# the challenger

A publication of the National Alliance on Mental Illness in Buffalo & Erie County

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Summer 2017

## *Mark Your Calendar & Find Support Meeting Location* Info*

***Family education** meetings are held at St. Paul's Evangelical Lutheran Church, 4007 Main St., Amherst (near Eggert Rd.) on the 2nd floor (main entrance at the back of the church), on the 2nd Thursday of the month.*
*Two **family support meetings** are held on the 3rd Wednesday of the month: *NORTH at St. Paul's, on the 1st floor (church entrance at ground level at left rear of the building); and *SOUTH, at Lake Shore Behavioral Health, 3176 Abbott Rd., Orchard Park, 14127. The *CITY family support meeting is postponed until further notice.*
***Board meetings** are held at 636 Starin Ave., Buffalo, 1st floor; members are welcome.*

***July***

***No board meeting for July – happy Summer!***

***13 Thurs Education Meeting. 7 pm Library/coffee hour, 7:30 pm Program.*** *Guests: Kristin Adduci, LMHC, MA, Crisis Services; and a CIT trained officer. Topic: "Update on Crisis Intervention Team (CIT) Training for Police"*

***19 Wed Family Support Groups*,*** *NORTH and SOUTH, 7–8:30 pm*

***August***

***1 Tues Board Meeting, 7 pm***

***10 Thurs Education Meeting. 7 pm Library/coffee hour, 7:30 pm Program.*** *Guest: Ronald Schoelerman, LCSW, Director of Intensive Adult (Forensic) Mental Health Services, Erie County Holding Center. Topic:Mental Health Services in the Erie County Correctional System--Advocacy, Approaches, and Roles of ECFMH within a Collaborative Model of Service Delivery*

***16 Wed Family Support Groups*,*** *NORTH and SOUTH, 7–8:30 pm*

***September***

***5 Tues Board Meeting, 7 pm***

***14 Thurs Education Meeting. 7 pm Library/coffee hour, 7:30 pm Program.*** *Guests: Anna McCarthy Schwartz and Katie Mullaney, Art therapists from BryLin Health Systems. Topic: "Art Therapy: What is it and How Does it Work? A Demonstration."*

***20 Wed Family Support Groups*,*** *NORTH and SOUTH, 7–8:30 pm*

***October***

***3 Tues Board Meeting, 7 pm***

***12 Thurs Education Meeting. 7 pm Library/coffee hour, 7:30 pm Program.*** *Guest: Kiran Khalid, MMBS and Amber Saunders, MD Topic: "Anything Can Set Off His Mood! Is He Bipolar?"*

***18 Wed Family Support Groups*,*** *NORTH and SOUTH, 7–8:30 pm*

***28 Sat Healthy Minds Empowerment Conference*** *at Medaille College*

# President's Corner

Welcome to our **new Executive Director, Michele Brooks**, who joined our staff this April. Michele, our Board Treasurer for the past year, and Volunteer of the Year along with her husband Eric, had the distinct advantage of on the job training: working on our finances, implementing new software and becoming familiar with NAMI's administrative procedures. The board had debated this step for the last year and finally agreed that this position is critical to increase our outreach in WNY to those who need assistance. Too many family members tell us that they wish they had heard about us sooner. With Michele's full-time presence in the office, we can use more of our energy and resources on new endeavors like the NAMI Faithnet program, chaired by **Rev. Daryl Bennett**, which reaches out to religious communities and a new initiative to bring mental health education to our schools led by our **Chair of Education, Patricia Foster**.

**Thank you** to **Co-Chairs, Barb Utter, Liz Carone** and our **office coordinator, Sherry Byrnes** for their hard work on another successful Annual Dinner. The audience was moved by our speaker **Keith O'Neil**, a former NFL Super bowl champion who inspired us by sharing his personal journey to recovery from bipolar disorder. Thank you also to all the committee members who gave their time and talent to making the evening a night to remember.

Five NAMI Buffalo members--**Michele Brooks, Liz Carone,**

**President's Corner** *cont.'s on Pg. 2*

**President's Corner** ***from pg. 1***

**Patricia Foster, Terry Fleig and I**--attended **NAMI's national conference** in Washington, D.C. the last week in June and joined 1000 other NAMI members from across the country to visit and educate lawmakers on Capitol Hill. At stake is the outcome of the Senate's re-design of the healthcare proposal. If it had passed as last proposed, the Senate bill would have slashed Medicaid, jeopardizing care for the seriously mentally ill, the developmentally disabled, and the elderly in nursing homes; and dropped up to 24 million people from coverage. We must keep a steady stream of phone calls and letters to our Senators and Representatives about the importance of health care coverage for all of our citizens.

At the end of June, Governor Cuomo signed the **Kendra's Law** renewal bill extending it until June 30, 2022. The law was named for Kendra Webdale, from Fredonia, NY, who was pushed to her death by a young man with mental illness while waiting for a subway in Manhattan in 1999. We've included background on the story in this newsletter. This five year extension of Kendra's law provides judges the authority to order psychiatric treatment for individuals who are considered to be at risk for violence to themselves or others.

This newsletter also offers a review of **DJ Jaffe**'s latest book *Insane Consequences* which examines and explains how the mental health system fails so many of those who live with serious mental illness.

On April 10, 2017, Governor Cuomo signed the **Raise the Age** bill into law. New York had been only one of two states that continued to prosecute 16 and 17 year olds as adults in criminal courts even for non-violent offenses. Young people in adult facilities are 36 times more likely to commit suicide than those in juvenile facilities. Most of the youth who were penalized by this practice, had a history of poverty, trauma and/or abuse. Let us thank our state legislators and the Governor for passing this long-awaited legislation which will reduce the school to prison pipeline. Barry Price, a member of Educators for Excellence-New York, urges schools like our criminal justice system, "to move away from overly punitive consequences and invest the resources to implement practices that address the root causes of misbehavior and set students on a path to long-term success".

In 2008, July was designated as **Bebe Moore Campbell National Minority Mental Health Awareness Month** in order to Improve access to mental health treatment and promote public awareness among minorities about mental illness. Bebe Moore Campbell was an author, advocate, co-founder of NAMI Urban Los Angeles and national spokesperson, who passed away in November 2006. She received NAMI's 2003 Outstanding Media Award for Literature. Campbell advocated for mental health education and support among individuals of diverse communities. So it seems especially timely this July to announce our **AKA (Alpha Kappa Alpha) sorority-NAMI Buffalo** collaboration on the Healthy Minds Empowerment Conference for parents and teens from diverse communities. It will be held Saturday, October 28, 2017, at Medaille College. We hope you will share word of the event, and perhaps volunteer for it.

To all of our readers, we send you our wishes for a summertime when "the living is easy".

Ann Venuto

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**Thanks to the many "hands" of NAMI's work:**

**Virginia Eberle,** our newest Education Meeting welcome and set-up volunteer.

Education committee volunteers **Patsy Foster** and **Ann Venuto** who have been meeting with area school administrators and teachers about education and training around mental illness awareness.

This Spring's Family-to-Family teachers, **Liz Carone** and **Jackie Thompson.** Congratulations to all who completed the class!

...and a warm welcome to **Bryan Taylor as a** new board member**.**

## Our Deepest Sympathy

To **Pam and Kurt Beehler** on the loss of their son, Kurt, Jr.

To **Linda Mallia,** on the loss of her mother, Ingeborg Cappello.

We learned a short time ago as well of the sad loss to the family of NAMI friend **Sharman Staschak** of her son, Justin.

Our thoughts are with them all.

*Please consider*
*naming NAMI*
*in your will.*
*Your legacy gift can help ensure*
*that our work continues,*
*in honor of your memory.*

# Creativity and Mental Illness: Richard Kogan on Rachmaninoff

*September 14, 2016 | Cultural Psychiatry*

*By Natalie Timoshin*

If you've ever been to one of the American Psychiatric Association's annual meetings, you probably know who Richard Kogan is. If you've been really lucky, you have heard one of his lecture-concerts. Dr. Kogan is Clinical Professor of Psychiatry at Weill Cornell Medical College as well as Artistic Director of the Weill Cornell Music and Medicine Program. A graduate of the Juilliard School of Music, Harvard College, and Harvard Medical School, Dr. Kogan is a virtuoso concert pianist and a distinguished psychiatrist—which turns out to be in Dr. Kogan's case a brilliant combination.

The nascence of Dr. Kogan's lecture-concert series was a forum on creativity and mental illness presented at the APA in 2001. In preparing for the presentation, he researched the lives of composers whose music he had played his entire life and discovered that many of them had signs and symptoms of serious psychiatric illness. Beethoven, for example, had paranoid, persecutory delusions; Tchaikovsky had recurrent bouts of suicidal depression; and Schumann had panic attacks and mood swings and spent the final years of his life in an asylum.

While recognizing the inherent impossibility of confirming retrospective diagnoses on historical figures, Dr. Kogan observed that many of the great composers of the classical music pantheon were prolific letter writers and kept meticulous diaries, thereby affording a window into their mental state for nearly every day of their adult lives. Dr. Kogan has done numerous benefit performances on these composers (playing their masterpieces and explaining their psychic distress) for organizations like the National Alliance on Mental Illness in an effort to reduce the stigma associated with psychiatric illness. He notes that "it seems perverse to stigmatize a group whose members include individuals who have made such extraordinary contributions to civilization."

The link between creative genius and mental illness has been recognized since ancient times, and modern research suggests that the incidence of psychiatric illness is greater in populations of writers, artists, and musicians than in the general population. An important question for clinicians is whether treatment of a psychiatric disorder will enhance or diminish creativity. Dr. Kogan cautions that "it is important not to over-romanticize mental illness and its impact on the creative process . . . most depressed individuals are too paralyzed to compose a symphony and most psychotic individuals are too disorganized to create anything that is coherent."

But Dr. Kogan expressed concern that presenting programs on Schumann, Tchaikovsky, and other composers with florid psychopathology who had monumental creative accomplishment while living in an era without effective psychiatric treatment might be contributing to this tendency toward over-romanticization. Hence his current focus on the case of the great Russian composer Sergei Rachmaninoff. In recent performances including "The Psychiatrist at the Keyboard" for the BBC in London and as soloist with conductor Marin Alsop and the Baltimore Symphony in Rachmaninoff's Piano Concerto No. 2, Dr. Kogan explored how Rachmaninoff's most beloved music "owes its very existence to a timely intervention by a mental health professional."

Rachmaninoff was born in 1873 and endured considerable hardship as a youngster. His father was a wealthy landowner but squandered his entire fortune through gambling, and the family was forced to move to a cramped apartment in St. Petersburg where there was a diphtheria epidemic. The 9-year-old Sergei and his older sister contracted the illness. She died and although he eventually recovered, he was left with a fear of death that lasted his entire lifetime.

Rachmaninoff was a talented young pianist but was undisciplined. At age 12 he was sent by his family to what can be likened to piano "boot camp" in Moscow, where the strict regimen of practicing scales improved his technique but increased his tendency toward despondency. As a teenager, he discovered that composing music provided an ideal outlet for expressing his internal feeling states.

As a composition student at the Moscow Conservatory, he fell under the influence of his musical idol, Pyotr Ilyich Tchaikovsky. Tchaikovsky recognized Rachmaninoff as a kindred spirit in writing emotionally charged music and effectively anointed the younger man as his successor. After Tchaikovsky's death in 1893, Rachmaninoff was determined to live up to this legacy and began to compose a symphony. The world premiere performance of the Rachmaninoff Symphony No. 1 was a disaster—the orchestra did not rehearse sufficiently and the conductor, Alexander Glazunov, was apparently drunk during the concert. The reviews were scathing. Dr. Kogan notes that "Rachmaninoff always had a gloomy disposition, and this artistic setback precipitated a full-scale emotional crisis, plunging him into a major depressive episode that lasted 3 years." Rachmaninoff developed insomnia and feelings of worthlessness and hopelessness, lost his appetite and, most disturbingly, his ability to compose. He recalled that he felt

**Rachmaninoff** *cont's, pg. 4*

**Rachmaninoff** *cont'd. from pg. 3*

"like a man who had suffered a stroke and had lost the use of his head and hands."

The London Philharmonic Society commissioned Rachmaninoff to compose a new piano concerto. Because he needed the money, he accepted the assignment, but by this point he had lost all confidence and had complete writer's block. In desperation he sought consultation with Dr. Nikolai Dahl, who had recently cured Rachmaninoff's aunt of an unspecified psychosomatic ailment.

After graduating from Moscow University Medical School, Dr. Dahl became intrigued by the therapeutic use of hypnosis and went to France to study with hysteria and hypnotism expert Jean-Martin Charcot. When Dr. Dahl returned to Russia, he opened a practice devoted exclusively to the use of hypnosis in treating psychiatric problems. In addition to his medical practice, Dr. Dahl was an accomplished amateur violist and founded his own string quartet. Dr. Kogan points out that "violists in string quartets are almost required to be good listeners, constantly attuned to the violin voices above and cello line below, and good listening skills are similarly invaluable in treating psychiatric patients."

Dr. Kogan speculates that Dr. Dahl may have utilized **cognitive therapy techniques** in his treatment, persuading Rachmaninoff that an inadequate performance of his Symphony No. 1 did not mean that it was an unworthy piece. ….Dr. Dahl seems to have focused on subduing the automatic negative thoughts that interfered with the composer's creative flow. In his memoirs, Rachmaninoff wrote that in every single session, after an extended conversation, Dr. Dahl would put him in a trance and then repeat the same posthypnotic suggestions over and over "...you will write your concerto... you will work with great facility...your concerto will be of excellent quality...."

The 2 men met daily starting in January 1900, and by April of that year Rachmaninoff noted a considerable improvement in mood and appetite. He began work on what would prove to be one of the iconic works of the classical music canon, dedicating his Piano Concerto No. 2 to Dr. Nikolai Dahl.

Rachmaninoff flourished creatively after his successful course of treatment. His fellow composer Igor Stravinsky commented that it was as if he had transitioned from using water colors to doing oil paintings. After the Bolshevik Revolution of 1917, Rachmaninoff and his family fled Russia and eventually settled in New York City. He developed a phenomenally successful career as a concert pianist. (His prowess as a pianist was aided by his enormous hand size, which may have been due to Marfan syndrome.) According to Dr. Kogan, Rachmaninoff in his years in America had "an embarrassment of riches—a wife who loved him, children and eventually grandchildren who adored him, wealth and worldwide fame, but he was nevertheless tormented by depression....His preoccupation with death grew dramatically as he got older. He managed to use this preoccupation to his creative advantage by incorporating the Dies Irae motif (the medieval chant for the dead) into at least 20 of his compositions."

Rachmaninoff feared more than just death. He developed phobias about strangers, darkness, and small animals. "He openly acknowledged that he was mentally ill," says Dr. Kogan, "and he recognized that he had to struggle mightily with his melancholic inclinations."

Rachmaninoff never consulted another psychiatrist after his experience with Dr. Dahl. Dr. Kogan speculates that Rachmaninoff was not motivated to seek treatment for his mood disorder, that he sought out Dr. Dahl not because of depression but because of writer's block. Rachmaninoff was not creatively blocked during his exile years, and he kept up a feverish pace of concertizing to regulate his moods and preserve his sanity.

As he grew older, he developed a series of physical ailments including arthritis, eye strain, back pain, and bruised fingertips, which prompted his internist to strongly advise him to curtail his grueling concert schedule. Rachmaninoff refused, explaining that "this is my only joy, the concerts... If I have a pain, it stops when I am playing. Sometimes the neuralgia on the left side of my face and head torments me for 24 hours, but before a concert it disappears as if by magic...no, I cannot play less....It is best to die on the concert stage."

Rachmaninoff continued to concertize even after receiving a diagnosis of a fast-spreading malignant melanoma, and he died 4 days short of his 70th birthday. Like Rachmaninoff, Dr. Dahl emigrated from Russia after the Bolshevik Revolution and settled in Beirut, Lebanon, where he practiced psychiatry and played viola in the orchestra of the American University of Beirut. He even once played viola in a performance there of the Rachmaninoff Piano Concerto No. 2, the work that was dedicated to him.

The case of Sergei Rachmaninoff underscores the complex relationship between mental illness and artistry and the essential role of mental health professionals in reducing suffering and enhancing creativity. Rachmaninoff is universally regarded today as one of the outstanding musicians of the 20th century but likely would have been a barely remembered footnote in music history were it not for the effective intervention by Dr. Nikolai Dahl.

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*Dr Richard Kogan, psychiatrist and concert pianist, will play at Kleinhan's on January 17th, 2018 a program called "Rachmaninoff and His Psychiatrist". Dr Kogan will recount the story and play the Piano Concerto No. 2 dedicated to Rachmaninoff's psychiatrist, Dr. Nikolai Dahl, who was also a violinist.*

# *2017 NAMI-NYS Training Schedule*

*Please contact NAMI Buffalo & Erie County at 716-226-6264 or namibuffalony@gmail.com for more information and on how to enroll.*

***NAMI Homefront Teacher Training***
*September 16th-17th 2017*
*Trainers: Pam Solomon & Jerry Burton*
*Location: NAMI-NYS Office Albany*

***NAMI Family-to-Family Teacher Training***
*October 20th-22nd, 2017*
*Trainers: Patti Sacher & Bonnie Goldberg*
*Location: NAMI-NYS Office Albany*

## Alpha Kappa Alpha Sorority and NAMI Buffalo & Erie County Are Planning Something Special Together!

Sat., Oct. 28, 2017 at Medaille College

## Healthy Minds Empowerment Conference

To improve access to mental health treatment and promote awareness across diverse communitiesabout mental illness.

Thank you to AKA committee members working with us on this event:
Co-chair Josephine Cross,
Lois Alexander, Pat Baxter, Fern Beavers, Sharon Bradley, Cambria Daniels, Juanita Hunter, and Gizelle Stokes

For details, or to volunteer, contact:
NAMI Buffalo at 716-226-6264
or namibuffalony@gmail.com

## 33rd Annual Awards & Dinner Celebration April 6, 2017: a memorable evening

**NAMI Buffalo's 33rd Annual Awards & Dinner celebration in April was a great success,** thanks to all of the sponsors and friends, families, and agencies who attended. Our keynote speaker **Keith O'Neil**--a former NFL star--is the founder, and now president, of the 4th and Forever Foundation. The foundation supports programs to raise awareness of mental illness and funds research to alleviate mental illness and its challenges.

Keith (above L) told a moving, heart-felt--at times humorous--story of his life with bipolar disorder. His journey provided us all an example of recovery and hope.

Awardees above with NAMI Buffalo president Ann Venuto and VP Liz Carone: (top R) the Mitten Tree Project of the Social Action Committee at Sts. Peter & Paul RC Church, Amherst; (row 2, L) Eric & Michele Brooks; (row 2, R) Mary Wolf, St. Paul's Lutheran Church; (direct L) Monica Bell, HSBC Bank; (bottom L) Nike Carli and Alan Jay, The Noble Family Trust Foundation.

Once again, we are especially thankful to our event sponsors:
Gold Sponsors: ECMC, Lake Shore Behavioral Health Services, Spectrum Human Services; and
Silver Sponsors: Horizon Health Services, Living Opportunities of DePaul, Inc., UBMD Psychiatry

We hope you will plan to join us next Spring (2018) for our 34th.

# Peer Corner

*I had everything planned out,*
*of failure, I had no doubt,*
*I was gonna be important in a big way.*

*Then I caught an illness,*
*and my life took on a stillness,*
*and time just kinda slipped away.*

*If I can't have it all, why bother trying,*
*So I gave up and fantasized about dying,*
*Seemingly every single day.*

*But I can't leave my family behind,*
*that would be most unkind,*
*so for now, in this world I do stay.*

*Sometimes I view my life as not that bad,*
*When I don't focus on all the things I had,*
*Which does nothing but cause dismay.*

*Depression which never seems to clear,*
*combined with anxiety and fear,*
*hopefully I'll get better someday.*

*I still have a chance at a normal life,*
*get a job, maybe settle down with a wife,*
*that's what my social workers all say.*

*But no one seems to want to hire the mentally ill,*
*no matter my education level or skill,*
*"Managed Out", I become often without delay.*

*I'm college educated but begging for menial jobs,*
*rejection after rejection, my confidence it robs,*
*Life's not easy when your considered "cray".*

*Holes in the history of my employment,*
*which sadistic interviewers view with enjoyment,*
*This was when I was Ill, is that what I'm supposed to say!?*

*So I don't even try anymore,*
*I thought God had so much for me in store,*
*But my situation doesn't improve no matter how much I pray.*

*The medications do relieve,*
*but for my trim waistline I do grieve,*
*Because they dramatically increase how much I weigh.*

*What's gonna happen to me when my family is gone?*
*How could my life have gone so wrong?*
*Some of the questions I ponder, which keeps sleep away.*

*I might end up in a group home,*
*or living by myself all alone,*
*but my own self, if statistics are right, I'll probably slay.*

*But who knows, maybe I'll find some friends,*
*maybe I'll not be my own ends,*
*maybe I just need to be positive, come what may.*

*So for now, I think I'll cling tightly to hope,*
*cause self pity is a slippery slope,*
*and hope I don't turn out that way.*

*An Arsenal of antidepressants and uppers do give aid,*
*to help feelings of worthlessness and despair to fade,*
*in the battle against depression, they're pivotal in the fray.*

*I'm stubborn and I refuse for now to give in,*
*Even if my hopes and dreams I don't win,*
*I got to find the beauty in each and every day...*

*By Rob S.*

*I must take medication, by court order. So in terms of medication, I have no choice. I feel like I've lost my voice in the matter. On the one hand, I miss the manias I used to get, but on the other, I like the calmness and serenity the medication provides.*

*The only issue I have with the medication is the fact that antipsychotics helped me gain extreme amounts of weight. To the tune of fifty plus pounds. The medication can cause permanent metabolic changes. It also can result in the development of tics, tremors and involuntary twitches. Which can also be permanent. I've started to notice those, just over the past year or so. It's called Tardive Dyskinesia and it scares the hell out of me. For I have been in the psych wards, with elderly patients who've been on antipsychotics for years and years. Their TD's are so bad, some of them can barely write or feed themselves with a utensil.*

*So I am caught between a rock and a hard place. Because, if history shows anything, if I stop taking the Meds, I rapidly deteriorate into a manic paranoid mess. But if I continue to use them, damage--some of it permanent--may be done. This is all done for the sake of "normalcy".*

*I wonder how many unique and individualistic people we have lost to its demands? In this poem, I try to express that frustration...*

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With the launch of this Peer Corner feature, we invite submissions of prose and poetry for *Challenger* publication. We will also begin a column called Family Voices in our next newsletter to give families an opportunity to share their story. Names can be changed and the author may be listed as "Anonymous" if desired. To submit an item for the editors' consideration, send to: namibuffalony@gmail.com or NAMI BUffalo & Erie County, PO Box 146, Buffalo, NY 14223. Publishing decisions rest with the editors.

# FDA Approves First Medicine For Tardive Dyskinesia

**By Ken Duckworth, M.D. | Apr. 19, 2017**

Tardive dyskinesia (TD) is a movement disorder that occurs in some people who take first-generation antipsychotics (such as haloperidol, chlorpromazine), and to a lesser degree second-generation antipsychotics (such as aripiprazole or paliperidone). TD results in repetitive, involuntary movements commonly of the face, lips and limbs. Movement disorders were described in people living with schizophrenia before the advent of first generation antipsychotics, but the clear majority of these movement symptoms currently are clearly induced by medicines. TD is a neurologic disorder that can be disabling and stressful and had no FDA-approved treatment—until recently.

Last week, the FDA approved a new medication for the treatment of TD with the trade name Ingrezza and generic name valbenazine. The FDA fast-tracked this medicine's approval process, given this unmet medical need. The clinical trial that led to the approval evaluated the movements of 234 individuals with TD who were also diagnosed with schizophrenia, schizoaffective disorder, or bipolar disorder. These research subjects were randomly assigned valbenazine or a placebo (a sugar pill). At six weeks, a clear difference emerged in the movement symptoms of the two groups, which led to the approval.

If you have TD, this new medicine is worth a fresh conversation with your prescriber. In study trials, this medicine appears to have been well tolerated, though as with most treatments, there are common and serious side effects (usually for people with heart rhythm issues). There is also another medicine currently seeking FDA approval for TD, so the tool box for treatment of this condition may soon increase even further.

The clinical focus for TD to date has been largely on prevention, which hasn't been very successful given the prevalence of TD. Doctors assess TD symptoms with the Abnormal Involuntary Movement Scale (AIMS) scale. This should be performed on aregular basis, typically every 6 months. The AIMS exam is an assessment of a person for movements that could suggest TD; if TD is suspected, a discussion with the person about lowering their medication dose or switching medication to one with less risk is typically advised. TD can be avoided in some cases, but with long term use of the medicine (tardy or emerging over time), the risks are increased. It's hard to predict who will develop TD, but we do know that African American, Asian American, people with diabetes, and individuals over 55 are at a greater risk. Many people take antipsychotics for decades, so the risk of developing TD is real and needs to be weighed against the benefits for symptom reduction and alternative treatments.

I have felt a bit helpless in the past when I see people who live with TD. We didn't have any treatment for TD approved by the FDA. We now have a new tool and I look forward to learning more about this medication from my patients' experiences and scientific literature.

**Note:** *NAMI does not endorse any treatments, and this brief blog is only informational to introduce a new treatment approach to a difficult condition.*

*Ken Duckworth is medical director at NAMI*

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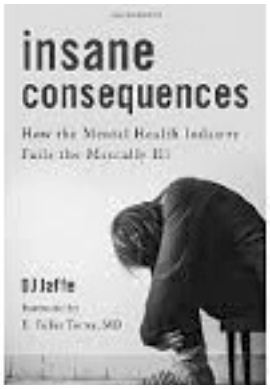
Congratulations
to former NAMI Buffalo President
Marcy Rose,
named 2017 Mental Health Association of Buffalo & Erie County
Roger Stone Advocate of the Year
Pictured (L) with MHA President Ken Houseknecht; (R) with Karl Shallowhorn, Director of Community Advocacy

Book Review

## Insane Consequences by DJ Jaffe




The image on the cover jacket of DJ Jaffe's new book, Insane Consequences, is of a man in tattered pajamas and slippers slumped over at the waist as he sits in a chair embracing his ankles. It is a perfect metaphor for our mental health system, so broken; a rebuke for the state of health care for many who are seriously mentally ill in America. It's not pretty. It's abysmal.

The first paragraph of the introduction to the book grabs your attention immediately. He states: "America's mental health system is insane, expensive, and ineffective. Under the guise of increasing freedom, it increases incarceration. Under the guise of facilitating recovery, it ensures that fewer recover. In the name of protecting privacy, it causes suicide. America treats her least seriously ill (the "worried well") and forces the most seriously ill to fend for themselves. The ability to get help is inversely related to need." Strong words, indeed, but he continues throughout the book to justify and explain what he means.

He speaks to the loss of needed hospital beds, sacrificed to the promise of "community services". The sickest among us will still need hospitalization at some point and as of 2006, we were short 95,000 beds. He explains the consequences of ignoring treatment for this group in terms of community cost and human tragedy. He defines serious mental illness as: those mental illnesses listed in the DSM that result in functional impairment which substantially interfere with or limit one or more major life activities. Usually this means major bipolar, schizophrenia spectrum disorders, or severe major depression which make up the bulk of people with serious mental illness. He states, "While other illnesses may also be serious if they substantially affect the ability to function, including them does not raise the percentage by much". The Center for Mental Health Services has estimated that 4 percent of the population over 18 years old has serious mental illness, yet the mental health industry utilizing federal funds insists that "all mental illness is serious". This book explains why that is disturbing.

Mr. Jaffe repeats over and over the need to recognize how seriously mentally ill people have been disenfranchised and speaks to how we can work to improve on their care. While acknowledging that every person who has mental illness needs good care, he points out that we need to do better for those who are too ill to speak out for themselves.

Organizations and programs that lack scientific evidence of effectiveness are named and discussed. He speaks of wasted funds that could be better utilized on methods of treatment that are evidence-based, and he describes those. For every study he quotes, the reader can access his source in 78 pages of notes. This is a book that shows you where to go and how to get there. It is a book that every NAMI family <u>needs</u> on their bookshelf. We have two copies in our NAMI Buffalo library but I highly recommend you buy one for yourself.

Marcy Rose
Past President, NAMI Buffalo & Erie County
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## Volunteers Are the Center of Our Strength - We Invite You to Find Your "Space", Too

Are you interested in legislative advocacy? Outreach and raising awareness of mental illness and NAMI services, fighting stigma? Training to serve on our Helpline, or teach our signature Family-to-Family and other NAMI signature classes and family support groups? Helping with special events?

Volunteer time can be customized to a volunteer's schedule.

For details, contact the office at 716-226-6264

or namibuffalony@gmail.com.

At the end of June, a NAMI Buffalo delegation attended the NAMI national convention with over 1000 NAMI members from across the country. They also had private appointments with members of Congress in the House and Senate to advocate for better health care, and urged them to protect Medicaid, the backbone of services for many who live with mental illness.

Above: Some of our key NAMI Buffalo volunteers at the 2017 NAMI national convention in Washington, DC.
L to R: vice president **Liz Carone**, president **Ann Venuto**, board member **Patsy Foster**; and executive director **Michele Brooks.**

# Higher Death Rate Among Youth with First Episode Psychosis

*NIH-funded study highlights need for increased early intervention programs*

April 6, 2017 • Press Release

A new study shows that young people experiencing first episode psychosis (FEP) have a much higher death rate than previously thought. Researchers analyzed data on approximately 5,000 individuals aged 16-30 with commercial health insurance who had received a new psychosis diagnosis, and followed them for the next 12 months. They found that the group had a mortality rate at least 24 times greater than the same age group in the general population, in the 12 months after the initial psychosis diagnosis. This study, funded by the National Institute of Mental Health (NIMH), part of the National Institutes of Health, underscores that young people experiencing psychosis warrant intensive and proactive treatments, services and supports.

The research, led by Michael Schoenbaum, Ph.D., Senior Advisor for Mental Health Services, Epidemiology, and Economics at NIMH, was published online April 6, 2017 in the journal *Schizophrenia Bulletin*.

*The 12-month mortality rate for these young people—from any cause—was at least 24 times higher than their peers in the general population.*

The research team used insurance claims data to identify young people aged 16-30 who had been diagnosed diagnosed with a first episode of psychosis in 2008-2009. They used data from the Social Security Administration to identify deaths in this population within 12 months of the initial psychosis diagnosis. Data on cause or manner of death were not available for this research. The 12-month mortality rate for these young people—from any cause—was at least 24 times higher than their peers in the general population. In the general United States population, only individuals over age 70 come close to a similar 12-month mortality rate.

"These findings show the importance of tracking mortality in individuals with mental illness," said Schoenbaum. "Health systems do this in other areas of medicine, such as cancer and cardiology, but not for mental illness. Of course, we also need to learn how these young people are losing their lives."

In addition to mortality, the study examined the health care individuals received in the 12 months after the initial psychosis diagnosis. Those data showed that young people with a new psychosis diagnosis had surprisingly low rates of medical oversight and only modest involvement with psychosocial treatment providers. Overall, 61 percent of them did not receive any antipsychotic medications, and 41 percent did not receive any psychotherapy. Those who died within 12 months of diagnosis received even less outpatient treatment and relied more heavily on hospital and emergency care.

"Other studies have shown that early coordinated treatment for psychosis produces the best results. However, we know that the typical duration of untreated psychosis in the United States is around 17 months," said Robert Heinssen, Ph.D., director of the NIMH Division of Intervention Services and co-author on the paper. "This study reinforces federal and state support for funding evidence-based psychosis treatment programs across the country, and the need for communities to invest in more treatment programs."

"Grants from the Substance Abuse and Mental Health Services Administration promote many of these programs in communities throughout the U.S.," said Acting Deputy Assistant Secretary Kana Enomoto, head of the Substance Abuse and Mental Health Services Administration (SAMHSA).

"The future of this research will show us what is happening with young people in this population, and help us tailor interventions to address their risks,"added Schoenbaum. "In the meantime, this study is a wake-up call telling us that young people experiencing psychosis need intensive, integrated clinical and psychosocial supports."

Reference

Schoenbaum, M., Sutherland, J., Chappel, A., Azrin, S., Goldstein, A., Rupp, A., Heinssen, R. Twelve-Month Health Care Use and Mortality in Commercially Insured Young People with Incident Psychosis in the United States. Schizophrenia Bulletin, April 6, 2017.

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*For information and linkage about intensive services and area programs for young people experiencing First Episode Psychosis, contact the Helpline at NAMI Buffalo & Erie County at 716-226-6264 or namibuffalony@gmail.com*

# Background on Kendra's Law

The law was named for Kendra Webdale, from Fredonia, New York, who was pushed to her death while waiting for a subway in Manhattan in January, 1999. A witness described her attacker, Andrew Goldstein, as average –looking and reported that he approached Kendra and asked her for the time. But Andrew was anything but average. He had been diagnosed with schizophrenia and had a history of assaulting 13 people over a two-year period, none of whom he knew and the majority, women. It is alleged that upon arrest, he said "Take me to a hospital."

An NBC Dateline report in 2007 told his story. In 1992, Andrew had voluntarily been admitted to Creedmoor, a psychiatric center in Queens, NY. While there, he attacked two social workers and a nurse. He believed the staff was poisoning him with cyanide and repeatedly asked for help, specifically a supervised residence. After 8 months he had improved enough to be moved to a group home on the hospital grounds. Despite evidence in his medical records that Andrew discontinued medication when he went home on weekends and that he had failed evaluations that he could live on his own, after one year, he was discharged to an unsupervised apartment in the city. From 1996 on, he went through repeated hospitalizations for unprovoked assaults. However he was always discharged after a short time, to live independently with a small amount of medication and a referral for outpatient treatment. Long waiting lists for supervised housing made it unlikely that his request for more supports would ever be met. A few months before his brutal murder of Kendra, he was admitted to Brookdale hospital after another impulsive assault and during his stay there, attacked a nurse and a psychiatrist.

Released from the hospital, he had stopped his medication. The 29-year-old man had once been a promising science student. New York Times reporter Michael Winerip, who researched his confidential psychiatric file, reported:

> *At one point or another Andrew Goldstein got almost every kind of treatment that we have in our mental health system. But that care was never coordinated, it was sporadic. He was at crucial points denied all kinds of treatment that he needed."*
>
> *In 1999, New York State enacted legislation that provides for assisted outpatient treatment for certain people with mental illness who, in view of their treatment history and present circumstances, are unlikely to survive safely in the community without supervision. This law is commonly referred to as "Kendra's Law."*

**Overview of Assisted Outpatient Treatment**

Kendra's Law establishes a procedure for obtaining court orders for certain individuals with mental illness to receive and accept outpatient treatment. The prescribed treatment is set forth in a written treatment plan prepared by a physician who has examined the individual. The procedure involves a hearing in which all the evidence, including testimony from the physician, and, if desired, from the person alleged to need treatment, is presented to the court. If the court determines that the individual meets the criteria for assisted outpatient treatment (AOT), an order is issued to the director of community services (DCS) who oversees the mental health program of a locality. The court orders will require the director to provide or arrange for those services described in the written treatment plan that the court finds necessary. The initial order is effective for up to 6 months and can be extended for successive periods of up to one year. The legislation also establishes a procedure for evaluation in cases where the individual fails to comply with the ordered treatment and may pose a risk of harm."

*More information about AOT, including who can petition, and AOT criteria, may be found on the OMH webpage. https://www.omh.ny.gov/omhweb/Kendra_web/KHome.htm*

*The Erie County Department of Mental Health (ECDMH) administers an Assisted Outpatient Treatment (AOT) program based on Kendra's Law and as set forth set forth in §9.60 of the Mental Hygiene Law (MHL). For more information, please contact Lisa McNeil at ECDMH Single Point of Access (SPOA) at 716-858-7059*

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## SAVE OUR WNY CHILDREN'S PSYCHIATRIC CENTER

**Tell Governor Cuomo to sign off on the legislature's request!**

Write or call:
The Honorable Andrew M. Cuomo
Governor of New York State
NYS Capitol Building
Albany, NY 12224

gov.cuomo@chamber.state.ny.us
or Call Gov. Cuomo 518- 474-8390 (office hours 9 am-5 pm)

Send a Facebook message @GovernorAndrewCuomo

Send a Twitter message @nygovcuomo

## Chapter News

New NAMI dues rates have taken effect as of July 1, 2017, as noted on the membership form to the left.

The Niagara St. family support meeting is postponed until further notice. Please feel welcome to attend one of the meetings held on the 3rd Wednesday of the month (see calendar for details).

We have a new telephone system! We think it will be easier to get straight to the help you are looking for when you call. We hope you will find it helpful and easy to use. Early response is very positive. Please let us know how you like it.

We are in a new transition and considering listing and thanking new and renewing members and donors annually or in every other newsletter issue (e.g., twice a year) rather than with each quarterly edition so that we can include more articles and content in the "off" months. This issue does not contain our usual listing, but we are grateful for every membership and donation we receive. If you have thoughts about this as a new format, please feel free to email them to us at namibuffalony@gmail.com or call the office at 716-226-6264.

## A Very Special Thanks to the 2017 Annual Awards & Dinner Committee:

Co-chairs Liz Carone & Barb Utter

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|---|---|
| Mary Lou Bond | Sherry Byrnes |
| Philisa Fazio | Patsy Foster |
| Barb Hoekstra | Alana Madrid |
| Marcy Rose | Pat Seifert |

Jackie Thompson

*Great job, folks!*

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## Are you interested in taking our Family-to-Family Class?

For advance notice on when classes will be offered in the Fall, contact the office at 716-226-6264 and press '2', then '3' to be put on the list. Space is limited and we recommend pre-registration to be sure of a spot!

## We invite you to join NAMI Buffalo & Erie County

in helping us make a difference for people living with mental illness and their families.

Mail to:

NAMI in Buffalo & Erie County
P.O. Box 146, Buffalo, NY 14223

Name_____

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☐ **Membership $40 Individual**

☐ "Open Door" Membership - $5 option
(for those in financial need)

☐ **Membership $60 Household:**

**NOTE: must include all household member names when joining in order for benefits to apply. Attach separate sheet if needed.**

**Names:**_____

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Membership includes local, state, and national NAMI.

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☐ **Donation**; amount $ _____

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