



NAMI SYRACUSE

National Alliance on Mental Illness

Newsletter

JANUARY/FEBRUARY 2017

Meeting Schedule

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

AccessCNY

420 East Genesee Street, Syracuse 13202

(parking and entrance in rear of building)

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

CARING

SHARING

EDUCATION

ADVOCACY

Events Calendar

- January 17, 2017 **Support & Sharing Meeting**
7:00pm - AccessCNY
- February 21, 2017 **Support & Sharing Meeting**
7:00pm - AccessCNY
- March 21, 2017 **Support & Sharing Meeting**
7:00pm - AccessCNY

Support and Sharing Meetings are free, confidential and a safe group of families helping other families who live with mental health challenges by utilizing their collective lived experiences and learned group wisdom.

Contents

Message from The President	2
Carrie Fisher Put Pen and Voice in Service of "Bipolar Pride"	3
Ketamine Saved My Life!:	
A Mental Health Success Story	4
Spring Lake Ranch - A Therapeutic Community in Vermont	5
Personal Accounts: Becoming the Mother of a Child with Schizophrenia	5
What Is DBT, and Who is it For?	6
Notes from the NAMI NYS Conference	7
NAMI Announces Legislative Priorities for 2017	8
Groups Seek End to Solitary Confinement for Teens	9
U.S. Surgeon General Spotlights Addiction	9

MESSAGE FROM THE PRESIDENT

Dear Members:

Our fearless leader is under the weather with a concussion. She's a caretaker who now needs to take care of herself and rely on others. I'm one of the folks she now has to rely on to do the opening letter for the newsletter!

So here goes:

It's the start of a new year. Time to reflect on what we accomplished in 2016 and what are we looking towards in 2017.

2016 was a successful year with our two conferences reaching over 200 people. We raised over \$10,000 with our Harvest Hopela. We have received a \$5,000 grant to expand our website and provide a resource guide online for consumers and families to find treatment. We have continued our efforts to reach churches and schools. Our community and local businesses have supported us with donations to our silent auctions. Our garage sale was a big success in raising funds and reaching out to new people. We've continued to grow in our membership. Our art show featured over 30 artists. Family support nights continue to educate and support families. Our board and members have been devoted to insuring our success.

Thank you to all of you for your energy, contributions, and help.

2017 looks to be another year full of opportunities to reach out to more families and consumers. We will continue to need your help to keep up our efforts and momentum. We don't do this work alone. This is a family effort. Never think your contributions are too small. Whatever time or energy you can contribute will be appreciated.

We want to thank the board members whose terms have expired but who will remain involved, Susan Zdanowicz and Kris Neagle. We welcome new members: Sunny Aslam, Tom Bassett, Allyson Kemp, Patricia Moore and Phuong Pham. NAMI Syracuse has been around since 1980 helping us through the tough and challenging times. There are many more families out there who could use our message of hope. Think about trying to get at least one more family to join NAMI. If each of us got one more member, we'd double our membership. Let's make that a resolution for 2017!

Sincerely,

Marla Byrnes

Recording Secretary

NAMI Syracuse Officers

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

Board of Directors

- Dr. Sunny Aslam
- J. Thomas Bassett
- Judy Bliss-Ridgway
- Carol Sheldon Brady
- Sandra Carter
- Steven Comer
- August Cornell
- Allyson Kemp
- Sheila Le Gacy
- Deborah Mahaney
- Patricia Moore
- Phuong Pham
- Sherie Ramsgard
- Krysten Ridgway
- Lacey Roy
- George Van Laethem

Consultant to Board

- Dr. Mantosh Dewan
- Dr. Stephen Glatt
- Ann Canastra

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



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

Register your current Amazon account with NAMI Syracuse Inc. today by going to:

smile.amazon.com

and Amazon will donate 0.5% of the price of your eligible AmazonSmile purchases to NAMI Syracuse!

NAMI Syracuse Receives Grant

We are pleased to announce that the **Central New York Community Foundation** has awarded NAMI Syracuse a grant of \$5000 from the **Durston Sanford & Doris Sanford Fund**. The proposal for the grant was submitted by NAMI Syracuse Board Member Steven Comer and committee for the purpose of developing a database for NAMI Syracuse so that our mental health community can access mental health providers in the community.

We received two additional grants from the **CNY Community Foundation Small Grants and Initiatives Fund** - a \$200.00 gift, made at the request of Christina Whiteside and a \$100.00 gift made at the request of Danielle Hurley.

We thank the **Central New York Community Foundation** for recognizing and supporting the efforts of NAMI Syracuse!

**New Membership Structure
Coming in July 2017**

The National NAMI Board of Directors has voted to add a Household membership category to the membership structure and to increase the dues for Regular and Open Door memberships. These changes will become effective as of July 1, 2017.

- Household Membership \$60.00
- Regular Membership \$40.00
- Open Door Membership \$5.00

CARRIE FISHER PUT PEN AND VOICE IN SERVICE OF "BIPOLAR PRIDE"

by Benedict Carey, December 28, 2016,
The New York Times

She was all there, all the time: exuberant in describing her mania, savage and tender when recalling her despair.

And for decades, she gracefully wore the legacy of her legendary role as Princess Leia, worshiped by a generation of teenage girls as the lone female warrior amid the galactic male cast of the "Star Wars" trilogy.

In her long, openhearted life, the actress and author Carrie Fisher brought the subject of bipolar disorder into the popular culture with such humor and hard-boiled detail that her death triggered a wave of affection on social media and elsewhere, from both fans and fellow bipolar travelers, whose emotional language she knew and enriched. She channeled the spirit of people like Patty Duke, who wrote about her own bipolar illness, and Kitty Dukakis, who wrote about depression and alcoholism, and turned it into performance art.

Ms. Fisher's career coincided with the growing interest in bipolar disorder itself, a mood disorder characterized by alternating highs and lows, paralyzing depressions punctuated by flights of exuberant energy.

Her success fed a longstanding debate on the relationship between mental turmoil and creativity. And her writing and speaking helped usher in a confessional era in which mental disorders have entered the pop culture with a life of their own: Bipolar is now a prominent trait of another famous Carrie, Claire Danes's character Carrie Mathison in the Showtime television series "Homeland."

"She was so important to the public because she was telling the truth about bipolar disorder, not putting on airs or pontificating, just sharing who she is in an honest-to-the-bone way," said Judith Schlesinger, a psychologist and author of "The Insanity Hoax: Exposing the Myth of the Mad Genius."

In a characteristic riff, answering a question about the disorder from the

audience at the Indiana Comic-Con last year, Ms. Fisher said: "It is a kind of virus of the brain that makes you go very fast or very sad. Or both. Those are fun days. So judgment isn't, like, one of my big good things. But I have a good voice. I can write well. I'm not a good bicycle rider. So, just like anybody else, only louder and faster and sleeps more."

She then grabbed the mike and sang, in mock-ballad voice, "Oh manic depression... oh how I love you."

That last line is a reminder too, that in Ms. Fisher's lifetime, even the name of the condition had evolved, to bipolar from what was once more commonly known as manic depression.

Ms. Fisher has said that she was first given a diagnosis of bipolar disorder at age 24 but did not accept it until five years later. In time, she spoke often about her lifelong struggles with both addiction and bipolar disorder and her desire to erase the stigma of mental illness. She wrote her 1987 novel, "Postcards From the Edge," after a stint in rehab after a near-fatal drug overdose. It was during her autobiographical one-woman stage show, "Wishful Drinking," that she first posited the idea for "Bipolar Pride Day."

Like the disorder itself, the wave of attention that occurred during Ms. Fisher's life had its excesses. Through the 1990s, research scientists - many of them supported by drugmakers - expanded the definition of the disorder, describing "sub-syndromes" and permutations like bipolar II and "hypomania." By the 2000s, doctors were diagnosing the condition in groups of people who had never been identified before, mostly young children - leading to thousands of children being unnecessarily treated with strong psychiatric drugs.

In recent years, that overheated enthusiasm has finally begun to run its course.

"I remember being at a psychiatric association event where Carrie Fisher was interviewed, and people were beginning to talk about the imperialism of bipolar," how the diagnosis was expanding beyond its bounds, said David Miklowitz, a professor of psychiatry at the Semel Institute at the University of California, Los Angeles. He added, "I think doctors are much more careful now, in being sure they're diagnosing the real thing."

The American Psychiatric Association's latest diagnostic manual discourages applying the label to young children.

Ms. Fisher's vivid prose, wicked humor and striking performances inevitably led many people, including herself, to wonder whether bipolar mania fuels creativity.

"My experience is that it does spur creativity and insights and the ability to express connections you see but could not otherwise express," said Terri Cheney, author of the best-selling memoir "Manic." "But normalcy is so much preferable, being able to remember what I did - I tend to forget manic episodes."

Scientists, scholars and writers have speculated for years about the connection between madness, and in particular mania, and artistic wizardry. The painters Edvard Munch and Vincent van Gogh, among many others, have been posthumously diagnosed with bipolar disorder.

"There is a particular kind of pain, elation, loneliness and terror involved in this kind of madness," wrote the psychologist Kay Redfield Jamison, a prominent proponent of this connection. "When you're high, it's tremendous. The ideas and feelings are fast and frequent like shooting stars, and you follow them until you find better and brighter ones."

But the debate remains contentious, and given the vagueness of so many diagnoses, not to mention the devastating effect of depression or psychosis on discipline and concentration, it is unlikely to be settled anytime soon.

"The case has really been built on sand," Dr. Schlesinger said. "It's been oversold." She added, "Every course of bipolar is different, there is no one progression, no one symptomology, no one cure, so the effects are very individual."

All the more reason that one particularly outspoken, charismatic and large personality could project so much toughness and vulnerability at the same time. Ms. Fisher learned to live a public life at a very early age, as the child of celebrities and with her early stardom.

"In an interview with CBS this year, she said she liked being Princess Leia, understanding that "it's a great role for women." But, she added: "I'm not really one of those actresses like Meryl Streep. Those actresses travel outside themselves and

play characters. And I'm more of an archaeologist. I play what I am."

Ms. Fisher's advocacy, visibility and public self-examination was made for the era of online self-confession. For good and bad, in part because of Ms. Fisher's example, the language of bipolar and mental disorders has swept into the shared popular culture, seeding online support groups, punctuating texted exchanges - "so OCD" - and becoming featured in dimensions of movies and TV shows like "Monk" and "Home-land."

Paul Cumming, a longtime advocate in San Diego who works for a company that helps people with mental disorders find housing, said, "The power of celebrity was best shown by Carrie that by being public, and funny, she demystified our diagnosis and showed by example we can live well and thrive."

~Ryan Burselson and Tara Parker-Pope, contributed reporting.



KETAMINE SAVED MY LIFE!: A MENTAL HEALTH SUCCESS STORY

by Katelin Arnold, HR Professional turned Health & Wellness Advocate

Mental illness in and of itself is a sensitive topic. Add with it the controversial use of a drug more well known for its recreational street use, and I completely understand anyone's pause to discuss the topic openly. Unfortunately for me, this is not merely a topic of discussion, but this is my life, and I cannot in good conscience stay quiet any longer about my internal demons because I am a quintessential success story. America loves a success story. Here you have a young heroine and a happily ever after. It could almost be a fairy tale if you didn't include the words mental illness or substance

abuse, but that's the unfortunate state of our society and healthcare system that a heroine is only a heroine if she is beautiful and relatable and so many people cannot relate with mental illness. That's where I come in.

Many of you know me only for my role in the Human Resources profession, but there is much more to me. I am 34 years old, and I suffer from treatment resistant bipolar depression. My earliest memories of exhibiting symptoms of mental illness go back to 4th grade, and the first time I remember thinking about suicide I was 12 years old. My first hospitalization was at 18, and my first suicide attempt was at 26. Over the past 20 years I have tried with little or no success over 40 medications, dozens of doctors and therapists, various types of therapy, and transcranial magnetic stimulation. College educated and in the early years of a successful career in Human Resources for a global company, I was put on short-term disability by my employer in August 2009 and was declared permanently disabled by the Social Security Administration and began receiving SSDI benefits in March 2010 due to the debilitating symptoms of my illness. I am also a recovering addict, as drugs and alcohol were at times my means of self-medicating.

Desperate and out of traditional treatment options, I participated in a clinical trial at Columbia University from April-June 2014 under Dr. Joshua Kantrowitz. The clinical trial was to test the efficacy of ketamine infusion in individuals with treatment resistant bipolar depression. The trial was a success, and for the first time in nearly 20 years, I no longer experienced chronic, debilitating depression. Unfortunately, the trial only lasted 12 weeks and then I was back to being resourceless. However, I found a doctor in New York City who was willing to take me on as a patient to continue the treatment I received during the clinical trial. I began getting ketamine infusions at the clinic in New York City every four weeks beginning in October 2014 coupled with a daily regimen of ketamine capsules and the prescription Nuedexta to elongate the time necessary between infusions as ketamine infusions by themselves are documented to last approximately 10-14 days. Since that time, my condition has improved exponentially, experiencing no major depressive epi-

sodes, finding a happiness I never before knew existed, and in November I returned to the workforce full-time and went off Social Security disability.

My problem at this point is the expense and time that it requires to travel to New York City every four weeks to receive these ketamine infusions while attempting to balance a full time work schedule and being a single mom. Because ketamine use for psychiatric illnesses is considered "investigative" by insurance companies, I have to pay for the infusions and prescriptions 100% out of pocket and cannot even count those costs toward the deductible on my private health insurance. Since 2012, I have paid \$35,793.33, and counting, in out of pocket medical expenses, which does NOT include any costs related to travel or lodging.

Although I have found a successful treatment to treat my mental illness and have returned to the workforce full-time as a tax paying citizen because of the treatment and am no longer receiving SSDI, it would not surprise me if the excessive medical costs eventually require me to stop getting the necessary treatment, which would in turn cause the return of my debilitating mental illness, unless dramatic changes are made to the availability and cost of treatments. In October I celebrated 5 years clean and sober and 1 year without a depressive episode. What a tragedy it would be for the system to push me back into the devastation of mental illness! That is why I want to use my experience and my voice to create awareness and change in this much talked about and controversial area.

I am sure few, if any, who know me on a professional level would have imagined the struggles I have been through. It is because I have fought so hard to achieve success without making my disability known that I now want to use my network to spread awareness and hope. Mental illness is entirely treatable given the right resources, and more people need to start a discussion to battle this disease for good.

SPRING LAKE RANCH - A THERAPEUTIC COMMUNITY IN VERMONT

by Sheila Le Gacy, Director of the Family Support & Education Center, AccessCNY

During the NAMI NYS Conference in Albany this past November, I visited with representatives from Spring Lake Ranch, a marvelous program that has flourished for over 84 years. SLR is a residential treatment program offering adults with psychiatric illness and dual diagnosis an opportunity for healing and recovery. They offer a farm-based work program - all residents work 5 hours a day - because they believe work is central to recovery. Their rural campus resembles a small village. Many staff and their families live on site.

There is a high staff to client ratio, a consulting psychiatrist, a full time nurse, and clinician led resident support teams.

There are 30 beds in the residential program which accepts men and women over 18. Diagnoses of residents include Depression, Bipolar, Schizophrenia, Anxiety, PTSD, Substance Abuse and other disorders.

AA/NA meetings are held daily, plus groups on coping skills, dual diagnosis and hearing voices.

Horsemanship, yoga, music and sports are also available.

The length of stay is 6 months and up.

There are step down and extended care programs in nearby Rutland, Vermont.

This is a privately run community and it is relatively expensive (The daily rate for the Ranch is \$375, for the Transitional program, \$285). However, I was informed that they do accept some insurance, and they also offer some scholarships.

For admission information call:

802-492-3322

website: springlakeranch.org.

e-mail: info@springlakeranch.org

PERSONAL ACCOUNTS: BECOMING THE MOTHER OF A CHILD WITH SCHIZOPHRENIA

Susan Inman

I never expected to be the mother of someone with a severe mental illness. My undergraduate education and graduate education in the 1970s left me with a comforting notion about child rearing; as long as children had parents who were loving, sensitive, responsible, and supportive, they would not be in danger of developing mental illnesses.

My personal ignorance was compounded by the common lack of mental illness literacy in the United States and in Canada, where I lived when I had children. When our younger daughter began to flounder as a teen, we didn't understand what was happening. Only much later did we learn that our daughter's puzzling cognitive losses, her strange physical gait, and her growing lack of connection to the world around her were well-known prodromal signs of schizophrenia.

Unfortunately, the therapist to whom we took our daughter for over two years knew even less than we did about bipolar disorder and schizophrenia. The program at the university in Vancouver where she had trained for her master's in counseling psychology hadn't required any science-based curriculum on psychotic disorders. Only much later did our daughter help us understand that as her symptoms grew worse, this therapist continued to reassure her that once they could finally discover "the family secret," all these difficulties could be resolved.

Although the search for this nonexistent family secret was futile, our daughter developed, with our naive support, a strong attachment to the therapist. This bond eventually increased the chaos of our situation once our daughter finally had a clear psychotic break. We watched, helpless at that point, as the therapist told our vulnerable daughter not to trust the very experienced psychiatrist who had agreed to work with her. When this psychiatrist gave up, she located a replacement for us who managed to sever the unhealthy relationship with the therapist. At the same time, this psychiatrist restored the close relationship

with us that our daughter had relied on for most of her life.

However, the new psychiatrist wasn't experienced in dealing with the schizoaffective disorder our daughter was developing. When our daughter had a new and severe psychotic break, she didn't receive adequate doses of an antipsychotic medication, and she became ever more psychotic over the next two years.

In the second year of her debilitating psychosis, she could not be left alone in our home. If she tried to use the microwave, for instance, she would try to heat something for 40 minutes when it just needed 40 seconds. She liked baths and would turn the faucets on but then wander away unaware while the tub overflowed. She also couldn't walk places by herself anymore. Not only did she get lost trying to find familiar places, but also she could not remember how to navigate traffic as a pedestrian.

Eventually, following a trip to the Menninger Clinic, our daughter received the high dose of an antipsychotic that she needed to escape the horrors of psychosis. During these two years, I had imagined what it might be like if some medication finally worked and how this hell could be just a part of a longer, better story. I hadn't found any Canadian stories like this, and eventually I wrote a memoir. Sadly, since its publication, I hear from both Canadian and American families that they have made dangerous mistakes similar to mine because they are missing essential information about psychotic disorders.

Our daughter was fortunate to receive the brief involuntary hospitalizations in British Columbia that she was too ill to understand she needed. She now tells other families that she hopes never to be left in untreated psychosis in the future.

Our daughter was also lucky that once she was no longer psychotic, she had access to extensive, science-based psychoeducation about her illness. This education has helped her and the friends she has made who also live with psychotic disorders to understand, accept, and learn to manage their illnesses.

The psychiatrist who got our daughter the help she needed is a Canadian expert on schizophrenia and has worked with our daughter and collaborated with us for the past 13 years. Our daughter was once one

of the most severely psychotic teens the local refractory psychosis team had seen, but she has since benefited from years of stability.

Unfortunately, our daughter has the well-researched cognitive losses that commonly occur with schizophrenia. Her difficulties with working memory and short-term memory, focusing, sequencing, problem solving, judgment, and social skills make the basic tasks of daily living extremely difficult. Canada has done very little to implement the evidence-based cognitive remediation programs that are now available.

One way that I have responded to the lack of cognitive remediation programs has been to write about the problem. For the past four years I've been writing for Huffington Post Canada about mental illness policies from the perspective of family caregivers (www.huffingtonpost.ca/susan-inman). When I first wrote about cognitive losses associated with schizophrenia, I was inundated with messages from families who had never heard about the extensive research about these problems. They were witnessing the daily confusion caused by family members who forgot to relay phone messages, kept losing keys, and had trouble completing household tasks. However, they had never been told that these problems are a common part of schizophrenia even when other symptoms are well controlled by medications. This knowledge was clearly going to impact how they responded to these problems.

Figuring out how best to help our daughter deal with her complicated disorder has been only part of the steep learning curve for me. The other part has been trying to understand the dysfunctional mental health systems in both Canada and the United States. Eventually I realized that, in both countries, mental illness policies and services are being informed by two paradigms that are not very compatible with each other.

I better understood these differing belief systems after examining the Web sites of the National Institute of Mental Health (NIMH) and the Substance Abuse and Mental Health Services Administration (SAMHSA). I saw the NIMH as offering science- and evi-

dence-based ways of understanding and responding to mental illnesses. Here was the pathway that eventually led my daughter to recover her sanity. On the other hand, SAMHSA's Web site seemed to barely acknowledge the existence of mental illnesses; I was not surprised that their chief medical Officer, Dr. Elinore McCance-Katz, recently resigned and has written about why she left "an agency that, for the most part, refused to support evidence-based psychiatric treatment of mental disorders".

During the 16 years that we have been dealing with our daughter's illness, I have seen more mental health services in Vancouver and elsewhere in Canada offer the alternative practices that SAMHSA has helped cultivate. Our new national guidelines for training peer support workers, like SAMHSA's, don't recommend providing any information on mental illnesses. Equally problematic, they promote the notion that people must always be free to choose whether they want to be treated. I have now become very cautious about recommending local programs to my daughter. Even with her solid psychoeducation, I know it would not be good for her to be around a group of potential friends who do not believe that the "medical model," as the alternative "antipsychiatry" movement calls it, can help people understand and manage mental illnesses.

I hope that the legislation currently pending in the U.S. Congress can create sensible policies and services for people with severe mental illnesses such as my daughter's. Enactment can help the many American families I know whose sons and daughters with untreated psychotic illnesses have ended up homeless or incarcerated, and I believe that changes in the influential U.S. mental health system could lead to better trends in the delivery of mental health care in Canada.

I still don't really know how to be the mother of an adult daughter whose disabilities prevent her from managing the tasks of daily life. But I do know that her future will be better, especially when her parents are no longer alive, if she can be surrounded by services and a culture that acknowledge the difficult reality of her mental illness.

Ms. Inman (e-mail:

*susaninman.vanc@gmail.com) lives in Vancouver, British Columbia, and has published a memoir, **After Her Brain Broke, Helping My Daughter Recover Her Sanity**. Jeffrey L. Geller, M.D., M.P.H., is editor of this column.*

WHAT IS DBT, AND WHO IS IT FOR?

from HealthyPlace.com

Dialectical behavior therapy, or DBT, is a specific approach to mental health therapy. DBT can be confusing; the term itself is sometimes hard to understand, and it's not always clear who benefits most from this approach. Here's a brief look at what DBT is and who it's for.

DBT comes from cognitive behavioral therapy (CBT). DBT emphasizes thoughts, emotions, and behaviors. The term "dialectical" refers to the fact that people understand concepts in relationship to their opposites. Just as we know summer in the context of winter, we know depression in relation to happiness and ourselves in the context of others. With DBT, people learn to manage strong emotions by coming to understand their opposites.

There are certain aspects of this therapeutic approach that are important to know. DBT:

- Reduces black-or-white thinking.

- Helps people reduce time spent in crisis.

- Teaches acceptance, mindfulness, interpersonal skills, distress tolerance, and emotional regulation.

- Allows people to develop and use what is called wise mind.

With its emphasis on emotional regulation, DBT was originally designed to help people with borderline personality disorder. However, because its skills are so useful in helping people live a life of wellness, DBT is used with many different people with many different mental health conditions.

NOTES FROM THE NAMI NYS CONFERENCE

from Sheila Le Gacy, Director of the Family Support & Education Center, AccessCNY

I had the opportunity to attend the Annual NAMI New York State Educational Conference in November of 2016. The conference was held at the Desmond Hotel in Albany from Nov. 11-13.

I was grateful for the opportunity to attend workshops and learn from experts in many fields. For example, I learned from research scientists that resilience is in fact inherited and that aerobic exercise improves both aerobic fitness and neurocognitive function. I have included reviews of detailed information from a few of the workshops I attended. I recommend that NAMI members try and attend state and national conferences. The next NAMI national conference will be in Washington, DC and every NAMI member should have the experience of attending with 3000 fellow family members. If you benefit from our local educational conference, attending at the national level will provide you with an absolutely life changing experience!

The "Ask the Doctor" Session.

This session is part of every NAMI conference, including the national conference which provides several "ask the doctor" sessions for specific diagnoses. Family members and consumers line up at a microphone and ask the resident expert for advice about their treatment. It is an excellent opportunity for individuals to receive expert advice and for the audience to learn about the latest informed treatment options.

Lewis A. Opler, MD, PhD., formerly at Albert Einstein College of Medicine, Columbia University, Director of OMH's Research Division, first Director of OHM's Adult Psychopharmacology Service.

Since 1988, Dr. Opler has been writing the "Ask the Doctor" column for the NAMI-NYS newsletter. He has authored over 200 articles in prestigious journals.

This information comes from Opler's response to questions from families and consumers at the conference.

Re: Lithium

Lithium can interfere with the release of thyroid into the system. (My question which follows: Is there an optimum time when patients should take their thyroid medication to avoid this situation?).

Re: Bipolar

Opler prefers Carbamazepine (Tegretol) to Trileptal because it works on both mania and depression.

He finds it ridiculous that the DSM5 did away with bipolar diagnosis if a child is under 17. Psychiatrists have lots of experience with younger children with bipolar symptoms.

Misc. "Nobody should be on Symbyax, which is a combination of Prozac and Zyprexa.

Tobacco companies are targeting the chronic mentally ill!

He likes Molindone - it does not cause weight gain. Mobane is a generic molindone.

Re: ADHD

Concerta is a good drug for ADHD. (He takes it!) It is a psychostimulant. But you need to be careful; Concerta can promote cycling so you should have a mood stabilizer as well if you are bipolar.

Texex - an old hypertensive drug, inexpensive and good for ADHD.

Re: Clozapine

A study in Finland found Clozapine the safest drug, leading to longer life, and even controlling for suicide. Clozapine should be a first line drug.....Lamictyl added to Clozapine helps.

Clozapine saves lives, treats psychosis, cuts down cigarette craving, decreases hospitalization and violence, is anti-suicidality and **reverses tardive dyskinesia.**

It can sometimes cause OCD but this can be treated by Zolof. Never use Juvex which blocks all the metabolic pathways of Clozapine.

We now know how to treat agranulosis. Therefore, the threat of agranulosis with clozapine is no longer a reason to not try the drug.

In this study Seroquel was one of the unsafest drugs, closely followed by Zyprexa, which is very unsafe. Haldol at low doses is better than Zyprexa. Zyprexa,

though good for short term treatment, is bad for diabetes, mortality, weight gain.

A NAMI Board Member, Dr. Laitman MD, has become an expert on Clozapine. He is a nephrologist who treated his own son.

ECT added to Clozapine makes a huge difference for some. (What about Transcranial Magnetic Stimulation? See review of Dr. Ghaly's workshop on TMS).

Dr. Ghaly's presentation on **Transcranial Magnetic Stimulation** was excellent. I highly recommend that our local Syracuse NAMI affiliate invite him to present this information at our annual conference in the Fall.

Dr. Ghaly began discussing the physical effect of depression, which as many of you are aware, is a body/mind disorder that is often accompanied by severe back pain, migraines, weight gain and/or weight loss, increased cortisol levels, and other physical symptoms.

Depression is associated with 20 to 30% incidents of cardiac disease.

There are approximately 21 million adults with some depressive disorders and 12 million people have bipolar disorder.

Adequate treatment of depression is the exception, not the norm.

At least 20% of patients do not respond to trials of 2 or more anti-depressant medications.

Only 33% have complete remission. Most common residual symptoms are insomnia, fatigue, pain, loss of concentration, loss of interest.

Of 14 million Americans with depression, 7.2 million are treated; the other 7 million are not treated.

(The most dangerous age for suicide in younger individuals is between the ages of 15 and 16).

Algorithm for Resistant Depression

Lots of things have to be ruled out to have an individual diagnosed with resistant depression. Most individuals with Major Depressive Disorder have a chronic course, often with considerable symptomatology and disability between episodes.

We need more effective treatment for the 49.4% who do not respond well to current treatments.

The inadequate response to treatment results in more hospitalizations, more expense, more work loss.

In his explanation of how depression is a brain malfunction, Dr. Ghaly discussed how in Major Depressive Disorder some areas of the brain are hypoactive, other parts are hyperactive. For example, part of the prefrontal cortex, the anterior cingulate cortex has high activity in depression. The amygdale is hyperactive, **the hippocampus is smaller.**

Transcranial Magnetic Stimulation

There are 500 doctors in the US using this technology. There are two other psychiatrists in our area using it although Dr. Ghaly was the first. TMS has a long and interesting history. The early Egyptians used electric fish to shock depressed patients! A controversial individual in the west, Mesmer, used electric currents to treat patients. The first magnetic therapy was used in 1902 in Vienna, something similar to TMS. Again used in 1910 in England. In America the FDA approved Vagus Nerve stimulation in 1990. In 2006 it approved TMS.

Dr. Ghaly uses a Magstim machine. Dantec is another machine from Scandinavia. Neurostar is another company. In Europe they are using robotic assistants to administer TMS.

TMS applied to the right side of the brain is used for OCD, Parkinson's, Bipolar Disorder, ADHD and other problems. TMS applied to the left side of the brain is used for Major Depressive Disorder. (Some surgeons are using gamma knife of the brain for Obsessive Compulsive Disorder).

In Europe, TMS is being used for **dementia, treating both sides of the brain.**

Brainsway Deep TMS (developed by an Israeli company - FDA approved) This is the technique used by Dr. Ghaly.

This is a non-invasive treatment which stimulates the brain region responsible for depression and brings significant improvement to patients. It is an outpatient procedure which does not require hospitalization or anesthesia, and entails no memory loss or systemic side effects.

In each session the patient is comfortably seated in a chair, and a cushioned helmet is gently placed over the head.

The helmet generates brief magnetic fields, similar to those used in magnetic resonance imaging (MRI) systems. These magnetic fields briefly stimulate the targeted brain area and improve depressive symptoms.

How Long Does the Treatment Take?

20 minute daily sessions, six times a week for four to six weeks. Then tapers off over three weeks. The experience feels like having an MRI. There are few side effects compared to medication or ECT. The most common side effects are headaches and local discomfort, both usually temporary and mild. ECT is three times more expensive with more risk and more side effects.

Women respond better than men. 77% response rate. Over age 60, 60% response rate.

Dr. Ghaly will try TMS after 2 failed medication trials. He would like to do it after one failed med trial but the insurance companies are controlling the guidelines.

Studies are currently underway for using TMS for OCD, PTSD, and other disorders.

While now used for adults, there are clinical trials being done for 10 to 18 year olds.

~for more information contact The Ghaly Healing & Wellness Center at 315-463-0421 or www.ghalyhwc.com

NAMI ANNOUNCES LEGISLATIVE PRIORITIES FOR 2017

ARLINGTON, Va., January 3, 2017 - The National Alliance on Mental Illness (NAMI) is pleased to announce its legislative priorities for 2017 as part of our ongoing efforts to ensure that policymakers maintain a focus and continue to address the needs of the mental health community.

"Last year, Congress overwhelmingly passed the most significant mental health legislation in years. But we're not done," said Mary Giliberti, NAMI's Chief Executive Officer. "We look forward to working with Congress to ensure that the progress we made serves as a foundation for improving mental health care in America."

The 2017 legislative priorities are as follows:

Invest in Mental Health and Innovation

Reject Medicaid caps or block grants that drive down innovation and force state

program cuts, putting individuals with mental illness and families at risk.

Support Medicaid expansion, with income-based eligibility, to provide coverage and a pathway to self-sufficiency for individuals with mental health conditions.

Ensure insurance market reforms include mental health and substance use disorder coverage in every health plan and at the same level (parity) as other health conditions.

Increase investment at NIH and NIMH in understanding, diagnosing and treating mental illness.

Promote Early Intervention

Promote early intervention for serious mental illness through continued federal funding set aside in the Mental Health Block Grant to support research-based First Episode Psychosis programs.

Improve Integration of Care

Improve integration of health and mental health care through policies and financing that:

Support the Collaborative Care Model, integrating behavioral health expertise into primary care.

Expand Certified Community Behavioral Health Clinics that integrate primary care into behavioral health care clinics.

Support Caregivers, Military Service Members and Veterans

Support our nation's caregivers by extending existing national caregiver support programs to include family caregivers of people with mental illness.

Increase capacity for mental health care and promote continuity of care for military service members and veterans with mental health conditions.

End The Criminalization of Mental Illness

Reduce the high cost of jailing people with mental illness by investing in policies and funding to ensure that every community has:

24/7 behavioral health crisis response teams.

Subacute and respite care.

Assertive Community Treatment and Forensic Assertive Community Treatment (ACT/FACT) teams.

"These priorities will guide our efforts as we look to keep what works and improve where needed to make it better for millions of Americans who live with mental illness and their families," Giliberti said.

Thank you for this moment!

The following note from a grateful mother to her son's treatment team is a reminder to families to remember to thank the people who help our loved ones.

I feel like I don't tell your teams thank you often enough.

I can't tell you how much I appreciate having my son back. We talk daily, we joke, and we enjoy our time together. We discuss books and movies, friends and interests. I am blessed everyday I'm able to talk to him and know he's okay.

None of us are guaranteed anything in life. Our lives can change with a visit to the doctor or a phone call. We each have this moment.

In this moment I want you to know I am thankful for the time you spend getting to know my son.

Even when he resisted your efforts, you stuck with him. You have developed relationships that he trusts. You have been there through his psychosis, mood swings, homelessness, and hospitalizations. You have been there when things have improved with a new apartment, new friends, and fewer symptoms. I thank you. I thank you for caring. I thank you for supporting me. I thank you for your dedication and compassion.

Recovery is not a straight path. You have been there when he has made steps forward and made steps back.

Thank you for all you've done for my son and the countless others you walk beside on their journeys.

God bless you,
Marla Byrnes

GROUPS SEEK END TO SOLITARY CONFINEMENT FOR TEENS

Patrick Lohmann, The Syracuse Post Standard, 12/25/16

Two New York civil rights organizations are pushing to expedite their lawsuit against the Onondaga County jail regarding solitary confinement of 16 and 17 year olds, saying the jail "continues to throw children into solitary."

The class-action lawsuit seeks to end the jail's practice of solitary confinement for 16 and 17 year olds, saying it violates their constitutional rights and harms young minds. If the request is granted, the teens would be taken out of solitary confinement as the lawsuit proceeds in federal court.

The Onondaga County Sheriff's Office, which operates the jail, did not immediately respond to a request for comment.

The new court documents, filed as part of the lawsuit from the New York Civil Liberties Union and Legal Services of Central New York, claim that of 131 teens admitted to the jail between October 29, 2015 and October 19, 2016, 79 of them spent time in solitary confinement. Inmates spend 23 hours a day in their "barren" cells that are 7 feet by 9 feet, according to the lawsuit.

Corrections officers place inmates, including teens housed there charged as adults, into its "segregation housing unit" after they allegedly commit infractions and for other reasons. The lawsuit claims officers arbitrarily punish teens with segregation.

The lawsuit also names the Syracuse City School District and says it has failed to adequately educate kids who are confined in the segregation unit. Earlier court documents included a packet of educational materials that teens receive while housed there.

Of the 131 juveniles admitted to the facility between October 29, 2015 and October 19, 2016 with stays lasting more than 6 days, 79 (60 percent) spent time in solitary. On average, the children spent 26 days in solitary.

U.S. SURGEON GENERAL SPOTLIGHTS ADDICTION

Calling it one of the most pressing public health crises of our time, U.S. Surgeon General Vivek Murthy, MD, issued a landmark report on tackling substance abuse disorders as a nation that he hopes will be a "cultural call to action."

More than 400 pages long, "Facing Addiction in America" calls for evidence-based early interventions for young people, investing in substance abuse prevention and research on treatment, and expanding treatment programs with a proven track record. Murthy said the view that substance abuse is a "moral failing" creates shame and stigma that makes people less apt to seek help and increases the challenge of marshalling the necessary investments in prevention and treatment.

"We must help everyone see that addiction is not a character flaw - it is a chronic illness that we must approach with the same skill and compassion with which we approach heart disease, diabetes, and cancer," he said.

~from bp magazine, Winter 2017

The **Circare Behavioral Health Clinic** (formerly Onondaga Case Management Svcs. Inc.) is accepting new referrals for adults and transition age youth as well - as long as they are 17 1/2 years of age at the time of referral.

Please contact Clinic Reception at 472-7363 x 400 with any questions about insurances that they accept. Please note that they do not accept any out of state insurances.

Hutchings Psychiatric Center Family and Community Education Schedule

Tuesday, February 14, 2017, 10am-12 noon

The Phases of Psychosis and Early Warning Signs

Presenter: Eehwa Ung, M.S.

Doctoral Clinical Psychology Intern - HPC Adult Outpatient Services

Classes are free and held in room 102 of the HPC Education & Training Building, 545 Cedar St. To register, call 315-426-6873 or 426-6870. Paid parking is nearby.

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: _____

Mail to: NAMI Syracuse Inc., 917 Avery Avenue, Syracuse, NY 13204

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.)**