Beck
- Judy Bliss-Ridgway
- Carol Sheldon Brady
- Ann Canastra
- Sandra Carter
- August Cornell
- Stephen Glatt Ph.D.
- Kristin Neagle
- Sherie Ramsgard
- Steffany Rose
- Susan Zdanowicz

**Consultant to Board**

- Dr. Mantosh Dewan
- Sheila Le Gacy

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Follow us on **twitter**:



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**Memo to NAMI Syracuse Members:**

In the very near future NAMI Syracuse will be able to offer our newsletter via e-mail.

If you would like to receive this newsletter and other NAMI Syracuse updates through your e-mail, please send us an e-mail indicating so.

[namisyracuse@namisyracuse.org](mailto:namisyracuse@namisyracuse.org)

Many of you have asked for this option for your convenience and to save NAMI Syracuse resources.

# Harvest Hopela

a fall fundraiser presented by NAMI Syracuse

Sunday, 9/13/15

4pm to 7pm

2260 Lamson Road

Phoenix, NY

*Not too late to register!*

*Call or e-mail NAMI  
Syracuse today!*

*Event hosted by  
Dr. Paula Zebrowski & Pam Fortino*

*Catering by Marie Mahar  
Music by Bob Switalski  
Silent Auction  
Special bourbon & vodka tastings*

*\$75/person*

## NAMI Syracuse Educational Conference

### Supports and Strategies for Recovery

Thursday, October 8, 2015, 9:00am-3:00pm, Empire Room, NYS Fairgrounds, Syracuse

#### presenters

**Erik Lilly, SHRM-CP, PHR, Laila Keysor, SHRM-SCP, SPHR, Employee Representatives, Wegman's Food Market** will discuss what employers are looking for in successful candidates, how they support persons with disabilities, what to expect in a job interview, how to handle disclosure.

**Jacqueline Colello, Artist** will share her story of struggle, strength and hope. Her wish is that her life may inspire, enlighten and *give hope to the hopeless.*

**Kirsten Hubel, Director of the Sunrise Peer Recovery Center** will talk about the role of peer advocate.

**Nathan Baird, Peer Specialist** has been in recovery for 8 years and will talk about how work has affected his recovery.

**Sunny Aslam MD,** considers himself a recovery-oriented psychiatrist and will speak on negotiating with your psychiatrist when returning to school or work.

**Sherie Ramsgard, Owner/Psychiatric Nurse Practitioner at Whole Mental Wellness** will discuss stress management and self-care.

**NAMI Syracuse Educational Conference: Supports & Strategies for Recovery**  
Thursday, October 8, 2015 \* 9:00am-3:00pm \* Empire Room, New York State Fairgrounds, Syracuse  
Please register by Friday, October 2, 2015

<input type="checkbox"/>	Professional/Provider/Non-NAMI Member	\$65.00
<input type="checkbox"/>	NAMI Member	\$50.00
<input type="checkbox"/>	Student/Recipient of MH Services	\$30.00
<input type="checkbox"/>	Become a member of NAMI Syracuse & attend the conference	\$80.00

NAME: \_\_\_\_\_  
ADDRESS: \_\_\_\_\_  
PHONE: \_\_\_\_\_ E-MAIL: \_\_\_\_\_

*Registration Includes Continental Breakfast & Lunch - Request vegetarian lunch [ ] Request Display Table [ ]  
Mail registration form along with payment to NAMI Syracuse, 917 Avery Avenue, Syracuse, NY 13204*

## PSYCHIATRY'S IDENTITY CRISIS

*New York Times, Richard A. Friedman,  
7/17/2015*

American psychiatry is facing a quandary: Despite a vast investment in basic neuroscience research and its rich intellectual promise, we have little to show for it on the treatment front.

With few exceptions, every major class of current psychotropic drugs - antidepressants, antipsychotics, anti-anxiety medications - basically targets the same receptors and neurotransmitters in the brain as did their precursors, which were developed in the 1950s and 1960s.

Sure, the newer drugs are generally safer and more tolerable than the older ones, but they are no more effective.

Even the new brain stimulatory treatments like repetitive transcranial magnetic stimulation don't come close to the efficacy of electroconvulsive treatment, developed in the 1940s. (Deep brain stimulation is promising as a treatment for intractable depression, but it is an invasive treatment and little is known about its long-term safety or efficacy.)

At the same time, judging from research funding priorities, it seems that leaders in my field are turning their backs on psychotherapy and psychotherapy research. In 2015, 10 percent of the overall National Institute of Mental Health research funding has been allocated to clinical trials research, of which slightly more than half - a mere 5.4 percent of the whole research allotment - goes to psychotherapy clinical trials research.

As a psychiatrist and psychopharmacologist who loves neuroscience, I find this trend very disturbing. First, psychotherapy has been shown in scores of well-controlled clinical trials to be as effective as psychotropic medication for very common psychiatric illnesses like major depression and anxiety disorders; second, a majority of Americans clearly prefer psychotherapy to taking medication. For example, in a meta-analysis of 34 studies, Dr. R. Kathryn McHugh at McLean Hospital found that patients

were three times more likely to want psychotherapy than psychotropic drugs.

Finally, many of our patients have histories of trauma, sexual abuse, the stress of poverty or deprivation. There is obviously no quick biological fix for these complex problems.

Still, there has been a steady decline in the number of Americans receiving psychotherapy along with a concomitant increase in the use of psychotropic medication in those who are treated in the outpatient setting. These trends are most likely driven by many factors, including cost and the limited availability that most Americans have to mental health practitioners. It is clearly cheaper and faster to give a pill than deliver psychotherapy.

The doubling down on basic neuroscience research seems to reflect the premise that if we can unravel the function of the brain, we will have a definitive understanding of the mind and the causes of major psychiatric disorders. Indeed, an editorial in May in one of the most respected journals in our field, *JAMA Psychiatry*, echoed this view: "The diseases that we treat are diseases of the brain," the authors wrote.

Even if this premise were true - and many would consider it reductionist and simplistic - an undertaking as ambitious as unraveling the function of the brain would most likely take many years. Moreover, a complete understanding of neurobiology is unlikely to elucidate the complex interactions between genes and the environment that lie at the heart of many mental disorders. Anyone who thinks otherwise should remember the Decade of the Brain, which ended 15 years ago without yielding a significant clue about the underlying causes of psychiatric illnesses.

Sure, we now have astounding new techniques for studying the brain, like optogenetics, in which neurons can be controlled by light, allowing researchers to understand how neurons work alone and in networks. But no one thinks breakthrough biological treatments are just around the corner.

More fundamentally, the fact that all feelings, thoughts and behavior require brain activity to happen does not mean that the only or best way to change - or understand - them is with medicine. We know,

for instance, that not all psychiatric disorders can be adequately treated with biological therapy. Personality disorders, like borderline and narcissistic personality disorders, which are common and can cause impairment and suffering comparable to that of severe depression, are generally poorly responsive to psychotropic drugs, but are very treatable with various types of psychotherapy.

There is often no substitute for the self-understanding that comes with therapy. Sure, as a psychiatrist, I can quell a patient's anxiety, improve mood and clear psychosis with the right medication. But there is no pill - and probably never will be - for any number of painful and disruptive emotional problems we are heir to, like narcissistic rage and paralyzing ambivalence, to name just two.

Anyone who doubts the need for psychotherapy research should consider the case of post-traumatic stress disorder, for which the mainstay of treatment has been exposure therapy.

This requires patients to re-experience the circumstances of their traumatic event, which is meant to desensitize them and teach them that their belief that they are in danger is no longer true.

But we know that many patients with PTSD do not respond to exposure, and many of them find the process emotionally upsetting or intolerable.

Dr. John C. Markowitz, a professor of clinical psychiatry at Columbia University, recently showed for the first time that PTSD is treatable with a psychotherapy that does not involve exposure. Dr. Markowitz and his colleagues randomly assigned a group of patients with PTSD to one of three treatments: prolonged exposure, relaxation therapy and interpersonal psychotherapy, which focuses on patients' emotional responses to interpersonal relationships and helps them to solve problems and improve these relationships. His federally funded study, published in May's *American Journal of Psychiatry*, reported that the response rate to interpersonal therapy (63 percent) was comparable to that of exposure therapy (47 percent).

PTSD is a serious public mental health problem, particularly given the rates of PTSD in our veterans returning from war. This study now gives clinicians a powerful

new therapy for this difficult-to-treat disorder. Imagine how many more studies like Dr. Markowitz's might be possible if the federal funding of psychotherapy research were not so stingy.

The brain is notoriously hard to study and won't give up its secrets easily. In contrast, psychotherapy research can yield relatively quick and powerful results. Given the critically important value - and popularity - of therapy, psychotherapy research deserves a much larger share of research dollars than it currently receives.

Don't get me wrong. I'm all for cutting-edge neuroscience research - and lots of it. But we are more than a brain in a jar. Just ask anyone who has benefited from psychotherapy.

### **LEARNING TO LET GO: RECOGNIZING FAMILY GRIEF AND MENTAL ILLNESS**

*by Lucy Lu (Counselor and Art Therapist)*

When a loved one dies, we are able to seek support to mourn our loss and to learn to move on without their presence in our lives. In our society we have social rituals of letting go to help with grief and mourning - tears are shared and shed at a funeral, we celebrate and commemorate the life of the person at a wake, family and friends send us cards of condolences and we seek their company to share in the loss and find comfort in the memories of good times. In this normal process of loss through death, friends and family know how to support someone who is grieving and help them find closure over their loss. When a loved one is struck with a serious mental illness, family members experience the loss of the individual they once knew, and are left to cope with learning how to live with a person who is physically present, but psychologically and emotionally different. What social rituals exist to deal with this loss that is so real, yet so difficult to grasp?

There are no funerals, wakes, cards or tears shared with family and friends when mental illness strikes a family. Researcher and clinician, Pauline Boss

(1999) has called this difficult experience of loss, as an "ambiguous loss," as family members are "frozen in their grief" because we lack the social rituals that help comfort people and allow them to mourn the multiple losses they will encounter in their mental illness experience. Family members experience feelings of denial, anger, guilt, fear, sadness, and despair on their own as they try to cope with the consequences of mental illness. Often their energies are focused on understanding the mental illness and seeking help and services for their loved one. Family members supporting their loved one may experience many losses as they learn how to cope with their loved one with a mental illness. The delicate relationship balance is tipped, as family members "walk on eggshells" in order not to "trigger" the person with mental illness, spouses become caregivers for their ill partner, parents continue to care for their adult children, and young children learn to parent their parents as they live with mental illness.

This "ambiguous loss" is experienced in witnessing your loved one undergo a number of losses due to the consequences of mental illness - loss in competence and independence, losses of joy and pleasure in life, loss of dreams for the future, and sometimes dealing with the real or near loss due to attempted suicide. For the family member supporting the loved one with mental illness, people may experience many internal losses that go unrecognized by others or even by oneself - loss of self-esteem, loss of dreams, loss of control, loss of pleasure in child's successes, loss of hope, loss of security and certainty both of the illness and future, loss of religious faith, loss of positive sense of family life (MacGregor, 1994). As well, family members may experience external losses involving a change in balance in the family dynamic, loss of privacy, loss of a sense of spontaneity, loss of the social support and network, loss of faith in the mental health system, loss of financial resources and loss of freedom as the caregiver becomes the primary support for the person living with mental illness (MacGregor, 1994).

Without recognizing this mental health experience as a process of coping with losses, our emotional reactions are not recognized for what they are - as normal grief

reactions to a great loss in our lives (Lafond, 2002; MacGregor, 1994). As stigma and prejudice around mental illness is prevalent in society and even in the mental health system, family members living with mental illness are unable to openly acknowledge their loss and grief, publicly mourn it and receive the social support necessary to do the "grief work" that can help them learn to adapt, to cope, to let go of the expectations they had for their loved one, in order to find resolution and integration of mental illness in their lives. When family members experience ambiguous loss and unaddressed or unexpressed grief, they can become stuck in some aspect of their grief, such as denial, anger, guilt or despair (MacGregor, 1994). Some current theories on grief propose that grief may not be experienced in moving through stages (as outlined by Elisabeth Kubler-Ross), but rather we swing like a pendulum from focusing on our losses (loss-orientation) to focusing on adapting to changes (restoration-orientation) (Strobe and Schut, 1999). Thus a healthy form of coping with mental illness may fluctuate between thinking of the losses to attending to life changes; experiencing denial and avoidance to distraction from our pain through activity, realizing our old relationship has changed and learning to build a new kind of relationship. However, when we become stuck in some of these more difficult feelings, we have a harder time swinging towards focusing on adapting and restoring our senses of self. By being fixed on what has been lost, it becomes hard for us to change the way we relate to our loved one and see them for who they really are with the mental illness, as well as their potential to grow and change.

### **Creating space and a ritual to mourn mental illness**

How can we become unstuck from the grief feelings we are caught with? How do we let go of our perceptions that make it difficult to move on? Normal grieving is a social event, which requires interaction and validation from others of our losses. Virginia Lafond (1994) discusses in her book *Grieving Mental Illness*, that in order for us to resolve our grief over mental illness, we need to engage in a conscious grieving process. Some family members who have used services at Friends for Mental Health, such

as support groups, NAMI, Art Therapy and individual counseling have been able to seek that validation and support regarding their feelings concerning mental illness. These services provide a safe space for people to be heard and be validated for their feelings. Although these services provide much relief and address many issues, sometimes we may feel that we need some more guidance to deal with grieving mental illness in our lives.

Recently, the psycho-educational support group we offer for family members living with Borderline Personality Disorder took part in a “letting go” ritual, as many of them shared the feelings of being stuck, doubtful, hopeless and unable to create change for the future because of the losses and difficulties they experience in their lives. I offered using methods drawn from my creative arts therapies training, to create a ritual, which is a mindful space where we can acknowledge these feelings of grief and be witnessed and validated by others. In this one-session event, family members created artwork representing what they wanted to let go and what they wanted to create in the relationship to their loved one. By sharing a meal, using music, movement and a sacred ceremony of “letting go” of their difficult feelings, family members were able engage in a creative process that helped make “letting go” into a concrete process, as well as focusing on what they wanted to create for the future.

#### **“Letting go: grieving mental illness”**

Some of you may be interested in participating in a similar guided process of conscious grieving using the creative arts therapies- where we can mourn and focus on what has been lost, so that we can welcome what still remains and what can be created. For those who have experienced the positive benefit of expression through art therapy or experienced a strong emotional release through listening to a meaningful song or reading, you may understand the benefit of using metaphor and creativity to work through your emotions. This spring Friends will be offering a 5-week group “Letting Go: Grieving mental illness”, where family members who have used our other services (NAMI, Art Therapy, Support

Groups, Counseling, BPD training) will be invited to participate in a creative exploration of addressing grief and finding ways of letting go of it through a ritual that the group members will create. It is not necessary to have any experience in art, just a willingness to engage in conscious grieving process using the creative modalities. The group will focus on grieving the impacts of mental illness and not grieving the person in your life with mental illness. It is a way to help us separate the illness from our loved one. It is a way to acknowledge the sadness, hopelessness, anger and frustration about the mental illness experience while engaging in conscious grieving process of letting go, using art and other creative modalities. The objective of the group will be to share the ambiguous loss that mental illness has left you with and to help you move towards the resolution of your grief. Through the creative process you may be able to mourn the way things used to be, so that you can make space to see the person with mental illness in your life and implement changes towards a relationship you want to create.

#### **A FIRST-PERSON ACCOUNT OF A PSYCHOTIC EPISODE**

*Science of Us, 7/23/2015*

*NYAPRS Note: First-person accounts of experiences of psychosis, and not just personal stories of recovery, could be influential in changing the way clinicians and criminal justice personnel relate to people in crisis. An understanding of the different perceptions inherent to these experiences may be particularly helpful in offering new guidelines about stimuli in a person's natural environment, language that is used and avoided, and the time necessary to process new information.*

“You find my thinking jumbled and confused,” writes the author, addressing doctors and nurses, “the quantity and register of my speech is fluctuating wildly. But I’m also hyper-attentive to language, as anyone would be in a high stakes situation (was that “talk to” or “torture”?). In an idle moment a nurse at the foot of my bed has concluded an anecdote with a hearty “I could have killed him,” and perhaps she

thought that was boring or inaudible, but I heard it. And I thought you wanted me to hear it, that it was in the script. (Just as I’m sure you wanted me to hear the sounds of pain just the other side of that curtain.) Because for now, you and I differ about what we think this building, this institution, is for.”

This passage, excerpted from the first in a series of a “patient-led series” of articles in the *British Medical Journal*, recounts the anonymous author’s paranoid dealings with medical personnel as he or she dealt with a psychiatric emergency. It’s a fascinating account, bringing us inside a world we don’t often get to glimpse.

It also contains many important practical suggestions for medical personnel. For instance, the author explains that while doctors might have their heart in the right place when they want to weigh very carefully the evidence before deciding to, for example, commit someone to a short inpatient stay in a mental-health facility, a delay like this can have consequences: “Sleep deprivation plus questioning is a powerful combination,” the author writes. “Someone with an onset of acute psychosis is probably already experiencing the effects of sleep deprivation. So it doesn’t help if doctors are over-cautious in making a decision, because a deferred decision equals more questioning, which means more sleeplessness and growing desperation.”

The author also explains that for someone in a scared, paranoid state, the tone of conversation matters a great deal:

In my experience, the best communicators use calm and clarity; they treat the distressed person as a person. Paramedics are often good at this. For example, an ambulance crew applying the seat belts made this much more bearable for me by talking through the procedure-as if demonstrating it to someone in training. Granted, a psychiatric interview is not wholly transparent and doesn’t try to be. But the tone of the consulting room - quasi-conversational curiosity yet unmistakable authority - is alarming. By contrast, a psychologist who gave me cognitive behavioral therapy for psychosis (both as an inpatient and after discharge) often explained the process behind what she was doing - transparency is therapeutic.

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## **SOCIETY CANNOT IGNORE PROBLEM OF UNTREATED MENTAL ILLNESS**

*The Treatment Advocacy Center*

Last April, Oklahoma State Labor Commissioner Mark Costello thanked mental health advocates for the help they gave his family. Now, a little over four months later, Costello is dead—allegedly stabbed to death by his mentally ill son (“Mark Costello had spoken about need for better mental health care in Oklahoma,” the Oklahoman, Aug. 24.)

During his speech, Costello urged the audience “...we must be understanding and understand that society cannot ignore this problem, and if it does so, it does so at its peril.”

The Costello family had struggled for more than five years to find consistent mental health treatment for 26-year-old Christian Costello, who had been diagnosed with schizophrenia and suffered from paranoid thoughts about his parents, according to a family spokesman. Christian also had multiple run-ins with law enforcement since 2010, according to police records.

But mental health treatment was, and still is, hard to come by in Oklahoma.

For now, Christian remains in jail, with the scores of other people with mental illness who were also unable to receive treatment.

With just 10.7 public psychiatric beds per 100,000 people, Oklahoma fails to meet the 50 bed minimum standard considered necessary to provide adequate treatment for individuals with severe mental illness.

This is especially concerning, since Oklahoma ranks second in the nation for the highest rates of adults with serious mental illnesses, according to the Substance Abuse and Mental Health Services Administration.

Tragedies like this will undoubtedly continue until policy makers, lawmakers and society at large recognizes the peril that is caused when consistent, quality mental health treatment is not made readily available for those with the most severe psychiatric illnesses.

## **MENTAL ILLNESS AWARENESS WEEK**

*October 4 -10, 2015*

In 1990, the U.S. Congress established the first full week of October as **Mental Illness Awareness Week (MIAW)** in recognition of NAMI's efforts to raise mental illness awareness. Since then, mental health advocates across the country have joined with others in their communities to sponsor activities, large or small, for public education about mental illness.

This year it takes place between October 4-10. This year, the theme revolves around building a movement through the new StigmaFree initiative.

Being Stigma Free means learning about and educating others on mental illness, focusing on connecting with people to see each other as individuals and not a diagnosis, and most importantly, taking action on mental health issues.

Why is **MIAW** important? Each year millions of Americans face the reality of living with a mental health condition. During the first full week of October, NAMI and participants across the country are bringing awareness to mental illness. Each year we fight stigma, provide support, educate the public and advocate for equal care. Each year, the movement grows stronger.

We believe that these issues are important to address year round, but highlighting these issues during **Mental Illness Awareness Week** provides a time for people to come together and display the passion and strength of those working to improve the lives of the tens of millions of Americans affected by mental illness.

**“Whether an illness affects your heart, your leg or your brain, it’s still an illness, and there should be no distinction.”**

*~~Michele Obama, speaking at a mental health summit about the need to challenge stigma and reduce barriers to treatment by changing social attitudes.*

## American Foundation for Suicide Prevention - Out of the Darkness Walks

Liverpool/Syracuse Walk  
Join us on October 10, 2015

### Event Details

Walk Date: 10/10/2015

Walk Location: Long Branch Park  
(Westshore Trail)

Check-in/Registration Time: 10:00 am

Walk Begins: 11:30 am

Walk Ends: 2:00 pm

For more information, please contact:

Contact Name: Debra Graham

Contact Phone: 315-664-0346

Contact Email: [dgraham@afsp.org](mailto:dgraham@afsp.org)

When you walk in the **Out of the Darkness Walks**, you join the effort with hundreds of thousands of people to raise awareness and funds that allow **AFSP** to invest in new research, create educational programs, advocate for public policy, and support survivors of suicide loss.

As the leader in the fight against suicide, and thanks to walkers like you from cities across the country, AFSP has been able to set a goal to reduce the annual suicide rate 20% by 2025.

### “SEE ME TOO” SHOWCASES THE WORK OF PEOPLE COPING WITH MENTAL HEALTH

by Gulnaz Khan, *The Post Standard*

Artists are sharing their personal stories about mental health at the National Alliance of Mental Illness' second annual art and poetry exhibit at the Community Folk Arts Center thru August 15.

“NAMI Syracuse is about educating the public and fighting stigma, and art is a perfect opportunity to do that,” said Marla Byrnes, member of the Board of Directors at NAMI Syracuse.

The title of the exhibit, “See Me Too,” encourages people to see others beyond their label or diagnosis, Byrnes said. “I often think of mental illness as a modern day leprosy - we have to overcome that kind of fear and stigma,” she said.

Contributing photographer, Willson Cumber, 47, said he's lived with recurring depression over the last 35 years.

“The show is about recognizing people who are struggling with mental illness and making them visible,” Willson said. “The idea was to create a safe space for people to reveal their personal lives through art.”

Willson submitted two photographs he took in a park near his home, titled, “There is so much darkness in the summer”. The photographs of thick trees creating shade during the bright summer illustrate darkness in a time of light, he said.

Approximately 1 in 5 Americans has a mental illness, including 90,000 people in Onondaga County, according to the county Department of Mental Health.

A 2014 health department report revealed the county has higher rates of suicide, self-inflicted injury and binge drinking compared to the New York State average. The report named mental health promotion as a top priority in Onondaga County.

“The biggest obstacle for people getting treatment is that they feel they're alone,” Byrnes said, “Any efforts we can make to get positive publicity out there about mental illness helps more people come forward to seek help and get support.”

Tanisha Wiggins, 28, said she was 13 years old when she started struggling with depression. The first time she shared her feelings with her mother was through a poem, Wiggins said.

“My family is the type that hides everything. We don't really discuss what we feel inside,” Wiggins said, “but sometimes you have scars on the inside that people can't really see.”

When Wiggins was 16, her school principal read one of her poems at a schoolwide gathering - her mother was in the audience.

It was a turning point in their relationship, Wiggins said. Her mother was more aware of her mental health problems, and they became more expressive and open with each other, she said.

“There are a lot of people struggling out there that just need encouragement, or to know that they aren't alone. If it weren't for the people that supported and encouraged me, I probably would've been a different person,” Wiggins said.

### MAJORITY OF YOUTH PRESCRIBED ANTIPSYCHOTICS HAVE NO PSYCHIATRIC DIAGNOSIS

*In The News, August 3, 2015*

The majority of children, adolescents and young adults prescribed antipsychotic medications have not been diagnosed with a mental disorder, according to a recent study published in *JAMA Psychiatry*. The study, led by Mark Olfson from Columbia University, examined trends in the treatment of young people with antipsychotics in the United States between 2006 and 2010 and raised concerns about the safety and efficacy of prescription practices.

“Most of the younger children (60.0%), older children (56.7%), adolescents (62.0%), and young adults (67.1%) treated with antipsychotics had no outpatient or inpatient claim that included a mental disorder diagnosis,” the study said.

Among those who did receive a diagnosis for a mental disorder, the study raised the additional concern that antipsychotics had not been FDA approved for treatment. Although the FDA has approved the use of antipsychotics for diagnoses such as schizophrenia and bipolar disorder, many children, teens and young adults are prescribed these medications off-label. In children and adolescents treated with antipsychotics the most common accompanying diagnoses are ADHD and depression.

The authors advise that the frequency with which antipsychotic medications are being prescribed by non-psychiatrists may point to potential gaps in treatment for children presenting for mental health care. This finding was especially concerning for preschool aged children who were found to be in the age group least likely to receive antipsychotic prescriptions from a psychiatrist.

Clinical guidelines suggest extreme caution in the use of antipsychotic medications with young children. Due to the possibility of serious side-effects, antipsychotics are suggested only in the most severe cases and should be paired with psychosocial interventions. Of those prescribed antipsychotic medications, however, only 13.5% of younger children, 20.4% of older children,

24.8% of adolescents and 18.8% of young adults were found to have a claim for psychotherapy.

The study's lead author, Dr. Olson, commented:

“Relatively few of these young people are receiving psychotherapy. We may need to put greater effort into increasing access to psychosocial interventions that can treat symptoms and behaviors that are currently being addressed with antipsychotic medications.”

NAMI Syracuse sends its sympathy to Peg Gentile, whose son Michael recently passed away. Peg, and her late husband Joe, were long-time NAMI members and supporters. Joe Gentile served for many years as an assertive and dynamic president of NAMI Syracuse and was responsible for our community getting the ACT TEAM in place as well as other benefits to NAMI.

Dr. Mantosh Dewan, former head of the Department of Psychiatry at SUNY Upstate University and a long time consultant to our Board, has suggested that we establish *The Joe and Peg Gentile Advocacy Award* to be given every year to the best piece of writing, reporting or legislation that benefits the lives of individuals with serious psychiatric disorders. The award would be presented with a plaque and a small honorarium at our fall conference. The NAMI Syracuse Board is pleased to approve of this advocacy award to honor the Gentiles.

Condolences and sympathy also to Thomas Szczygielski on the passing of his wife Anne. Anne had been a member and supporter of NAMI Syracuse for the past 20 years.

Thank you to both the Gentile and Szczygielski family for designating donations made in their loved ones memory be sent to NAMI Syracuse.

## LATEST INFORMATION FROM THE BIPOLAR NETWORK NEWS

*Vol. 19, Issue 4, 2015, edited by Sheila Le Gacy, Director of the Family Support & Education Center, AccessCNY*

### MUTATIONS IN DOZENS OF GENES CAUSE AUTISM

Studies from more than 50 labs worldwide have linked mutations in over 60 different genes for being responsible for autism. So-called de novo (Latin for “afresh”) mutations do not appear in the genes of parents without autism, but arise newly in the affected child.

Before the new studies, only 11 genes had been linked to autism, and researchers expect to find that hundreds more are related to the illness.

**BIPOLAR NEWS** Editor's Note: This new research explains how autism could be increasing in the general population even as most adults with autism do not have children. It should also put to rest the idea, now totally discredited, that ingredients in childhood immunizations cause autism. It is clearer than ever that kids who will be diagnosed with autism are born with these mutations.

With these genetic findings, the search for new medications to treat this devastating illness should accelerate even faster.

Bottom line: Childhood immunizations don't cause autism, newly arising mutations in the DNA of parents' eggs or sperm do. However, parental behavior could put their children and others at risk for the measles and other serious diseases if they do not allow immunizations. The original data linking autism to immunization were fraudulent, and these new data on the genetic origins of autism provides the best hope for future treatments or prevention.

### LONG-TERM LITHIUM TREATMENT STILL HAS RISKS FOR KIDNEY FUNCTION

Long term lithium use has long been associated with decreased renal function. In the 1980's, when this became clear, doctors began to institute new safety measures for lithium users, including monitoring of blood levels and of creatine, a substance that is excreted by the kidneys. Recently,

researcher undertook a new study to examine whether the protocols instituted in the 1980's had reduced the renal risks of long-term lithium use. Unfortunately, they found that some reduced renal function is still common among people who use lithium for longer than 10 years, and this risk does not necessarily decrease when patients stop taking lithium.

Lithium treatment requires careful monitoring, especially over the long term. Patients must consider the risk/benefit ratio of lithium treatment. Since prevention of mood episodes can preserve an average ten years, patients must weigh the risks of insufficiently treated bipolar illness against the possibility for long-term decreases in kidney function.

## MENTAL HEALTH PARITY PROBLEMS IN U.S. PERSIST: NAMI REPORT

Despite parity regulations in the U.S. designed to end health insurance discrimination against behavioral health services, a new report from NAMI says barriers remain.

NAMI said about 62 million patients now have better insurance coverage, but many people have serious problems finding mental health providers or psychiatrists in their insurance plan network. Other challenges: getting inpatient care, having behavioral health services denied unnecessary, and high out-of-pocket costs for both medications and mental health treatment.

Many insurance policies aren't clear on how behavioral services are covered and how that coverage compares to medical services, the *Baltimore Sun* reports.

Mary Giliberti, NAMI's executive director, said progress is being made but noted that “discrimination still exists toward mental health and substance use conditions.”

~~from *esperanza*, Spring 2015



## OUR DESTINATION IS DIGNITY

by Ron Manderscheid, PhD

With the clarion cry, "Our destination is dignity," they set out across the National Mall in Washington, D.C., on one of the hottest days of our southern summer. They came from all corners of America - California, Georgia, and New York - with the solitary purpose of seeking dignity for all persons with mental illness. What a noble goal for very honorable people.

The **Destination Dignity March** proved to be a landmark event in the annals of American mental health. Almost a thousand people gathered on the National Mall at noon on August 24 to demand the simplest of things, that which most of us take for granted and never think twice about - basic human dignity. Just imagine being required to seek one's own basic human dignity. The National Mall has never before been witness to such an event.

Many present had been robbed of their human dignity by traumatic events in their lives, by stigma from their neighbors, by a care system that did not care. Now, they were here to reclaim that simple human dignity loudly and proudly. They were here reclaiming the voice they had lost in their own past.

"What do you want?" In unison, they responded, "Dignity!" "When do you want it?" "Now!" they shouted, "Now!"

You might ask, where does one find basic human dignity. I suspect it is near the corner of recovery and respect, and just down the street from support and good friends.

Speakers ranged broadly from the D.C. community and beyond. Among others including me, they featured Judge Ginger Lerner-Wren of Florida, who brought peer supporters into her court room to assist with disposition of cases involving persons with mental illness, and Brian Hepburn, the very new Executive Director of the National Association of State Mental Health Program Directors, who supported consumer activities in Maryland for many years. The refrain from all speakers was similar: We are here in solidarity with you; we support

you in your just cause; we will be here to support you in the future.

The **Destination Dignity March** was held in the shadow of the U.S. Capitol. Hence, we must ask whether the current mental health bills in the House and Senate promote or detract from the basic human dignity of persons with mental illness. Clearly, the first principle of any bill must be to do no harm to those with mental illness and to preserve and promote their human dignity.

The march now is being planned as an annual event to raise consciousness and to give voice to more mental health consumers seeking basic human dignity. The National Mall can hold about 2 million persons. It would take seven National Malls to accommodate the estimated 14 million American adults with serious mental illness. Just think about it - seven National Malls!

Our hats are off to Eduardo Vega, CEO of Mental Health America of San Francisco. Harvey Rosenthal, Executive Director, New York Association of Psychosocial Rehabilitation Services, and Deborah Plotnick, Policy Director, Mental Health America, for taking the lead in organizing and coordinating this very impressive event. We all owe them a debt of gratitude.

Next year, let's hope that 100,000 persons come to seek restoration of their basic human dignity. I plan to be there. I hope that you do as well.

## BORDERLINE PERSONALITY DISORDER

Borderline personality disorder (BPD) is a condition characterized by difficulties in regulating emotion. This difficulty leads to severe, unstable mood swings, impulsivity and instability, poor self-image and stormy personal relationships. People may make repeated attempts to avoid real or imagined situations of abandonment. The combined result of living with BPD can manifest into destructive behavior, such as self-harm (cutting) or suicide attempts.

It's estimated that 1.6% of the adult U.S. population has BPD but it may be as high as 5.9%. Nearly 75% of people diagnosed with BPD are women, but recent research suggests that men may be almost as fre-

quently affected by BPD. In the past, men with BPD were often misdiagnosed with PTSD or depression.

People with BPD experience wide mood swings and can display a great sense of instability and insecurity.

Borderline personality disorder is ultimately characterized by the emotional turmoil it causes. People who have it feel emotions intensely and for long periods of time, and it is harder for them to return to a stable baseline after an emotionally intense event. Suicide threats and attempts are very common for people with BPD. Self-harming acts, such as cutting and burning, are also common.

The causes of borderline personality disorder are not fully understood, but scientists agree that it is the result of a combination of factors: genetics, environmental factors and brain function.

There is no single medical test to diagnose BPD, and a diagnosis is not based on one sign or symptom. BPD is diagnosed by a mental health professional following a comprehensive psychiatric interview that may include talking with previous clinicians, medical evaluations and, when appropriate, interviews with friends and family.

A typical, well-rounded treatment plan includes psychotherapy, medications and group, peer and family support. The overarching goal is for someone with BPD to increasingly self-direct his/her treatment plan as a person learns what works as well as what doesn't.

BPD can be difficult to diagnose and treat-and successful treatment includes addressing any other disorders somebody might have. A person with BPD may have additional conditions such as anxiety disorders, PTSD, bipolar disorder, eating disorders or substance use disorders.

~~from NAMI Fact sheet



## THE USE OF OMEGA-3 (FISH OIL) TO TREAT THE EARLIEST SYMPTOMS OF SCHIZOPHRENIA

from Dr. E. Fuller Torrey, *Treatment Advocacy Center*

Dear NAMI Members,

We think that NAMI members who are themselves or have a family member diagnosed with schizophrenia will find the following of interest.

The publication of the study by Amminger et al (Longer-Term outcome in the prevention of psychotic disorders by the Vienna omega-3 study. *Nature Communications*

<http://dx.doi.org/10.1038/ncomms8934>) suggests a major step forward in the treatment of schizophrenia. Previously the authors had shown that a 12-week course of omega-3 (fish oil) minimized one year later the emergence of symptoms in 81 individuals with prodromal symptoms characteristic of later schizophrenia (Amminger et al. Long-chain omega-3 fatty acids for indicated prevention of psychotic disorders, *Archives of General Psychiatry* 67: 146-154, 2010). With this current publication the authors are reporting that the effect of the 12-week omega-3 (fish oil) trial lasted longer than six years, a remarkable finding.

Omega-3 fatty acids include EPA (eicosapentaenoic acid) and DHA (docosahexaenoic acid), which together are important ingredients of naturally occurring fish oil. The individuals included in this study, carried out in Vienna, Austria, had experienced prodromal symptoms characteristic of later schizophrenia, such as mild or fleeting feelings that your thoughts were being controlled or you were being followed, often accompanied by symptoms of anxiety or depression. However, they had not yet developed the full manifestations of schizophrenia, and treating them with omega-3 (fish oil) at this early stage appears to have prevented the full manifestation of the disease in some individuals.

What mechanism might possibly explain the effectiveness of omega-3 (fish oil)?

Several studies have shown that in the early stages of schizophrenia there is evidence of inflammation, and omega-3 (fish oil) has been demonstrated to have some anti-inflammatory effects. Blood collected on the patients in the Amminger study support this possibility; the blood of the individuals who did not develop full schizophrenia had lower levels of cytokine markers of inflammation, especially interleukin-12, compared to the blood of the individuals who did develop full schizophrenia (Cotter, et al. Elevated inflammatory markers in individuals who transition to psychosis from the at-risk-mental-state, presented at the International Congress on Schizophrenia Research, April 2015). Further research is needed to clarify possible mechanisms of action.

Like all potentially important scientific findings, it is essential that these findings be replicated. Such replications are underway in Australia, continental Europe; Ireland and North America (the American Prodrome Longitudinal Study, or NAPLS). The initial findings from the first and last of these studies should become available late in 2016.

What are the implications of this research for persons with schizophrenia?

If the finding that omega-3 prevents transition from the prodrome to full-blown schizophrenia is replicated, this would be a major breakthrough in preventing this debilitating illness. Individuals who elect to use this treatment at this time for the prodromal symptoms should use purified fish oil that contains both EP (eicosapentanoic acid) and DHA (docosahexanoic acid); the ratio used in the present trial was 700 mg EPA and 500 mg DHA; or 1.2 grams total per day. Other studies done to date have used between 1.0 and 4.0 grams of omega-3 per day.

Should fish oil be used for individuals with fully-developed schizophrenia?

At least 8 studies have addressed this question. Three small studies reported promising results but 5 other studies did not. These included a Norwegian study in which the patients had had schizophrenia for between 3 and 5 years and a South African study in which fish oil was given to individuals following their first episode of schizophrenia to see whether it would prevent a relapse of their illness; it did not.

The Stanley Medical Research Institute (SMRI) funded the original study by Amminger et al in 2003 as well as the follow up study. Presently, SMRI is also funding the follow-up omega-3 (fish oil) studies in Australia (McGorry, et al); Europe (Kahn et al); and Ireland (Rooney, et al). In addition, SMRI is funding another trial of omega-3, used in combination with minocycline, for individuals with schizophrenia and a trial of omega-3 for individuals with bipolar disorder. At any given time SMRI supports approximately 50 ongoing treatment trials, mostly for repurposed drugs that will not be supported by the pharmaceutical industry because such drugs cannot be patented.

SMRI is a privately funded non-profit research organization dedicated to finding better treatments for schizophrenia and bipolar disorder.

### Hutchings Psychiatric Center Family and Community Education Schedule

#### September and October 2015

All classes are free and open to the public, and are held in room 102 of the H.P.C. Education and Training Building at 545 Cedar Street, Syracuse, N.Y. Paid parking is nearby. To register for classes please call the Education and Training Department at 315-426-6873 or 315-426-6870. Please register at least 1 week in advance.

**9/8/15:** 10am to 12noon:

Support Groups for Anyone Affected By Addiction and Mental Health

Information for consumers, families, caregivers and friends.

Presenter: Vincent Primiano, LMSW  
HPC Social Worker

**10/13/15:** 10am to 12 noon

Living with Borderline Personality Disorder

Information for consumers, families, caregivers and friends.

Presenters: Pam Fortino, LCSW-R and Bob Switalski, LMSW  
HPC Social Workers

## SEND YOUR MEMBERSHIP TO NAMI Syracuse TODAY

\_\_\_\_ Individual Membership (\$35.00)

\_\_\_\_ Open Door Membership (\$3.00 for Individuals on a limited income)

Donation (\$\_\_\_\_\_) In Memory/Honor (\$\_\_\_\_\_) Name: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Tel. #: \_\_\_\_\_ e-mail address: \_\_\_\_\_

### 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.)**