



NAMI SYRACUSE

National Alliance on Mental Illness

Newsletter

MARCH/APRIL 2014

Meeting Schedule

NAMI Syracuse - Support & Sharing Meeting
 Third Tuesday of each month, 7pm, Transitional Living Services,
 420 East Genesee Street, Syracuse

Madison County - Support & Sharing Meeting
 meetings have been cancelled until further notice

NAMI Syracuse - Information & Education Meeting
 as announced

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

March 18, 2014	Support & Sharing Meeting Syracuse - 7:00pm
April 15, 2014	Support & Sharing Meeting Syracuse - 7:00pm
May 14, 2014	NAMI Syracuse Children's Educational Conference: <i>Navigating Early Intervention Programs & Services for Children</i> (see page 3 for details)
May 20, 2014	Support & Sharing Meeting Syracuse - 7:00pm
June 17, 2014	Support & Sharing Meeting Syracuse - 7:00pm

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MESSAGE FROM THE PRESIDENT

Dear Members,

I hope you all are surviving the end of a very cold winter. Spring is right around the corner, and with that spring NAMI Syracuse has a lot of exciting things coming up. Our Children's Conference: *Navigating Early Intervention Programs and Services for Children* will be held at the Rosamond Gifford Zoo on May 14th. This promises to be our best children's conference to date. As always we have a lineup of wonderful speakers who will cover a lot of topics including: eating disorders, recovery, education and the first break - early intervention program. Please see details on page 3 of this newsletter.

NAMI-NYS is sponsoring a bus trip to their legislative conference on March 18th. Anyone interested in going, please contact our office as soon as possible. This is a wonderful opportunity to let our voices be heard!

We are working on co-sponsoring an art show this summer. Stay tuned for details.

NAMI Syracuse is also in the process of updating and revamping our website. This comes with the help of a wonderful new volunteer named Brook Gleaman. He's a specialist in automating sales and marketing for businesses. If anyone is in need of his services, please see below for his contact information. In the near future our website will be featuring a live interactive blog, new educational links, and the ability to register and pay annual dues online.

Speaking of dues, I'd like to personally thank our members for your continued support. Your annual dues go a very long way in helping many individuals. Thank you!

Keep your eyes out for robins and crocuses.

~~Karen

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

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Attention NAMI Syracuse Members

2014 membership renewal is due. If you haven't already done so, please take the time to renew your membership in NAMI Syracuse right now!

\$35.00 Individual/Family Dues

\$ 3.00 Open Door Membership

(for those where dues present a hardship)

Thank you for your support of NAMI Syracuse. Your donation helps us to carry out our mission of providing support, education and advocacy to individuals and families affected by mental illness.

NAMI Syracuse to sponsor art and poetry show this summer at the Community Folk Art Gallery

This year NAMI Syracuse wants to prioritize fighting stigma. We are going to try something new. We are meeting with staff from the Community Folk Art Gallery to put together an art and poetry show for 4-8 weeks this summer. It would be a competition open to family members and consumers. The title of the show would be **"SEE ME"**. We want people to recognize we are more than a diagnosis or label. **"SEE ME"** will be a new way to reach out to our community for recognition of the talents we possess.

More information will be coming with our next newsletter. Start thinking about what artwork or poetry you may want to submit!

NAMI Syracuse Children's Educational Conference

Navigating Early Intervention Programs and Services for Children

Wednesday, May 14, 2014

9:00am - 3:00pm

Rosamond Gifford Zoo, Syracuse

~~presenters~~

John H. Wohlers, Ph.D is currently a co-owner of Psychological Healthcare, a large multi-discipline private behavioral health practice in Syracuse. He is also co-owner, CEO and Clinical Director of Centre Syracuse, a partial hospital program for adults and adolescents with eating disorders. Dr. Wohlers' presentation is **Identifying Eating Disorders**.

Tanisha Wiggins and Katrina Castro are two young women working and attending school while battling a mental illness. Their presentation is a **Message of Hope**.

Stephen J. Glatt, Ph.D. is Associate Professor of Psychiatry & Behavioral Sciences and of Neuroscience & Physiology, Associate Director Psychiatry Research and Director of the Psychiatric Genetic Epidemiology & Neurobiology Laboratory at SUNY Upstate Medical University in Syracuse. The ultimate objective of Dr. Glatt's research is to facilitate earlier identification, intervention, and prevention of mental illnesses. His presentation is entitled **Breaking the Silence: Educating the Next Generation**.

Linda Lopez is Director of Children's Mental Health for Onondaga County, and the Project Director for OnCare, the Onondaga County System of Care. She and other panel members will give an update on **County & State Services for Children**.

Seetha Ramanathan, M.D. is a psychiatrist at Hutchings Psychiatric Center in Syracuse. Her current work is outpatient in nature helping individuals with serious and persistent mental illness in achieving their goals. She is also working with the Early Prevention Committee to help set up a program aimed at early identification and intervention in individuals with psychosis.

Julie Aspenleiter, Psy.D. has been in the mental health field for 20 plus years working with adolescents and young adults. Currently she is at Hutchings Psychiatric Center assisting in program development and work in the Early Intervention First Break Schizophrenia Clinic.

They will be presenting on the **Early Intervention First Break Program**.

| NAMI Syracuse Children's Conference: **Navigating Early Intervention Programs & Services for Children** |

| Wednesday, May 14, 2014 ~ 9:00am-3:00pm ~ Welch Allyn Room, Rosamond Gifford Zoo, Syracuse |

| Please register by Friday May 9, 2014 ~~~Registration Includes Lunch |

[] Registration Fee	\$35.00
[] Become a member of NAMI Syracuse and attend the conference	\$60.00
[] Sorry, not able to attend; but please accept my tax deductible donation	\$ ____

| NAME: _____

| FROM: (Agency, NAMI, School, other) _____

| ADDRESS: _____

| PHONE: _____ E-MAIL: _____

| Mail registration form along with payment to NAMI Syracuse, 917 Avery Avenue, Syracuse, NY 13204

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

ALCOHOL, TOBACCO, DRUG USE MUCH HIGHER AMONG MENTALLY ILL

UPI January 2, 2014

Rates of smoking, drinking and drug use are significantly higher among those with psychotic disorders than the general population, U.S. researchers say.

First author Dr. Sarah M. Hartz, assistant professor of psychiatry at Washington University, and colleagues said the finding is of particular concern because individuals with severe mental illness are more likely to die younger than people without severe psychiatric disorders.

The researchers analyzed smoking, drinking and drug use in nearly 20,000 people including 9,142 psychiatric patients diagnosed with schizophrenia, bipolar disorder or schizoaffective disorder.

The investigators also assessed nicotine use, heavy drinking, heavy marijuana use and recreational drug use in more than 10,000 healthy people without mental illness.

The study, published in the journal *JAMA Psychiatry*, found 30 percent of those with severe psychiatric illness engaged in binge drinking, defined as drinking four servings of alcohol at one time. In comparison, the rate of binge drinking in the general population was 8 percent.

In addition, among those with mental illness, more than 75 percent were regular smokers. This compares with 33 percent of those in the control group who smoked regularly. There were similar findings with heavy marijuana use: 50 percent of people with psychotic disorders used marijuana regularly, versus 18 percent in the general population.

Half of those with mental illness also used other illicit drugs, while the rate of recreational drug use in the general population is 12 percent, the study said.

"I take care of a lot of patients with severe mental illness, many of whom are sick enough that they are on disability," Hartz said in a statement. "And it's always surprising when I encounter a patient who doesn't smoke or hasn't used drugs or had alcohol problems."

During the last few decades, smoking rates have declined in the general population. For example, about 40 percent of those age 50 and older used to smoke regularly; among those age 30 and younger, fewer than 20 percent have been regular smokers. But among the mentally ill, the smoking rate is more than 75 percent, regardless of the patient's age, Hartz said.

"With public health efforts, we've effectively cut smoking rates in half in healthy people, but in the severely mentally ill, we haven't made a dent at all," she said.

NEW PROJECT ON PSYCHIATRIC, NEUROLOGIC, AND BEHAVIORAL GENETICS

PhysOrg; Hastings Center Release, 1/8/14

The Center for Research on Ethical, Legal, and Social Implications of Psychiatric, Neurologic, and Behavioral Genetics at Columbia University Medical Center unveils its mission today with the launch of its website. Two Hastings Center research scholars are core faculty members of the new center, which was recently awarded a five-year grant from the National Human Genome Research Institute.

As understanding of the genetic contributions to psychiatric, neurologic, and behavioral (PNB) traits and disorders grows rapidly, this knowledge is quickly being translated into clinical practice. But the information presents particular ethical, legal, and social challenges because of what it could reveal about characteristics associated with individual identity and many of our most feared afflictions. Because of the potential for stigma linked to many PNB disorders and traits, this information may negatively affect how people view themselves and how others see them. Examination of the impact of PNB genetic information and consideration of the implications for normative judgments and public policy are therefore critically needed.

"Scientific findings regarding PNB traits must be discussed with special

attention to the human and social context because such traits and disorders—from Alzheimer's, schizophrenia, and depression to empathy, aggression, and intelligence—can touch our sense of who we are as persons," said Erik Parens, PhD, a senior research scholar at The Hastings Center. Parens and Josephine Johnston, LLB, MBHL, a Hastings Center research scholar and director of research, are core faculty members of the new center, based in the Department of Psychiatry. "The new center is uniquely situated to offer such attention."

The center is focusing on three areas: 1) the impact of PNB genetic information in clinical and research contexts on patients, family members, and clinicians, including effects on treatment choices, health and lifestyle decisions, identity, and self-image; 2) the impact of PNB genetic information in nonclinical contexts in which such information may affect perceptions of autonomy and responsibility for behavior, with a special focus on attributions of responsibility in the judicial process and in everyday life; and 3) data to suggest how PNB genetic information should be used in policy judgments related to clinical contexts (e.g., diagnostic and treatment decisions), research contexts (e.g., access to genetic data), and nonclinical contexts (e.g., legal rules and health policy).

Parens and Johnston will lead the new center's investigation into the meaning of PNB genetics information and how it should be used in policies and practices, as well as the translation of the center's work into formats that can inform policies and practices.

"Our center offers the opportunity to advance knowledge of the ethical, legal, and social implications of one of the most rapidly developing areas of genetics. Drawing on our empirical studies and input from key stakeholders, we will develop strategies to guide the use of PNB genetic data in clinical and research settings, as well as in courts, legislatures, and regulatory agencies," said Paul Appelbaum, MD, director of the center and of the Division of Law, Ethics and Psychiatry in the Department of Psychiatry at Columbia University College of Physicians and Surgeons. "By integrating empirical researchers with experts in ethics, economics, law, and public policy, we hope to point the way toward beneficial use of the latest scientific findings in this exciting new area of genetics."

The web-site is:

<http://phys.org/wire-news/150655481/new-project-on-psychiatric-neurologic-and-behavioral-genetics.html>

HAVE YOU SEEN MY BROTHER STANDING IN THE SHADOWS?

by Sarah Dusseault

My brother John called me last summer to tell me that he had finally figured out our family secret. I was his mother, he said.

I am not, of course.

My brother is 38 years old, but I will always think of him as he was in his early 20s, when he was diagnosed with schizophrenia. His good looks landed him work as a model, and he was a math whiz.

Today, he is still attractive and wick- edly smart at times, but his skin is weath- ered from years of homelessness and he is missing half of a finger on his right hand from one of his "stays" in a county jail. He is unmistakably homeless but still charming enough to persuade pass- ersby to give him clothes or a beer, or to play a game of pool.

His homelessness always starts with stopping his medication. Eventually he gets into trouble, usually from self-med- icating with alcohol, and bounces from incarceration to forced hospitalization. It has happened over and over. He spent Thanksgiving locked up in Twin Towers for stealing a \$4 strawberry Budweiser.

His latest round of homelessness began last spring after his landlord lost his apartment building to foreclosure and all of the tenants were evicted.

John had stopped taking his medica- tion a few weeks before he lost his home, blaming the fact that yet another Valen- tine's Day had passed without someone to share his life. Since then he hasn't accepted offers of help because he has stopped thinking rationally.

Not being able to help him is im- mensely frustrating. In my profes- sional life, I have worked to build hous- ing and create programs to end homelessness. But the system is broken, especially for homeless people with severe mental illness, like my brother. My family and I just keep hitting dead ends trying to get him help.

It's not that money isn't being spent on him. Study after study from across the country has demonstrated that the cost of dealing with people like my brother, who

ricochet from the streets to hospitals and jails and back, is exorbitant. I estimate that, in the last year, the federal govern- ment, several counties, the state and local communities have spent more than \$1 million on John.

And all of us - taxpayers, my family and John - are getting nothing for that money. The government could have bought him a cute single-family home in Pasadena with a full-time social worker and spent less.

My older brother Steve has tried to get appointed as John's conservator, but each time the matter has come before the court, John has convinced a judge that he is capable of managing his own affairs. John passes his days in conversation with imaginary people, but he is still capable of repeating a few memorized sentences that a judge accepts as proof he can care for himself.

For weeks at a time, he goes missing. Then he turns up in an emergency room, police station or hospital. He's been picked up for throwing himself at cars or belligerently talking to himself. He spent July in a hospital where he imagined that family members were with him. The hos- pital released him to a board-and-care facility, claiming he'd been stabilized, but he stayed only briefly before leaving.

In September, a friend found John asleep at my house. I called an outreach worker from Housing Works to try to get him help. They came and worked out a plan with John for housing and health- care, but he changed his mind later in the day, walking away from the social worker, back into homelessness.

I found him again but couldn't per- suade him to accept help. He says that I don't understand his profound loneliness and that my "options" are not what he wants. His appearance has deteriorated. He is thinner and his skin is blistered from sun and cold. I tried to feed him, but he wasn't able to sit still long enough to eat much.

A few days later, he was forcibly hos- pitalized for a couple of weeks but wouldn't allow the social workers to con- tact me. I again lost track of him until I checked the police records on his birth- day, Nov. 13, and found out he was in jail.

There are programs that work to interrupt this kind of cycle, but there are far too few of them, serving far too few people. As a result, stories like my brother's are not unique.

I know from my professional experience that progress has been made to end homeles- ness. But I have also seen firsthand the over- whelming failures in parts of the system. Discharge plans after imprisonment or hospi- talization are required, but they are rarely useful. And gaining access to programs that work remains extremely difficult. For most of the chronically homeless mentally ill, we waste large sums of money on ineffective interventions.

My family and I live in dread that one day we will get "the call" informing us that John has lost his life. But my brother never gives up hope that he will find a girl/job/apartment.

We had breakfast together recently.

He had been released from jail the night before and walked through the night to Pasa- dena. He called at 6 a.m., and I went to meet him.

We made big plans about getting him a place to live and connecting him with ser- vices. I left him at a barbershop about to open because he wanted to get cleaned up. I went back after dropping the kids off at school, thinking things might get better. But by the time I returned, he was gone.

For the next few days, I drove around with a full duffel bag of clothes and supplies look- ing for my brother. I found him eventually. His medication had been stolen and he was holding on to a brick wall, talking to himself, on Colorado Boulevard.

~~from *The Treatment Advocacy Center*



**NEWS FROM THE FAMILY
SUPPORT & EDUCATION
CENTER AT TRANSITIONAL
LIVING SERVICES**

by Sheila Le Gacy

The spring semester of Supportive Family Training will be starting at the end of March, 2014. Sheila Le Gacy, the Director of the Family Support and Education Center and Vanessa Watts, the Assistant Director, completed teaching the fall section in the beginning of January. Approximately 50 individuals participate each year in this training and we are looking forward to the new classes. Supportive Family Training is a free 12 week course designed for the parents, siblings, spouses, partners and adult children of persons diagnosed with serious psychiatric disorders. NAMI's Family to Family course is directly modeled on Supportive Family Training, which preceded Family to Family by many years. Some participants have likened the training to a mini graduate course about bipolar disorder, schizophrenia, serious depression and other psychiatric disorders. The heart of the class, however, is the focus on self care for family members. Evaluations testify to the healing many family members experience after participating in the classes. It has been said about the training that "the heart of the work is the heart in the work." (All graduates of Supportive Family Training are eligible to attend the monthly problem solving group facilitated by Le Gacy and Watts. Call NAMI for information if you attended the classes over 10 years ago. You may not be on our mailing list.)

Although there is a waiting list for the spring classes, families are encouraged to contact Le Gacy or Watts for immediate support and linkage to services for their relatives. All families are eligible to attend the Support and Sharing group which NAMI sponsors on the third Tuesday evening of every month. This group meets at the Transitional Living Services offices at 420 E. Genesee St. Also, family members are encouraged to contact The Family Support and Education Center for free individual support and information, regardless of their attendance at the classes or the support group.

NAMI VA Family to Family Class

The next NAMI/VA Family to Family Class will be held at the **Syracuse Behavioral Health Outpatient Center, 620 Erie Blvd. West, Syracuse.**

Classes begin Wednesday, **April 2nd from 6-8:30p.m.**

Sessions will be weekly for 12-weeks, and the class is designed for family members of those living with mental health concerns. Please note that the individual with the diagnosis does not attend these classes, and it is for family members only (close friends and supports are always welcomed).

A light meal will be provided and all is provided free of charge.

If you would like to attend and/or refer someone to attend, please call **Ann at 315-425-4400x52717** or e-mail at: **ann.canastra@va.gov**

**MEDITATION SHOWS PROMISE IN
RELIEVING ANXIETY AND
DEPRESSION**

*by Kathleen Vogtle, NAMI
Communications Coordinator*

For many, the concept of meditation instantly brings to mind the quintessential image of the Buddha sitting with utter tranquility in the pretzel-like lotus position. The tranquility aspect is certainly accurate: meditation is a technique used to focus thoughts, reflect or relax.

Meditation is a means of developing wellness, an ongoing process of learning how to make choices that support a more successful, healthy life. A new review study, published in the **Journal of the American Medical Association Internal Medicine**, showed that taking the wellness approach can result in a 17 percent decline in total medical visits and a 35 percent decline in medical visits for minor illnesses.

NAMI has adapted the wellness process into its online Hearts & Minds program, which includes meditation as a promising practice to improve mindfulness.

One model of meditation is the Mindfulness Based Stress Reduction (MBSR). Usually taught in eight sessions, it is described by its founder, Dr. Jon Kabat-Zinn, as "Buddhist meditation but without the Buddhism. It's completely secular." This technique is currently receiving attention from researchers.

Meditation has been considered particularly helpful for many living with mental illness, as high levels of anxiety or constantly racing thoughts are common. Recently, the Johns Hopkins University School of Medicine published a new analysis based on previous research, suggesting that 30 minutes of daily meditation may improve symptoms of anxiety and depression.

The researchers looked back at more than 18,000 studies and ultimately selected 47 previous studies - all randomized trials - that involved 3,515 people. The study found that improvement in individuals experiencing mild symptoms of depression using mindfulness meditation was similar to individuals using antidepressants. They also found that there were no harmful effects of trying meditation.

"A lot of people have this idea that meditation means sitting down and doing nothing," said Madhav Goyal, M.D., M.P.H., an assistant professor in the Division of General Internal Medicine. "But that's not true. Meditation is an active training of the mind to increase awareness, and different meditation programs approach this in different ways."

The technique certainly shows promise, although more research has yet to be done. Also, mindfulness meditation takes time and practice, so do not be discouraged if you do not immediately notice the benefits.

More information on this study can be found at the Johns Hopkins University School of Medicine website.

NAMI's Hearts & Minds program can be accessed at any time for additional information and resources on mindfulness, wellness and the variety of options available.

ANTIPSYCHOTICS: TAKING THE LONG VIEW

by Thomas Insel, M.D., NIMH Director

One of the first lessons I received as a psychiatrist-in-training 35 years ago was the value of antipsychotic medications. These medicines have been available for the treatment of psychosis for over half a century, beginning with the prototype first generation drug chlorpromazine (Thorazine) and now extending to some 20 different compounds, including several second-generation medications, often called "atypical antipsychotics." Symptoms such as hallucinations, delusions, and paranoia are reduced reliably by these drugs. Although these symptoms can be frightening and dangerous for patients, family members, and providers, antipsychotics safely and effectively help people through the crisis of acute psychosis.

However, the long-term management of chronic mental illness is another matter. Recently, results from several studies have suggested that these medications may be less effective for the outcomes that matter most to people with serious mental illness: a full return to well-being and a productive place in society.

That is not to say that people are not remitting or recovering from serious mental illness. An article recently posted online in *JAMA-Psychiatry* tells an interesting story about medications and recovery. Wunderink and colleagues from the Netherlands report on a seven-year follow-up of 103 people with schizophrenia and related disorders who had experienced a first episode of psychosis between 2001 and 2002. After six months of symptomatic remission following antipsychotic treatment, patients were randomly assigned to either maintenance antipsychotic treatment or a tapering-off and discontinuation of the drug. As expected, the group that stopped taking their medications experienced twice the relapse rates in the early phase of the follow-up. But these

rates evened out after a few years, as some patients in the maintenance group also stopped taking their medication. Most important, by seven years, the discontinuation group had achieved twice the functional recovery rate: 40.4 percent vs. only 17.6 percent among the medication maintenance group. To be clear, this study started with patients in remission and only 17 of the 103 patients-21 percent of the discontinuation group and 11 percent of the maintenance group-were off medication entirely during the last two years of follow-up. An equal number were taking very low doses of medication-meaning that roughly one-third of all study patients were eventually taking little or no medication.

For me, there were three remarkable results in this study. First, the groups did not ultimately differ in their experience of symptoms: about two-thirds of each group reported significant improvement in symptoms at seven years. Second, 29 percent of the discontinuation group reported that they had also achieved a healthy outcome in work and family life-a number that should give hope to those struggling with serious mental illness. And finally, antipsychotic medication, which seemed so important in the early phase of psychosis, appeared to worsen prospects for recovery over the long-term. Or, as Patrick McGorry said in an accompanying editorial, "less is more." At least for these patients, tapering off medication early seemed to be associated with better long-term outcomes.

What does this say about the long-term use of antipsychotics? Are they potentially harmful? Are they necessary for an individual's entire lifetime? Earlier this year, Martin Harrow and Thomas Jobe reported an analysis of several long-term follow-up studies of people with schizophrenia to determine if antipsychotics, given long-term, facilitate a return to functional well-being. They describe the following pattern across these studies: (a) within the first 6-10 months after discontinuation, 25-55 percent of patients relapse; (b) for those who do not relapse during this period, subsequent relapses are much less frequent even after prolonged periods off medication.

It appears that what we currently call "schizophrenia" may comprise disorders with quite different trajectories. For some people, remaining on medication long-term

might impede a full return to wellness. For others, discontinuing medication can be disastrous. For all, we need to realize that reducing the so-called "positive symptoms" (hallucinations and delusions) may be necessary, but is rarely sufficient for a return to normal functioning. Neither first nor second generation antipsychotic medications do much to help with the so-called negative symptoms (lack of feeling, lack of motivation) or the problems with attention and judgment that may be major barriers to leading a productive, healthy life. Family education, supported employment, and cognitive behavioral therapy have all demonstrated efficacy in reducing the likelihood of relapse events, increasing the ability to function in daily life, and improving problem-solving and interpersonal skills.

NIMH is supporting research on interventions that focus on a combination of approaches-symptom remission, family engagement, and functional recovery. The Recovery After Initial Schizophrenia Episode (RAISE) project combines low-dose medication with family psycho-education, supported education/employment, individual resilience training, and other interventions to focus on more than just the psychotic symptoms. Combining current treatments, as done in RAISE, looks like a promising approach.

We realize that for too many people, today's treatments are not good enough. New, better treatments are essential if we are to improve outcomes for all - that is the promise of research. But in the meantime, we need to be thoughtful about the treatments we have. Clearly, some individuals need to be on medication continually to avoid relapse. At the same time, we need to ask whether in the long-term, some individuals with a history of psychosis may do better off medication. This is a tough call, where known risks need to be balanced against potential benefits. As the RAISE project has emphasized, shared decision-making between patients, families, and providers is essential for long-term management of psychotic disorders.

These new data on the long-term outcomes for people with "schizophrenia" remind us that 100 years after defining this disorder and 50 years after "breakthrough" medications, we still have much to learn.

FOR THE MENTALLY ILL, IT'S WORSE

Joe Nocera, 1/24/14

Recently, one of the landmark non-fiction books of the last 50 years was reissued by Vintage Books. "Is There No Place on Earth for Me?" by Susan Sheehan began in 1981 as a four-part series in *The New Yorker*; in 1982, it came out as a book, winning the Pulitzer Prize.

"Is There No Place on Earth for Me?" is about a woman who suffers from severe schizophrenia. In the book, Sheehan calls her "Sylvia Frumkin," a pseudonym meant to protect her privacy; her real name was Maxine Mason, which Sheehan divulged after Mason died, at the age of 46, in 1994. She was overweight and overbearing, a difficult person even in the best of times, but also, Sheehan told me recently, "bright and articulate" - when she wasn't delusional. The book's title was a question Mason "had first asked her mother in an ambulance transporting her from one hospital to another in 1964," as Sheehan wrote in an essay published after Mason's death. (It is included as a postscript to the new edition.) Mason was 16 at the time.

I have no idea what moved Vintage Books to republish "Is There No Place on Earth for Me?" but I'm glad it did. The story Sheehan tells is a terribly sad one, and not just because of the flashes Mason shows of what she might have become if she had not suffered from mental illness. It is also appalling to see what she goes through as a mental patient: the hospitals that overmedicate; the misdiagnoses by doctors after the briefest of examinations; the lack of any kind of safety net when she is not hospitalized. But here's the worst part: Even though the story Sheehan tells is more than 30 years old, there is only one real difference between then and now for the mentally ill. It's worse today.

The deinstitutionalization movement was well underway when Sheehan was doing her reporting. In the

1960s, during the Kennedy and Johnson administrations, the federal government passed a series of laws designed to liberate the mentally ill from the acknowledged horrors of mental hospitals, where they were often confined for decades. The idea was that with the introduction of powerful new antipsychotic drugs, people with schizophrenia could live outside a mental hospital - and that hospital stays would be much shorter. The federal government gave money to communities to set up local mental health centers as well as housing for the mentally ill.

In 1975, this trend was affirmed by the Supreme Court, which ruled that the mentally ill had a right "to live in the least restrictive setting necessary for their well-being," as Sheehan writes. By the time Sheehan met Mason, in 1978, the average stay at Creedmoor - the New York psychiatric hospital where much of the book takes place - was 38 days. Some 67 percent of the admissions were people who had had previous stays at Creedmoor.

On the one hand, many mentally ill people were able to lead fuller, richer lives thanks to the deinstitutionalization movement. But as Sheehan's book illustrates, there were also many people for whom the drugs did not have a pronounced effect - or who stopped taking the drugs as soon as they left the hospital. Yet there were no longer enough hospital beds for them, hence the need for hospitals to drug them up and move them out.

E. Fuller Torrey, perhaps the most vocal critic of the current mental health system, says that before deinstitutionalization there were 312 public psychiatric beds for every 100,000 people. That was clearly too many. But today there are a paltry 14 beds for every 100,000. Torrey estimates that we need at least 50 beds per 100,000.

Meanwhile, what happened to patients once they left the hospital was often horrendous. State mental hospitals would release patients with little idea where they were going. They often ended up on the streets, or in prison, which have become today's de facto mental hospitals.

In one sense, Maxine Mason was lucky. Though she had enormous difficulties with her parents, they clearly loved her and tried, as best they could, to help her. Her sister Trudy did the same after her parents

had died, pulling strings to get her into the kind of outpatient housing that was envisioned when the deinstitutionalization movement began. The problem was that Mason was simply too sick to last long in such an environment. She needed to be in a hospital - a humane hospital where she could get the care she needed. It never happened.

I remember thinking when Sheehan's articles first came out in *The New Yorker* that someday we would look back in horror at the way our society treated the mentally ill. Thirty three years later, that day still hasn't come. But it will.

WE CAN HELP BRAIN RESEARCH

by Judy Flint, NAMI Syracuse Member

As a long-term member of NAMI, I was very disappointed that I had not made arrangements before her death for my sister's brain to be donated for research. Today, I noticed in "NAMI Advocate" contact information for Harvard Brain Tissue Resource Center. When I called, I learned that my brain, as a first degree relative of a person with mental illness, is also useful to this research group. A simple preregistration form can be found at:

<http://www.brainbank.mclean.org>

Some past donations have been from people with Alzheimer's or unspecified dementia. The National Institutes of Health is, for some reason, no longer allowing such donations, so they are even farther behind in numbers of brains for research than they were before. The person I spoke with said that if they were able to get even just 100 brains of psychiatric patients or their first degree relatives, they would be pleased. They are also a collection point for brains on the autism spectrum.

Planning for death is often difficult, but if more of us can take this step, future generations may not suffer as we have.

Harvard Brain Tissue Resource Center

McLean Hospital

115 Mill Street

Belmont, MA 02478

800-272-4622

In Memoriam

NAMI Syracuse offers our sympathy and prayers to Jeanette Wagner and family on the recent passing of her husband Frederick. Jeanette and Frederick have been members of NAMI Syracuse since 1983. Jeanette served many years as a Board Member and Recording Secretary.

~from Sheila Le Gacy

We are very sad to report the death of Horst Kowlowsky, a long time volunteer for the Family Support & Education Center. Horst assisted us for many years with the Supportive Family Training classes. He manned the door, greeted participants, handed out and collected name tags and helped us with tech issues and other presentations. But most important was his wonderful presence-his gentle humor, his compassion for the family members in the classes, and his support for us. Horst was a graduate of Supportive Family Training and encouraged family members to enroll in the classes to help themselves deal with the stress of care giving and learn ways of self care. Horst was a funny and loving guy and we will miss him.

ACTRESS HALE BERRY TALKS ABOUT HER NEW MOVIE, FRANKIE & ALICE, MENTAL ILLNESS AND HOPE IN NAMI INTERVIEW

Actress Halle Berry appears on the cover of the latest issue of **The Advocate**, the magazine of the National Alliance on Mental Illness (NAMI), with an interview inside about her upcoming film, **Frankie & Alice**, which will be re-released April 4, 2014 by Lionsgate and Codeblack Films.

Based on a true story, Berry plays Frankie Murdoch, an African American

'70s-era go-go dancer living with dissociative identity disorder (DID). She is challenged by two identities: a scared 7-year old girl named Genius and a bigoted, white southern belle named Alice.

Besides giving Berry "the opportunity to embrace a challenging, complex role" as an actress, the film is important to her because it "helps put light into a dark space," she explains in the NAMI interview.

For full interview, please see www.nami.org/berryinterview.

"People who live with mental illness often struggle. Others look down on them or have negative opinions of them. Hopefully this film will do some good. It promotes the importance of compassion for others and helps educate the public."

"My main message is one of hope."

Berry's passion for the role of Frankie was influenced by her mother, who worked for 35 years as a psychiatric nurse for the Department of Veterans Affairs (VA).

"Stories of mental illness have been a part of my life and on my radar for a long time."

She also reflects in the interview about possible connections between creativity and mental illness: "Within my industry I have come across some of the most complicated individuals who are highly creative who have on some level suffered from mental illness."

DID is a condition in which two or more distinct personalities control an individual's behavior at different times. Once called multiple personality disorder, it frequently is the result of severe stress or trauma, such as incest or rape and serves as a coping mechanism. It includes a high rate of suicidality and affects women nine times more often than men.



TRAINING ANNOUNCEMENT: CRISIS INTERVENTION TEAM TRAINING

This 40-hour course, sponsored by the Onondaga County Police Mental Health Community Collaboration will provide officers with the skills and knowledge to recognize individuals with emotional disturbances, identify potential disorders, and minimize escalations in contacts with individuals in mental health crisis. Training focuses on developing techniques for assessing an individual in a mental health crisis, communication skills, de-escalation techniques, suicide risk factors, suicide by cop, cultural issues, scenario role plays, community resources, and individual and family perspectives. Crisis Intervention Teams (CIT) are now active in over 100 urban, suburban and rural police departments across the country as well as in cities in Australia, Sweden, and other countries. They are modeled after teams originally developed by the Memphis Police in 1988. In New York, a total of five counties have CIT training programs (Albany, Cortland, Monroe, Nassau and Westchester counties). CIT is a community partnership and a commitment to community change, not just a police training curriculum.

CIT training will provide officers and the community with the following outcomes:

- Improved Services to People in Mental Health Crisis
- Improved Efficiency and Effectiveness of Law Enforcement Response
- Diversion from the Criminal Justice System
- Reduction in Officer and Civilian Injuries
- Improved Officer Knowledge about Psychiatric Issues
- Effective Partnerships with the Mental Health Community

CIT trained officers are part of a department's regular patrol division.

- Officers volunteer to participate in CIT training
- Ideally 20-25% of a department's patrol division should be trained in CIT to facilitate immediate response across all shifts.

(continued on page 10)

CIT instructors are an interdisciplinary team of mental health providers and law enforcement professionals. Professionals from Syracuse City Police Department, Onondaga County Sheriff's Department, Onondaga County Department of Mental Health, Transitional Living Services, Contact Community Services, Upstate Medical University, CNY Legal Services, along with individuals and family members with mental health crisis experience will be providing the instruction in this course.

10 WAYS TO SHOW LOVE TO SOMEONE WITH DEPRESSION

The Darling Bakers, 2/14/14

Do you love someone with depression?

If you have a partner or are close to someone who struggles with depression, you may not always know how to show them you love them. One day they may seem fine, and the next they are sad, distant and may push you away. It is important that you know that as a person who is close to them and trusted by them, you can help your friend or partner have shorter, less severe bouts of depression. Mental illness is as real as physical illness and your partner needs you as much as they would need to be cared for if they had the flu.

Your relationship may seem one-sided during these times, but by helping your partner through a very difficult and painful affliction, you are strengthening your relationship and their mental health in the long term.

1. Help them keep clutter at bay.

When a person begins spiraling into depression, they may feel like they are slowing down while the world around them speeds up. The mail may end up in stacks, dishes can pile up in the sink, laundry may go undone as the depressed person begins to feel more and more overwhelmed by their daily routine and unable to keep up. By giving your partner some extra help sorting mail, washing dishes or using paper plates and keeping chaos in check in general, you'll be giving them (and yourself) the gift of a calm environment.

2. Fix them a healthy meal.

Your partner may do one of two things when they are in a depressed state. They may eat very little, or they may overeat. In either case, they may find that driving through a fast food restaurant or ordering a pizza online is just easier than fixing a meal. Eating like this, or neglecting to eat will only degrade your partner's health, causing her to go deeper into her depression. Help your loved one keep her body healthy, and her mind will follow.

3. Get them outside.

The benefits of getting outside for a depressed person are huge. And it is possibly the last thing on earth your partner will want to do. Take them to be somewhere in nature. Pack a picnic and lie in the sun, take a leisurely hike or plant a garden. Being barefoot in the dirt, or "earthing" helps ground the body and reverse the effects of living in a world of emf's, and digging in soil can actually act as an antidepressant, as a strain of bacterium in soil, *Mycobacterium vaccae*, triggers the release of serotonin, which in turn elevates mood and decreases anxiety. Sunshine increases Vitamin D production which can help alleviate depression.

4. Ask them to help you understand what they're feeling.

If your partner is able to articulate what they are going through, it will help them and you better understand what you are dealing with, and may give insight into a plan of action for helping your partner. Also, feeling alone is common for a depressed person and anything that combats that feeling will help alleviate the severity and length of the depression.

5. Encourage them to focus on self-care.

Depressed people often stop taking care of themselves. Showering, getting haircuts, going to the doctor or dentist, it's all just too hard, and they don't deserve to be well taken care of anyway in their minds. This can snowball quickly into greater feelings of worthlessness since "Now I'm such a mess, no one could ever love me." Help your loved one by being proactive. Tell them "I'm going to do the dishes, why don't you go enjoy a bubble bath?" can give them the permission they won't give themselves to do something normal, healthy and self-loving.

6. Hug them.

Studies show that a sincere hug that lasts longer than 20 seconds can release feel-good chemicals in the brain and elevate the mood of the giver and receiver. Depressed people often don't want to be touched, but a sincere hug with no expectation of anything further can give your partner a lift.

7. Laugh with them.

Telling a silly joke, watching a comedy or seeing a stand up comedian will encourage your partner to laugh in spite of herself. Laughing releases endorphins and studies show can actually counteract symptoms of depression and anxiety.

8. Reassure them that you can handle their feelings.

Your partner may be feeling worthless, angry and even guilty while they are depressed. They may be afraid that they will end up alone because no one will put up with their episodes forever. Reassure them that you are in the relationship for the long haul and they won't scare you away because they have an illness.

9. Challenge their destructive thoughts.

A depressed person's mind can be a never-ending loop of painful, destructive thoughts. "I'm unlovable, I'm a failure, I'm ugly, I'm stupid". Challenge these untruths with the truth. "You're not unlovable, I love you. You aren't a failure, here are all the things you've accomplished."

10. Remind them why you love them.

Look at pictures of happy times you've had together. Tell them your favorite things about them. Reminisce about your relationship and all the positive things that have happened, and remind your partner that you love them and they will get through this.

Happy Spring!



IS FACEBOOK TRIGGERING EATING DISORDERS?

Health Newsline, 3/9/14

That Facebook has addictive qualities is not surprising, but the more worrisome part is that it could be endangering your health as well. A new research found avid Facebook use may be leading young women towards disordered eating.

The social media site may be adding to the body image issues that young women and girls grapple with. It could be prompting them to make unhealthy comparisons with others. The study found female students who are hooked to Facebook are inclined to harbor negative feelings about their bodies and to suffer from more anxiety than those who surf the Internet for other things like scientific research.

Lead author of the study, Pamela K. Keel, a professor of psychology at Florida State University stated, "Facebook provides a fun way to stay connected with friends but it also presents people, especially women, with a new medium through which they are confronted by a thin ideal that impacts their risk for eating disorders."

Study involving 960 female college students

In order to determine whether frequent Facebook use can result in the onset of eating disorders, the researchers conducted a study involving 960 female college students. For the purpose of the study the subjects undertook a test to assess their eating habits and attitudes. In addition, they were evaluated on their average Facebook use, how important they considered "likes" on the social media site and whether or not they "untagged" photos of themselves.

Outcome of the study

The findings of the study suggest that Facebook may be downright toxic. The social media site may be offering an avenue for young people to compare themselves to others, obsess about their body image in ways that could prove dangerous.

"This is the first study to show that spending just 20 minutes on Facebook

actually contributes to the risk of eating disorders by reinforcing women's concerns about weight and shape and increasing anxiety," Keel noted.

Girls who were avid Facebook users and placed more emphasis on receiving remarks and "likes" on their status updates, untagged unflattering photos of themselves and compared their own pictures to friends' posted photos, were more likely to exhibit warning signs for eating disorders, the study found. Though the increased risk was moderate, the study found a positive link was found between duration of Facebook use and disordered eating.

Peer pressure and traditional media have long been criticized as risk factors for disordered eating. Apparently, Facebook combines those factors. "Your friends are posting carefully curated photos of themselves on their Facebook page that you are being exposed to constantly. It represents a very unique merging of two things that we already knew could increase risk for eating disorders," said Keel.

The results were published in the International Journal of Eating Disorders in a paper titled "Do You "Like" My Photo? Facebook Use Maintains Eating Disorder Risk."

OMEGA-3 HELPS MEDS WORK BETTER

Supplementation with long-chain omega-3 fatty acids, commonly found in oil from cold-water fish, could be beneficial for people with bipolar disorder, a new research paper says.

American researchers said fatty acid deficiencies are common with bipolar. They said studies show supplementation with omega-3 fatty acids makes medications for bipolar more effective and reduces the risk of suicide. Omega-3 supplementation is also associated with reduced risk of heart disease.

The study which appeared in the journal **Current Drug Discovery Technologies**, was entitled "Long-chain omega-3 fatty acid deficiency in mood disorders: Rationale for treatment and prevention."

~from *bp Magazine*, Fall 2013

Giving Up Is Never an Option

~~poem by: Tanisha Wiggins

No longer am I afraid to keep my hope alive

*Hiding behind shadows to survive
Reaching out my hand for someone to take hold*

Or happily giving pieces of myself marked sold

For now I look in the mirror and see who I am meant to be

Took away the crutches and standing independently

I thank all the people who helped me a long

But most of all I thank myself for standing strong

At times I felt like there was no way out

All the doors were bolted and fearfully locked

That couldn't stop me for where I had to go

For I climbed until I reached a window

And who knows the window may someday close

And if that happens I will gladly dig a hole

Who say at times I might not trip and stumble

A person that stays down is not who I am

I'm much to humble

As long as my heart is pumping blood

Is as long as I will stand back up

And NEVER give up

"It's amazing to me that any other organ in your body can break down and there's no shame and stigma to it. But if your brain breaks down, you're supposed to keep it a secret"

~~Pastor Rick Warren, founder of the mega-church Saddleback and author of *The Purpose Driven Life*, committing to anti-stigma efforts after the death by suicide of his son Matthew.

SEND YOUR MEMBERSHIP TO NAMI Syracuse TODAY

____ Individual/Family 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 and Vanessa Watts is held on the 3rd Tuesday of each month at 7:00pm at Transitional Living Services, 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.)