



NAMI SYRACUSE

National Alliance on Mental Illness

Newsletter

JANUARY/FEBRUARY 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

SHARING

EDUCATION

ADVOCACY

Events Calendar

January 20, 2015	Support & Sharing Meeting 7:00pm - Access CNY
February 17, 2015	Support & Sharing Meeting 7:00pm - Access CNY
March 17, 2015	Support & Sharing Meeting 7:00pm - Access CNY
May 6, 2015	SAVE THE DATE: NAMI Syracuse Children's Conference Empire Room, NYS Fairgrounds

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MESSAGE FROM THE PRESIDENT

Dear fellow NAMI Syracuse members:

We have a lot of goals for 2015, but before we fully set our sights on 2015, I want to take a look back at the many successes of 2014.

NAMI Syracuse-2014-The Year in Review

Partnering with OnCare:

NAMI Syracuse has partnered with OnCare. Thanks to their generous donations, we were able to provide scholarships to both our fall educational conference and NAMI-NYS Conference. OnCare was also instrumental in providing financial support for the Breaking the Silence program, fifty informational posters, and the formation of the Family Leadership Series, all which are described below.

Breaking the Silence:

Due to the drive and perseverance of board member Steve Glatt and his assistant Andy Beltran, we have gone from having just a handful of schools using BTS to thirty-one! BTS is a three part curriculum that provides stigma-busting education about mental illness to children in upper elementary, middle school, and high school. With this program we've managed to teach 1,000-1,500 students about mental illness in CNY. We will continue our efforts until every school in the area has adapted some sort of mental illness educational curriculum.

Informational Posters Completed:

Board member Marla Byrnes, was instrumental in creating a beautiful NAMI Syracuse poster complete with a tear off sheet of critical phone numbers. These posters will be placed in hospitals, clinics, doctors' offices, and any public area where it would be welcome. Please see our website or Facebook Page for the full color version of this important and eye-catching poster.

Formation of Family Leadership Series:

We have partnered with OnCare and the Syracuse public schools Parent University to form the Family Leadership Series. This is an educational program that will be offered free of charge to parents of children with mental illness to better prepare them for navigating the mental healthcare system and give them the skills to become better advocates and community leaders. Upcoming details will be posted on our website and Facebook Page.

The fight to keep and increase our children's beds:

Spearheaded by board member Sheila Le Gacy, NAMI Syracuse wrote a very powerful letter regarding the lack of children's beds in Upstate's Golisano Children's Hospital. This initiated serious discussions by our legislators regarding the current state of treatment of our youth suffering from mental illness. We have enlisted Assemblyman William Magarnelli, Senator John DeFrancisco, and Congressman John Katko in our efforts to work with the Office of Mental Health to improve outpatient and inpatient services in CNY. Two meetings with key players have already taken place. Our goals include but are not limited to: making it standard policy for Hutchings to accept payment from private insurance companies while keeping the existing beds in Hutchings. We are also lobbying for the addition of inpatient, outpatient, and respite services in association with Golisano Children's Hospital. By treating our children with neurobiological illnesses within this state-of-the-art facility, the stigma attached to mental illness will be greatly decreased.

Update of Our Website and Social Media:

Thanks to the very generous volunteer work of Brook Gleasman, as of New Year's Eve we have an updated, interactive website! We now have a PayPal account, a donation button on the website, and our members will soon be able to pay membership dues, conference registrations, and donations online!

Elizabeth Droge-Young, volunteered to post and Tweet important announcements and information on our Facebook Page and Twitter account. She is doing an excellent job! We will also be offering an e-newsletter in 2015!

First annual Art Show:

The Community Folk Art Center hosted our very successful first See Me!! Art Show! Thanks for all your hard work, Marla Byrnes and Tom Bassett!

Uno Pizzeria Fundraiser:

Board member Monica Lamont was instrumental in setting up this tasty fundraiser. We hope to do a few more of these in 2015.

(continued on page 2)

NAMI Syracuse Officers

- Karen Winters Schwartz.....President*
- Spencer Plavocos.....Vice-President*
- Frank Mazzotti.....Treasurer*
- Marla ByrnesRecording Secretary*

Board of Directors

- Judy Bliss-Ridgway*
- Carol Sheldon Brady*
- Ann Canastra*
- Sandra Carter*
- August Cornell*
- Stephen Glatt Ph.D.*
- Monica Lamont*
- Kristin Neagle*
- Sherie Ramsgard*
- Steffany Rose*
- Maria Sweeney*
- Susan Zdanowicz*

Consultant to Board

- Dr. Mantosh Dewan*

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**:



<https://twitter.com/NAMISyracuse>

Book Launch/Fundraiser at Kelley's Bar & Restaurant:

This was a well-attended and delicious book launch of **The Chocolate Debacle!** Thanks to all who attended and helped support this writer and NAMI Syracuse!

Two Successful Educational Conferences and Our Touched With Fire Concert:

As always the board members of NAMI Syracuse worked hard to pull together our spring children's and fall education conferences. These events are a tremendous amount of work, but well worth it for the information they provide. Our annual concert was especially joyful this year with wonderful talent from throughout the area.

Annual Picnic and Christmas Dinner:

These were great social gatherings. I'd love to see these events even better attended next year so that I can meet more of our members!

I believe we accomplished a lot in 2014. I want to thank each and every one of our board members and members who helped make this possible. I also believe that we can do even more in 2015! We have over 500 NAMI Syracuse members. Please consider getting more involved in your organization. Here are just some of the things you can do to help get our mission across: disseminate our new posters, manage our new website, help with upcoming fundraisers and grant writing, bring more schools on board with Breaking the Silence, put pressure on our legislators to fight for our family members, submit artwork and writing for the website, Facebook Page, and newsletter, help with the development of an e-newsletter, and help with repairs and maintenance of our facility.

Please contact us if you have any special skills in any of these areas or have suggestions on how we, as an organization, should move forward. Together we can make a difference! HAPPY 2015!

Karen Winters Schwartz
NAMI Syracuse President

ALWAYS LOOKING FOR VOLUNTEERS

by Marla Byrnes

The holidays are over, it's the beginning of a new year. Perhaps you are looking for something to get you through our long winter. Why not consider becoming more active in NAMI? Yes, we need your donations and contributions, but more importantly we are asking for your time.

Below you will see the many working committees NAMI uses to organize our efforts. We could use your talents to help on any of these work groups. Or, if you don't want to attend committee meetings, do you have a few hours a month to help in other ways?

We can always use an extra hand to help at our conferences. We can use help to gather items for the silent auctions we will be having at our May and October conferences. We can use your help to bake goodies for our concert in November. You could help in the office. We can put you to work doing minor fix up jobs at our residences or office.

What special talent do you have to share? Whatever talent you have, we can use it to promote education, support and advocacy efforts. There is always a place for folks who work behind the scenes to make NAMI work.

Standing committees you may be interested in:

2014-2015 NAMI Syracuse Committees

Fall Conference

- Marla Byrnes
- Kris Neagle
- Susan Zdanowicz
- Carol Brady
- Spence Plavocos

Holiday Party

- Spence Plavocos
- Kris Neagle

Picnic

- Frank Mazzotti
- Judy Bliss-Ridgway

Touched with Fire Concert

- Judy Bliss-Ridgway
- Sue Pietrantoni
- Carol Brady
- Frank Mazzotti

Membership/Community Outreach

- Joe Ridgway
- Monica Lamont
- Sue Zdanowicz
- Kris Neagle

Fundraising/Grant Writing/Finance

- Tom Bassett
- Steve Glatt
- Frank Mazzotti

Art Show

- Marla Byrnes
- Tom Bassett

Children's Conference

- Marla Byrnes
- Steve Glatt
- Carol Brady
- Judy Bliss-Ridgway

Breaking the Silence

- Steve Glatt
- Andy Beltran
- Monica Lamont

Technology/Social Networking

- Karen Winters
- Steve Glatt

Partnership with ONCARE/Parent University

- Karen Winters Schwartz
- Marla Byrnes

Mental Health Court

- Judy Bliss-Ridgway
- Dr. Paula Zebrowski
- Tom Bassett
- Sheila Le Gacy
- Monica Lamont

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 FORTUNATE MOTHER

by Rick Hampson, *USA Today*

She says she's lucky, even though her son's mental illness has driven her to bankruptcy, sidetracked her career and left her clinically depressed.

She's lucky, even though his illness cost her the time to plan her daughter's wedding and the money to pay for it. Even though her only friends now are ones who accept last-minute cancellations of long-made plans. Even though she can't recall the last time she went out on a date.

Lucky, even though her son has been hospitalized 13 times in six years. Even though he's repeatedly called 911 with fantasies -- a gunshot wound, a heart attack. Even though he has fantasies (he's rich), hallucinations (he's being followed) and delusions (Mom is a robot). Even though he's slept with a butcher knife under his pillow.

Laura Pogliano calls herself lucky even though Zac, her dear boy, has lived all his young adult life with schizophrenia.

Her gratitude makes sense only when you consider the state of America's system of mental health care.

This year USA TODAY has detailed the cost of caring so little about the nearly 10 million seriously mentally ill Americans. It's a cost borne disproportionately by families.

About 40% of the most disabled mentally ill are cared for by relatives -- but not forever. "In the end, most of them bail out. They can't take it any longer," says Doris Fuller of the Treatment Advocacy Center, which wants to make it easier to legally compel the recalcitrant mentally ill to accept treatment.

Families can force members to enter an institution or receive treatment only by proving they're dangerous to themselves or others. But a shortage of facilities ensures many are discharged prematurely. And families face exorbitant out-of-pocket costs.

So Laura Pogliano feels lucky she's been able to hang in, lucky Zac is not in jail or under a bridge.

Count her blessings: Zac's illness developed before he was 18, giving her legal control at the outset. He does not refuse his anti-psychotic medication. When he needs to be hospitalized, he usually does not object or exercise his right to deny Laura access to his medical caregivers.

For the past two years most of his medical bills have been covered by Medicare disability. He lives minutes from excellent psychiatric care at Johns Hopkins University. He is not homicidal or suicidal.

Despite her relative good fortune, Laura says she can never move forward because her son never stops dying. "Twice a year, right in front of me, he disappears into psychosis. Then medicine resurrects him for a few months, I have much of my child back, then he dies again."

Although she mourns the life Zac has lost, at 49 she also wonders: "What happened to *my life*?"

"Summer from hell - As his world shrank, so did mine."

In 2008 Zac was having what Laura thought were normal teenage problems. He totaled the car. He quit baseball. He broke up with friends. He smoked weed. She called it "the summer from hell." But it was a season that never ended.

The family -- Laura, Zac and his older sister Leah -- moved to Maryland from a small town in Illinois in 2004. Laura had gotten a good job as a software trainer. They rented a three-bedroom brick townhouse just north of the Baltimore line.

Zac was popular, athletic, musical, charismatic -- "a bit of a ladies' man," Leah recalls.

That summer, Laura noticed one of Zac's eyes was fluttering. His hands trembled. He lost sense of time. He threw fits over nothing, and broke things. He said he saw no point in celebrating his 18th birthday. He hid in the basement, and covered his face against germs.

A psychiatrist diagnosed obsessive-compulsive disorder. But Zac's symptoms got worse. He'd sleep 14 hours a day and lie in the shower for an hour under cold water. He was paranoid -- hence the knife under the pillow -- and when Laura got home from work, the front door always was dead-bolted from the inside.

Once, Zac opened the door but didn't recognize her. Another time, she had to

break a window to get in. When she went back to her car a few minutes later, he locked her out again.

Sometimes he stood stock-still in the middle of a room for several minutes. Sometimes he walked with a stiff, neurologically impaired gait that Laura thought of as "Frankenwalking." They were classic symptoms, and the doctor confirmed it: Zac was psychotic.

Laura's employers, she says, didn't accept the constant interruptions and sudden departures. A supervisor dismissively called Zac "Laura's little problem" in front of her team. She quit one job, then two more, to be with Zac, who stayed home from high school more often than he attended.

Her own mental health deteriorated. She had panic attacks, couldn't sleep. She felt isolated. "I wished he still played rugby, baseball. That he still had his old friends. What he gave up, I gave up. As his world shrank, so did mine."

But, she says, "I told myself I had to get over what I wanted. My attitude was, 'I'll enjoy nothing while he enjoys nothing.'"

She was stunned by the ignorance of mental illness -- she was asked how many different personalities Zac had (confusing schizophrenia with multiple personality disorder) and the fear. After one of several shooting sprees by a mental patient, she was asked, "Does he have a gun?"

Bills piled up -- for lawyers (Zac was busted twice for pot and once for heroin), ambulances and co-pays. She had to hire people to sit with Zac when she was working, to drive him to appointments and to do medical and insurance paperwork.

If Zac stopped taking his meds -- because of side effects or because he felt cured -- Laura knew a breakdown was coming, just not when. She asked a psychiatrist what triggers a breakdown. Change, he said: "The stress of daily living."

Out of the ward, down the aisle - a wedding and hospitalizations

In early 2012, Zac stopped taking clozapine, an antipsychotic with many unpleasant side effects. In April, he announced "I'm crippled," and slipped into bed. He complained of pulverized ankles, a brain tumor and a broken back.

He virtually quit eating, because he didn't trust anyone to bring him uncontam-

inated food, and drinking, because the water supply was poisoned. He used the toilet only if Laura helped him there.

"Make a good decision for yourself. See a doctor" Laura begged. But he was 20. She couldn't make him.

Two weeks later, she slipped out to appear before a judge, who ordered Zac hospitalized for evaluation.

But he was not treated for another 13 days. There were two hearings, one to determine whether Zac was competent to make decisions (no) and one to determine whether he was sick enough to be forcibly treated (yes).

Zac spent three months in the hospital.

Laura's inability during that time to help plan Leah's wedding epitomized what the mother calls "the sick kid syndrome. He gets all the attention." (Two years later, on the day Leah went into labor, Laura was rushing Zac to the hospital.)

In July, Zac was released. He put on a suit and walked his sister down the aisle.

In August, he moved with friends into an apartment.

In October, he stopped talking an anti-psychotic he said made it hard to swallow.

In November, claiming he had spiders in his throat and stomach, he was hospitalized for the 10th time.

A home of his own - "Schizophrenia is not a casserole illness"

Laura Pogliano sits at her dining room table, surrounded by her old life -- photos of Zac in his baseball uniform, with the dog, with his girlfriend -- and her new one -- stacks of financial and medical records.

She says she blew through the \$220,000 she had in the bank on Zac's care, and probably another \$80,000 in earnings. She lost a house she owned in Illinois to foreclosure. She drives a 12-year-old Mitsubishi with 100,000 miles. She says she's \$150,000 in debt.

Zac comes up from the basement, where he spends most of his time playing video games and listening to music.

He greets his mother's guest with a polite hand shake. But as he does so he ducks, as if something were falling from the ceiling. His affect is flat. He asks his mother for some money to get cigarettes.

She agrees, and reminds him, "Put on your coat!"

"He shouldn't smoke," she says, "but he has so few pleasures."

Laura has settled into a series of short-commute, limited-term jobs, allowing her to care for Zac. She sees a psychiatrist and takes medication for depression. She says she's better able to deal with the ups and downs, but she's lonely. "Who would date this?" she says, alluding to a few extra pounds she's picked up.

Her hope is that Zac, like many with schizophrenia, will stabilize as he ages, that maybe after a decade the illness will loosen its grip.

One day her watch will pass to Leah and her husband, Dan, who live in Michigan with their baby daughter. When Dan asked her for Leah's hand, Laura recalls, "I said yes, on one condition: 'You have to accept Zac and all the things that come with him. You have to treat him with compassion, always, or I will haunt you!'"

Leah says she feels guilty -- why did Zac get sick and not her? -- but that if she had to care for him while living hours from an appropriate hospital, "I'd be lost."

This month, Laura faces another potential crisis: Zac, 23, is moving out.

She found him an apartment three minutes away. A case manager will visit weekly, and a nursing assistant will check in three days and administer medication. Laura will cover the other days.

"He has to get out from under my wing and make friends on his own," she says, sounding a little dubious.

After six years, she also puzzled by the indifference or hostility to mental illness. She might understand people's reaction to the mentally ill -- mysterious disease, atrocious symptoms -- but what about their relatives? Why have autism advocates been able to mobilize public support, and not families of the mentally ill?

This year, Maryland rejected legislation that would have made it easier for families to force mentally ill relatives into treatment.

Laura thinks we see only the upsetting behavior and blame whoever seems in charge.

"Schizophrenia is not a casserole illness," she says -- no one is bringing food to the door. And no fundraisers, as for cancer

patients. "Who's going to come to a fundraiser for my son?" she asks bitterly. "To them, he's a problem."

Of all the costs borne by Laura Pogliano and millions like her, the one of not caring may be the cruelest of all.

STRUGGLING TO OVERCOME DEPRESSION AND RETURN TO THE WORKING WORLD

New York Times, John Otis, 11/21/14

Idleness has a way of creeping up on Kevin Williams.

As a man of many passions and hobbies, he speaks enthusiastically about his love of sketching characters and writing stories; of reading comic books, watching movies and whipping up a meal in the kitchen. It has been much harder, however, for Mr. Williams, 50, to define his ambitions, to pinpoint his purpose and to voice the depths of the internal struggle that has plagued him for more than two decades.

In 1992, Mr. Williams received a diagnosis of a major depressive disorder, which has made it difficult not only to find and keep a steady job, but also to acclimate to a wider world so often unaccommodating of mental illness.

"I want to be flowing more in society, be more interactive," said Mr. Williams, who has endured prolonged periods of limbo and stagnation.

The first sign that something was amiss came in his 20s. Mr. Williams said he would get into bed at night - and remain there well into the day. Weeks would roll by without his leaving home, days would pass without his showering. He was oblivious to the extent of his dormancy.

"My family members pointed it out to me," Mr. Williams said. "They said, You're not the same as you used to be." I was always good in school, very talkative, very vibrant. My family saw the change."

He was convinced that they were overreacting, that he was simply in a temporary slump. To ease their worry, Mr. Williams complied with his family's requests to visit a doctor.

"I'm a cooperative person," he said. "You don't know everything; otherwise you'd be king of the world."

He was upset and humbled by his depression diagnosis. He began attending an outpatient mental health program. In 1999, he completed a job-training course and held a few jobs over the next seven years, working as a messenger and a mailroom clerk.

"I'm happy getting a job," Mr. Williams said. "I'm working. But there's always that looming thought: Suppose I start showing symptoms of relapse."

None of the jobs lasted more than two years; Mr. Williams has not worked since 2006. He stopped going to his mental health programs shortly after completing his job training. "Sometimes when you stop working, you're reluctant to get back into a program because you think you're going to find a job," he said.

In 2012, Mr. Williams was advised by a therapist to return to a program. He began attending Brooklyn Community Services's MetroClub Personalized Recovery Oriented Services, which provides therapy, workshops, and job training to people with mental illnesses. Brooklyn Community Services is one of seven agencies supported by The New York Times Neediest Cases Fund.

"I really like it," Mr. Williams said. "It's tranquil. Sometimes at other places, there can be more hustle and bustle; sometimes the members can be more rowdy. It's very comfortable."

Mr. Williams receives \$698 each month in public assistance, most of which goes toward household expenses. He shares an apartment in Clinton Hill, Brooklyn, with his fiancée, a woman he has known for 16 years.

One of Mr. Williams's major goals is to find employment. For the past few months, he has been working with MetroClub on a variety of skills to make himself job-ready, including mock job interviews. In September, Brooklyn Community Services gave Mr. Williams \$80 in Neediest Cases funds to buy a shirt, tie and pants to wear on job interviews. He has his eye on a few job postings that excite him, including ones in clerical work and retail.

Job placement, however, can be a slow process for those in Mr. Williams's circumstances, MetroClub staff members say. So far he has been to only one

interview. "I see myself doing good," he said. "I have very little doubt or skepticism."

Mr. Williams is demonstrative when discussing his ambitions and his newfound abilities, reciting his hopes as if part of a mantra that bears repeating so it will come to fruition.

"The point I'm at now, more and more than ever before, I can see myself getting into work mode," Mr. Williams said. "When you practice something, you're more substantial with it. I feel more confident than I've been."

He closed his eyes as he spoke, as if beguiled by images of future possibilities.

ARE HEALTHY GIRLS AFFECTED PHYSICALLY BY THEIR MOTHER'S DEPRESSION?

Washington Post, Amy Ellis Nutt, 11/24/14

Researchers following adolescent and pre-adolescent healthy daughters of mothers with a history of depression, have found that the chromosomes of these high-risk girls show signs of cellular aging.

In a paper published in the Sept. 30 edition of **Molecular Psychiatry**, Stanford scientists found that telomeres, the caps at the end of chromosomes whose length shortens as a person ages, are shorter than normal in girls whose mothers have had multiple episodes of depression.

What was especially surprising, according to these researchers, was that these 10-to-14 year-old girls with telomere shortening showed no signs or symptoms of depression at the beginning of the study, when their telomeres were measured.

"How could healthy 10- to 14-year-old girls show signs of aging?" asked Thomas Insel, the director of the National Institute of Mental Health, on his NIMH blog last month. "The answer is not entirely clear but . . . the same girls with shortened telomeres has increased stress reactivity, indicated by a steeper spike in the hormone cortisol in response to a simple stress test."

Insel notes that while there is a significant amount of research "linking developmental stress to risk for depression" -- as the study progressed, 60 percent of the girls at high risk, because of mothers diagnosed

with depression, developed depression by the age of 18 -- the Stanford research suggests stress reactivity may be an important mechanism for cellular aging.

"Investigating the cause and timing of decreased telomere length -- to what extent it may result from abnormalities in stress responses or is genetically influenced, for example -- will be important for understanding the relationship between cellular aging, depression, and other medical conditions."

In the meantime, the head of the Stanford study, Ian Gotlib, and his colleagues are continuing their experiments with these high-risk girls by using neurofeedback to try to retrain their brains to better handle stress responses.

"It will be a few years before we will know how much this intervention reduces risk for depression," Insel wrote, "but anything that prevents or slows the telomere shortening may be an early indication of success."

SMOKING NOT "LESSER EVIL" IN MENTAL HEALTH TREATMENT SETTINGS

NBC 10, Maiken Scott, 11/25/14

Picture an AA meeting, and a gigantic coffee urn and a cloud of smoke come to mind.

In fact, the two men who started AA, Dr. Bob and Bill W. both died from tobacco-related illnesses.

Public health experts say smoking is still pervasive among people living with addiction and mental illness, and it's often not seen as a priority in treatment settings.

For example, smoking rates in Philadelphia have dropped significantly over 10 years, but haven't budged among people with mental illnesses and substance-abuse issues.

Smoking is often seen as a "lesser evil" in mental health and addiction treatment settings, explained Ryan Coffman, tobacco policy manager for Philadelphia's Department of Public Health. It's not a priority, and some providers assume it helps their clients cope.

Research shows the opposite to be true, says Coffman. "Individuals living with mental illness and substance-abuse disorder

ders who smoke have more severe symptoms, poorer well-being and functioning, they have more hospitalizations, and are at a greater risk for suicide,” he said.

Research also shows that people who quit smoking along with quitting other drugs have better recovery outcomes.

Philadelphia is increasing efforts to train mental health providers on tobacco-cessation programs, and to provide them with the most up-to-date resources available to their clients, Coffman said.

But for these efforts to really take root, a major cultural shift will have to occur, said University of Pennsylvania psychiatrist Robert Schnoll, who studies tobacco cessation.

“Research indicates that upwards of 25 percent of mental health care facilities still permit smoking on the grounds and on the premises,” he explained. “There’s pervasive use of cigarettes, or cigarette breaks, as a reward for pro-social behavior, so that’s certainly one of the issues we need to address going forward.”

Some providers think their clients don’t care about tobacco cessation, he said, or don’t understand the benefits. Some also simply don’t see it as their responsibility.

Research also indicates that smoking rates are high among people who work in mental health treatment settings, Schnoll said.

HAVING A SEVERE MENTAL ILLNESS MEANS DYING YOUNG

*Huffington Post, Allen Frances,
12/30/14*

People diagnosed with serious mental illness -- schizophrenia, bipolar disorder, or severe depression -- die 20 years early, on average, because of a combination of lousy medical care, smoking, lack of exercise, complications of medication, suicide, and accidents. They are the most discriminated-against and neglected group in the U.S., which has become probably the worst place in the developed world to be mentally ill.

In many previous blog posts I have bemoaned the shameful state of psychiatric care and housing for people with severe mental illness. My conclusion

was that the United States has become the worst place, and now the worst time ever, to have a severe mental illness. Hundreds of thousands of the severely ill languish inappropriately in prisons. Additional hundreds of thousands are homeless on the street.

But it gets worse. Having a severe mental illness also means that you will probably die very young. I have asked Dr. Peter Weiden to explain why, and to suggest what we should do about it. He is a professor of psychiatry at the University of Illinois College of Medicine and has spent his professional career working on improving outcomes and reducing side effects and complications for people with serious mental illness.

Dr. Weiden writes:

In the general population, our life expectancy in the United States is approximately 80 years (77.4 years for men, and 82.2 years for women). This is a stunning improvement in life expectancy since back in the 1970’s when life expectancies were a full decade shorter, around 70 years. The rapid and profound decrease in smoking is probably the single most important factor.

Certain groups do not share this good fortune. For example, black Americans live about 5 fewer years than whites. But one group suffers by far the most- with an average of 20 years of reduced life, in the ballpark of the life expectancy in Rwanda or Afghanistan.

Who is dying so young? You might think it would be people with HIV or severe asthma or some other serious medical condition. But it is not. As you have guessed by now, the group in question are those with a diagnosis of serious mental illness-schizophrenia, bipolar disorder or treatment resistant depression.

It has been known for many years that individuals with serious mental illness were more likely to have medical problems like diabetes, hypertension, or heart disease, but most of the mortality concern was on suicide prevention and other kinds of injuries that come from poorly controlled psychiatric symptoms.

The wake up call came in 2006 when a groundbreaking study of mortality statistics showed that individuals with severe mental illness were dying ranged between 13 and 31 years early, averaging to over 20

years of life lost relative to age matched general populations. Their causes of death were actually very similar to the causes of death in the general population, only happening on average about 20 years earlier.

While suicide and accidental deaths are still much more likely to happen in the severely mentally ill relative to general population, these are still relatively uncommon, whereas there is a doubling or tripling of the mortality from heart disease, diabetes, respiratory ailments, and cancer. People mostly die in their 50s of the same problems that kill off the rest of us 20 years later.

Many reasons conspire to create this shameful statistic. People with severe mental illness are less likely to take good care of themselves, more likely to smoke heavily and have sedentary lifestyles, and have more difficulty than most negotiating the complicated medical care system to go for appointments and follow-up care. And primary care physicians are not well trained or compensated for the additional complexities involved in diagnosing or treating medical problems in the severely ill.

A word about medications for mental illness, and their role in mortality. It is a complicated question because medications can be very effective in controlling psychiatric symptoms so that patients are better able to reduce medical risks and actively participate in medical care. On the other hand, some medications cause significant weight gain and dyslipidemia (increase in triglycerides and cholesterol) which can make the already bad situation worse. This dilemma is better now that there are effective medications that do not often cause weight gain or elevated lipids. Though this remains a vexing challenge for mental health professionals, the major problem seems to be the greater number of medical risk factors among persons with mental illness and their lack of access to high quality medical care.

A growing research literature shows that bringing the medical doctor to the psychiatric patient works much better than trying to bring the patient to regular medical services. The merging of primary psychiatric care with primary medical care is urgently needed.

Is this too much to ask? When we get surgery we expect other doctors to be available. The surgeon will be surrounded by a team including radiologists, anesthesiologists, and if there are heart problems a cardiologist. Having an appropriate medical team working together is usually not available for those who have psychiatric conditions.

Which throws the basic inequality into stark relief. Society would not tolerate 20 years of lost life expectancy for other groups, even those that also suffer discrimination like Latino or blacks or gays. If this were HIV or breast cancer or multiple sclerosis, we would not tolerate the total fragmentation of healthcare as we do with mental illness.

We are complacent because the lives of those with severe mental illness do not matter to us. Unless the person dying young is your parent or your child, or your brother.

Thanks so much, Peter, for this glum but much-needed assessment. Until recently I assumed that the reduced life expectancy in the severely ill was attributable to the "big four" factors of lousy medical care, heavy smoking, sedentary lifestyle, and antipsychotic use. To my great surprise a large and well-conducted study recently found the lowest mortality in the severely ill who had received low to moderate doses as compared with those who had taken no medicine or high doses. This is just one study, and it can be interpreted in different ways, but it does suggest that antipsychotics are less the culprit in early death than I had imagined.

This possibility should focus our attention even more on lousy medical care and smoking. Clearly we must not just improve the totally inadequate psychiatric care and housing currently provided for the severely ill. We must also follow Dr. Weiden's suggestion that medical care be an essential part of the package, along with smoking cessation and exercise.

Will anything change? The (non)treatment of severe mental illness in the U.S. is our national shame. This is a voiceless constituency in the U.S. that very few people seem to care about. It is different in much of Europe, where enlightened

policies and adequate funding for the severely ill lead to decent lives in the community and better health care.

There is always an outcry from the media and our politicians when there is poor health care for the military, children, women or ethnic minorities. Everyone rallied when one person died of Ebola. We should be deeply ashamed of ourselves for neglecting the severely ill, creating a system that imprisons them, renders them homeless, and allows them to die so young. We need a Charles Dickens to illustrate their plight, and a new Pinel to free them of their chains. Two centuries ago the Age of Enlightenment banished the idea that mental illness was caused by witchcraft or possession. As Harry Stack Sullivan put it, people with schizophrenia were more simply human than otherwise. It's long past time that we remembered this and acted accordingly.

BEATING THE BLUES

Beating the Blues is the most widely used and evidence-based *online* CBT program for the treatment of depression.

Beating the Blues has been proven to help people suffering with mild and moderate depression to get better and stay better and is based on *Cognitive Behavioral Therapy (CBT)*.

It is a way of helping people to learn to cope with anxiety and depression and has been recommended for use in the NHS by the National Institute for Health and Clinical Excellence (NICE).

Beating the Blues brings all the benefits of CBT directly to your patients by the use of computer and multi-media technology which means that you can access the treatment when and where you want.

Independent research has shown that CCBT works for many people with depression and anxiety by teaching practical, life-long skills to help them feel better and stay better.

This program was jointly designed and developed by Dr Judy Proudfoot and her team at the Institute of Psychiatry, Kings College, London and Ultrasys plc.

For more information go to:
<http://www.beatingtheblues.co.nz/>

SEASONAL AFFECTIVE DISORDER

What is seasonal affective disorder (SAD)?

The symptoms of depression are very common. Some people experience these only at times of stress, while others may experience them regularly at certain times of the year. Seasonal affective disorder (SAD) is characterized by recurrent episodes of depression, usually in late fall and winter, alternating with periods of normal or high mood the rest of the year.

Whether SAD is a distinct mental illness or a specific type of major depressive disorder is a topic of debate in the scientific literature. Researchers at the National Institute of Mental Health (NIMH) first posited the condition as a response to decreased light, and pioneered the use of bright light to address the symptoms. It has been suggested that women are more likely to have this illness than men and that SAD is less likely in older individuals. SAD can also occur in children and adolescents, in which case the syndrome is usually first suspected by parents and teachers rather than the individual themselves.

While no specific gene has been shown to cause SAD, many people with this illness report at least one close relative with a psychiatric condition-most frequently a severe depressive disorder or substance abuse. Scientists have identified that a chemical within the brain (a neurotransmitter called serotonin) may not be functioning optimally in many patients with SAD. The role of hormones, specifically melatonin, and sleep-wake cycles (also called circadian rhythms) during the changing seasons is still being studied in people with SAD. Some studies have also shown that SAD is more common in people who live in northern latitudes (e.g., Canada and Alaska as opposed to California and Florida).

What are the patterns of SAD?

For all depressive episodes, it is important to understand the pattern of the condition, in other words, what stresses or triggers contribute to the depressive symptoms. In SAD, the seasonal variation in mood states is the key dimension to understand. Through recognition of the pattern

of symptoms over time, developing a more targeted treatment plan is possible.

Symptoms of SAD usually begin in October or November and subside in March or April. Some patients begin to “slump” as early as August, while others remain well until January. Regardless of the time of onset, most patients don’t feel fully “back to normal” until early May. Depressions are usually mild to moderate, but they can be severe. Treatment planning needs to match the severity of the condition for the individual. Safety is the first consideration in all assessment of depression, as suicide can be a risk for more severe depressive symptoms.

Although some individuals do not necessarily show these symptoms, the classic characteristics of recurrent winter depression include oversleeping, daytime fatigue, carbohydrate craving and weight gain. Additionally, many people may experience other features of depression including decreased sexual interest, lethargy, hopelessness, suicidal thoughts, lack of interest in normal activities and decreased socialization.

In a minority of cases, symptoms occur in the summer rather than winter. During that period, the depression is more likely to be characterized by insomnia, decreased appetite, weight loss and agitation or anxiety. In still fewer cases, a patient may experience both winter and summer depressions, while feeling fine each fall and spring, around the equinoxes. Many people with SAD also report that their depression worsens or reappears whenever there is “less light around” (e.g., the weather is overcast at any time of the year, or if their indoor lighting is decreased).

Some people with bipolar disorder can also have seasonal changes in their mood and experience acute episodes in a recurrent fashion at different times of the year. It has been classically described that some people with bipolar disorder are more likely to experience depressive episodes in the fall/winter and manic episodes in spring/summer.

A person with any of these symptoms should feel comfortable asking their doctors about SAD. A full medical evaluation of a person who is experiencing these symptoms for the first time should

include a thorough physical examination as well as blood (e.g., thyroid testing) and urine tests (e.g., pregnancy testing, drug screening). A medical evaluation is appropriate because SAD can often be misdiagnosed as hypothyroidism, infectious mononucleosis or other medical conditions.

How is SAD treated?

Many people with SAD will find that their symptoms respond to a very specific treatment called light therapy. For people who are not severely depressed and are unable - or unwilling - to use antidepressant medications, light therapy may be the best initial treatment option.

Light therapy consists of regular, daily exposure to a “light box,” which artificially simulates high-intensity sunlight. Practically, this means that a person will spend approximately 30 minutes sitting in front of this device shortly after they awaken in the morning. Treatment usually continues from the time of year that a person’s symptoms begin, such as in fall, on a daily basis throughout the winter months. Because light boxes are created to provide a specific type of light, they are expensive and may not be covered by insurance. Unfortunately, having lots of lamps in one’s house and spending extra time outside is not as effective as this more expensive treatment.

Side effects of light therapy are uncommon and usually reversible when the intensity of light therapy is decreased. The most commonly experienced side effects include irritability, eyestrain, headaches, nausea and fatigue.

Scientific studies have shown light therapy to be very effective when compared to placebo and as effective as antidepressants in many cases of non-severe SAD. Light therapy may also work faster than antidepressants for some people with notable effects beginning within a few days of starting treatment. Other people may find that it takes a few weeks for light therapy to work, which can also be the case for most people who take antidepressant medications. Although not explicitly recommended, some people may elect for treatment with both light therapy and antidepressant medications and find the combination of these treatments to be helpful.

Antidepressant medications have been found to be useful in treating people with

SAD. Of the antidepressants, fluoxetine (Prozac) and bupropion (Wellbutrin) have been studied in the treatment of SAD and been shown to be effective. The U.S. Food and Drug Administration (FDA) has approved these medications for treatment of major depressive disorder but any person considering treatment with an antidepressant medication should discuss the benefits and risks of treatment with their doctors.

Some people may require treatment of their symptoms only for the period of the year in which they experience symptoms. Other people may elect for year-round treatment or prophylactic treatment that begins prior to the onset of the season in which their symptoms are most severe. This is yet another reason to discuss treatment options with one’s physicians. While not explicitly studied for the treatment of SAD, psychotherapy - specifically types of psychotherapy with documented clinical efficacy in the treatment of depression including cognitive behavioral therapy (CBT) - is likely a useful additional option for some people with SAD.

People with a history of bipolar disorder should be very cautious in approaching how they address depressive symptoms. Light therapy, like antidepressant therapy has been associated with increasing the risk of experiencing a manic episode. The specifics of this are beyond the scope of this review and again, should be discussed with one’s doctors.

What should I do if I think I have SAD?

Any person experiencing significant symptoms of depression should feel comfortable discussing their concerns with their doctors. Some primary care doctors (e.g., pediatricians and general practitioners) may be experienced in treating SAD and will feel comfortable treating this illness. Other doctors may want to refer people with SAD to a psychiatrist for treatment of this illness. This is more common in people with complex psychiatric illnesses or more severe symptoms. Before starting any treatment for SAD, a person should make sure to meet with their doctor to discuss the benefits and risks of treatment.

Friends and family members of people with SAD may be appropriately concerned for the well being of their loved one. The best way to be helpful to a person with SAD is for the people who care about them to be supportive in a non-judgmental fashion. This can include encouraging a person with symptoms to seek help for their condition.

**ALL NAMI MEMBERS INVITED
TO NAMI NEW YORK STATE 2015
LEGISLATIVE CONFERENCE**

When:

Tuesday, February 10, 2015

9:00am to 3:00pm

Where:

The Albany Room,
Empire State Plaza, Albany, NY

Make your voice heard during one of the most important legislative sessions in shaping the future delivery of mental health services.

NAMI-NYS's annual legislative conference will provide attendees with information on how the systems which deliver mental health services are changing through the introduction of health homes, managed care, the reduction of state hospital beds and the expansion of community-based services. The conference will examine these changes and explain how we need to adapt our advocacy voice to most effectively project it in this new landscape.

The conference includes complimentary buffet lunch and presentations from NYS Office of Mental Health Commissioner Dr. Ann Marie Sullivan and legislative leaders.

The items that comprise 2015 NAMI-NYS Legislative Action Agenda demonstrate NAMI-NYS belief that the best and most appropriate services are available to support all forms of recovery from mental illness and maximize mental health. Treatment options must be obtainable for people whose recovery would be best advanced in community settings as well as people with the most severe forms of psychiatric disorders who need the type of all-encompassing care that only a hospital can provide.

The 2015 priorities are:

1. Safe and Affordable Housing
2. Continued Reinvestment in Community Services
3. Improving the Criminal Justice - Mental Illness Interface in NYS

4. Mental Health Education in Schools
5. Mental Health Services for Veterans and the Military Community
6. Sustained Support of NYS Research Institutions

All NAMI Members are welcomed to join NAMI-NYS, as together we will let our legislators know the importance of having proper support services for individuals and families impacted by mental illness.

The Need for Safe and Affordable Housing for People With Mental Illness

Ever since NAMI-NYS was incorporated in 1982, safe, affordable housing has been an ongoing priority of ours. A stable environment is vital and fundamental to the recovery from psychiatric disorders. In 2005, the Campaign for Mental Health Housing estimated a need for 35,000 additional housing units to be built in New York State. While more than 14,000 units have been developed or planned since then, an additional 21,000 are still needed.

Safe and affordable housing programs which incorporate recovery oriented support services is the cornerstone of successful recovery from a mental illness within the community setting.

The lack of availability to decent, safe and affordable housing remains a tremendous challenge for adults with serious mental health disorders. It is important that appropriate services and supports are also provided so that our loved ones have the best chance possible to live in a residence that provides them with dignity and as much independence as possible.

Priority to the limited housing programs that are available is given to people who had been confined to state-run psychiatric hospitals. This leaves too many people who struggle with disabilities produced by psychiatric disorders unable to access these supported housing programs which could greatly advance their recovery.

People living with a mental illness who are transitioning out of jail and forensic units at state hospital facilities are also in dire need of supervised housing. Without appropriate housing in place, recidivism is especially high within this population.

We ask Governor Cuomo and our legislators to expand funding to provide hous-

ing and services to support people's recovery from mental illness and maximize their mental health. This is especially important for people who do not have the financial resources to afford the most basic human need...that of a safe, accessible, stable and affordable place to call home.

Continued Reinvestment in Community Services

The methods for delivering mental health services are changing in New York State. The number of hospital beds dedicated to treating psychiatric disorders is shrinking. NAMI-NYS strongly believes that the savings from this reduction be reinvested into services that would afford those living with a mental health disorder the best opportunity to advance their recovery in a community setting.

NAMI-NYS believes that it is the responsibility of government at all levels to develop and maintain comprehensive community support systems that include treatment and services to guide people's recovery from mental illness and maximize their mental health.

NAMI-NYS wants to see community support services in NYS which ensure:

- Practices and services that are recovery, resiliency and wellness oriented, culturally competent and readily accessible
- Safe and affordable housing
- Residential support services with transportation services and intensive case management
- The availability of all appropriate and effective medications
- Access to both inpatient and outpatient treatment options
- Vocational Training
- Wellness
- Round-the-clock services that are available seven days a week
- That no one would have to travel more than an hour to get to a psychiatric emergency room or crisis service unit.

While reinvesting in community services we must also ensure that proper services are in place for those with the most serious and persistent mental illnesses.

Improving the Criminal Justice - Mental Illness Interface in New York State

NAMI-NYS want to see improvements and expansions to several facets of the criminal justice system to help ensure the best outcomes for people living with a psychiatric disorder who enter or exit the system.

NAMI -NYS is calling for the following measures to be enacted:

Expansion of Crisis Intervention Teams

Contacts between law enforcement officers and individuals experiencing mental health disorder can be deadly, dangerous or result in poor outcomes for the individual. NAMI-NYS supports the expansion of Crisis Intervention Teams (CIT) which would save lives, reduce harm, and result in better outcomes for the individuals and the police. Crisis Intervention Teams consist of specially trained enforcement officers and mental health professionals working together to de-escalate situations and take appropriate action to assist an individual in the midst of a mental health crisis. In 2014, \$400,000 was earmarked for CIT, but these funds are not even close to being sufficient in providing communities across our state with police trained in CIT.

Expanded Mental Health Courts

Mental Health Courts are crucial in generating the most successful outcomes for people living with a mental illness who enter the system. Mental Health Court Judges evaluate each case individually to determine the best plan for each offender. If that person lives with a mental illness, recovery oriented treatment programs are often deemed to be better alternatives than incarceration. Mental Health Courts can be a vital point of entry to recovery services that can contribute to a reduction of arrests, recidivism, emergency room visits and long term in-patient care. Mental Health Courts are a sound investment as they can save the state money by proactively addressing issues that often lead to potential long-term expenses such as hospital stays and prison sentences.

Prevent Long Term Solitary Confinement

NAMI-NYS strongly supports the *Humane Alternatives to Long-Term (HALT) Solitary Confinement Act* (A8588/SO6566-A in the 2013-14 session). The bill would restrict the use of segregated confinement and create alternative therapeutic and rehabilitative confinement options, as well as limiting the length of time a person may be in segregated confinement and excludes certain persons from being placed in segregated confinement.

Mental Health Education in Schools

It is vital that New York's education system does a better job of creating a true comprehension of mental illness and mental health issues. Proper mental health is crucial to overall wellbeing, which is why it is necessary that mental health is incorporated into existing health education curriculums. Administrators, teachers and students must be given the tools to identify the potential warning signs of mental illnesses which are prevalent in children and adolescents, as well demonstrate the harmful and potential long-term mental health effects of body image issues, eating disorders, substance abuse and bullying.

The integration of mental health into our educational curriculums is long overdue. NAMI-NYS has partnered with three other organizations, the Mental Health Association in New York State, Families Together in New York State, and the American Foundation for Suicide Prevention to promote the passage of S5359-A/A7727-A: legislation that would formally introduce mental health education into our state's health education curriculum. This important step would significantly raise awareness of mental health issues.

Support Veteran's Mental Health

Supporting those who have served our country must be a top priority. We call on the Legislature and the Governor to assist veterans on all issues, but specifically those relating to mental health; our veterans deserve nothing less.

Returning combat veterans are experiencing very high rates of serious mental health disorders, suicide, addiction, homelessness and incarceration related to post-traumatic stress disorder and traumatic brain injury. More must be done in New York to provide services to America's returning heroes of combat.

- Nationally, 20 percent of returning veterans live with post-traumatic stress disorder, but only half seek and receive treatment for this condition.
- This means of the almost one million veterans living in New York State, approximately 100,000 are not receiving necessary treatment. Clearly, this is not acceptable, and reform must take place to improve the access and affordability of mental health services for veterans.
- The VA estimates that nationally there are 107,000 veterans homeless on any given night. Most of these suffer from PTSD or another serious mental illness. (Of all homeless men, it is estimated that 40 percent of them served in the armed forces).

Although New York State has taken tremendous strides and funding for mental health treatment has increased in recent years, significant numbers of veterans with serious mental illness are still falling through the cracks because they are not getting the services they need. We must increase funding for mental health and medical treatment for veterans with serious mental illness. Ensure that monies designated for mental health and substance abuse treatment for veterans are allocated to Veterans Medical Centers, Community-Based Outpatient Clinics and other programs serving veterans with mental illness and utilized for the treatment of these individuals. We have a moral obligation to provide our veterans the best and most readily available services we can offer.

Happy New Year!

**Time is like a flowing river,
no water passes beneath your feet twice,
much like the river, moments never pass you by again,
so cherish every moment that life gives you and have a wonderful New Year!**

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

**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.)**