the challenger

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

Vol 9—Number 1
Spring 2017

*Mark Your Calendar & Find Support Meeting Location * Information*

*Family education meetings are hed at St. Paul's Lutheran Church, 4007 Main St., Amherst (near Eggert Rd.) 14226 on the 2nd floor (Main entrance, back of the church), on the **2nd Thursday** of the month. The ***CITY** family support meeting is the **3rd Tuesday** of each month at Lake Shore Behavioral Health, 951 Niagara St., Buffalo 14213. Two family support meetings are held on the **3rd Wednesday** of the month: *NORTH at St. Paul's Lutheran Church (above, ground level entrance at left rear of building); and ***SOUTH** at Lake Shore Behavioral Health, 3176 Abbott Rd., Orchard Park 14127. Board meetings are held at 636 Starin Ave., Buffalo 14216, 1st floor; members are welcome.*

March

7 Tues NAMI Board Meeting, *7 pm*

9 Thurs NAMI Educational Meeting. *Library/Coffee Hour, 7 pm; Program, 7:30 pm. Guest: Daryl Taberski, Director of Social Work, BryLin Hospitals. Topic: A Talk About the Inpatient Experience*

15 Wed NAMI Family Support Meetings*, *NORTH and *SOUTH, 7–8:30 pm*

21 Tues NAMI Family Support Meeting, **CITY, 5-6:30 pm*

April

4 Tues NAMI Board Meeting*, 7 pm*

6 Thurs 33rd Annual Awards & Dinner Celebration

13 Thurs *No Education Meeting due to Dinner & Easter*

18 Tues NAMI Family Support Meeting, **CITY, 5-6:30 pm*

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

May

2 Tues NAMI Board Meeting*, 7 pm*

11 Thurs NAMI Educational Meeting. *Library/Coffee Hour, 7 pm; Program, 7:30 pm. Guest: Brandy Kaiser, OT, Chief Occupational Therapist and Acting Director of Rehabilitation and Recovery Services; Buffalo Psychiatric Center. Topic: The role of occupational therapy in recovery from mental illness*

16 Tues NAMI Family Support Meeting, **CITY, 5-6:30 pm*

17 Wed NAMI Family Support Meetings*, *NORTH and *SOUTH, 7–8:30 pm*

June

6 Tues NAMI Board Meeting

8 Thurs NAMI Monthly Educational Meeting. *Library/Coffee Hour, 7 pm; Program, 7:30 pm. Guest: Kelly Gotham, Mental Health Court Attorney. Topic: How to navigate the court system when your loved one is arrested*

14 Wed NAMI Family Support Meetings*, *NORTH and *SOUTH, 7–8:30 pm*

20 Tues NAMI Family Support Meeting, **CITY, 5-6:30 pm*

President's Corner

The NAMI Buffalo & Erie County chapter was a lively place these last few months as our staff and Board, organized holiday service projects, updated office technology, provided signature programs, launched a search for an executive director, became energized by the strategic planning process and prepared for the upcoming re-affiliation process with national NAMI.

Going forward, our affiliate will be known as a Model A chapter meaning we agree with NAMI national to document that we meet high standards of operation. These shared standards will help to build awareness of NAMI and make our name the strong, vibrant presence we want it to be in order to better meet the needs of individuals and families whose lives have been affected by mental illness.

We all watch with concern the efforts to undo the Affordable Care Act (ACA) by the new federal administration and wonder how access to treatment may change for those who live with mental illness. While we agree that ACA could be improved, many of the advances in coverage that have been achieved for treatment of those with mental illness and addictions have roots in "Obamacare". (See article – *What's At Stake for Mental Health Care,* pg.4). Please call your legislators and ask them to protect all the gains that have been made.

It's a pleasure to report that our two holiday drives, *Christmas is for Kids!* and *Christmas is for Adults Too!*, were both great successes and brought hundreds of gifts to children and adults who live with mental illness. A big THANK YOU

President's Corner *cont's pg. 2*

President's Corner, *from pg. 1*

to all those dedicated volunteers who gave so much of their time to these projects. A special thank you to **Mary Kirkland**, **Tom McNulty** and **Mary Lou Bond** who coordinated the *Christmas is for Kids!* project and **Liz Carone** who led the gift drive for hospitalized adults with her committee of shoppers extraordinaire: **Jackie Thompson**, and **Marcy Rose**.

We continue to work on improving our outreach to underserved individuals. Over the last year we have collaborated with Alpha Kappa Alpha (AKA) Sorority, Gamma Phi Omega chapter, to plan a one-day community workshop focused on mental health education for minorities, tentatively scheduled for October 2017.

Volunteers are the heart of our organization. Without volunteers we would not be able to provide NAMI programs, have a presence at health fairs, accomplish office tasks, or answer calls from distressed families. If you would like be more active, please let us know. We are so grateful to the new volunteers who came forward to help at our monthly educational meetings: **Mary Regula**, **Cindy & Bill Borton**, **Patsy Foster** and **Patricia Seifert**.

SAVE THE DATE: for our 33rd Annual Dinner on Thursday, April 6, 2017 at Salvatore's Italian Gardens. Invitations will be in the mail soon. We are delighted to have the former NFL football player Keith O'Neil as our featured speaker, a passionate advocate for helping those who are affected by mental illness.

Looking forward to seeing you at our Annual Anniversary Dinner on April 6th.

Ann Venato
President

We Get Mail

Dear Ann, Liz, Patricia, Katie, and NAMI Staff,

Holiday greetings and thanks to you all for your support at my art opening 10-29-16! It was a surreal event for me and would not have been the same without your help, and education. I'm happy to let you know I was able to donate $2,020 to the Dzirasa Lab to assist with their exciting research!

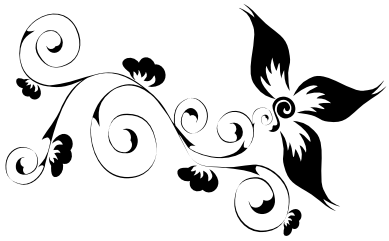
I'm also happy that I've been able to designate NAMI Buffalo as my donor organization through the Combined Federal Campaign. I'm pleased to assist NAMI in all you do for so many.

Again, have a blessed and happy holiday season, NAMI staff and families. Great things are ahead!

Kerima Collier

Sunshine Corner

- **Barb Utter** and her daughter Philisa and their team who provided refreshments at our strategic planning session in January
- **Clarence Presbyterian Church** which hosted our all day session of brainstorming and strategic planning
- **Lee Grunert** for facilitating our Strategic Planning Workshop
- **Susan Carson** for her help at education meetings last year
- **Mary Regula, Patsy Foster, Patricia Seifert, Bob & Cyndi Borton** for volunteering to help with hospitality and greeting at our monthly education meetings
- **Mary Regula** for heading the Library Committee with help from **Patsy Foster** and **Pat Seifert**



Get well wishes to Marcy Rose and **Jerry Keppel** as they continue their recoveries

Happy Spring!

Two Large Foundation Gifts to NAMI in Buffalo & Erie County End 2016 on a High Note

NAMI in Buffalo & Erie County was very fortunate to receive two significant, unanticipated donations at the end of 2016. One was from the Noble Family Foundation, established by long-time member Beatrice Noble. The second was from the Catherine Sandford-Kopp Foundation which has provided support for NAMI over the years, and whose most recent gift we greatly appreciate. Beatrice's biography, sent to us by her nephew, Trustee Alan Jay, reads in part:

Beatrice Noble, Ph.G. (July 21, 1917—July 1, 2014)

Beatrice Noble was born on July 21, 1917 in Rochester, New York.

In 1938 Beatrice proudly graduated from the State University of New York at Buffalo's School of Pharmacy and Pharmaceutical Sciences.

Beatrice was a true academic and professional pioneer. This was a time when many men (both students and professors), were openly opposed to women entering the pharmacy profession. Of the five women that began the three year course of study, Beatrice was the only one to graduate. Beatrice tirelessly served her community as a pharmacist for 52 years in retail, hospital and clinic settings. She recalled having to often work seventy hour weeks, and of not taking payment for medications when neighbors couldn't afford it. . .

Investing was a lifelong passion and pleasure of Beatrice's. . .

Beatrice, through hard work, study and selflessness, cared and provided for family, friends and strangers alike. By creating the Noble Family Charitable Foundation, Beatrice has insured that the good she did in life, continues in perpetuity. Beatrice and her siblings did not marry or have children. However, the Noble family name lives on through the good works of the Foundation and always in our hearts.

NAMI Buffalo is deeply grateful that Beatrice and Catherine remembered our mission and work as part of their legacy. We will do our best to honor that confidence and generosity.

A Great Big *Thank you* to Everyone Who Donated, Collected, Sorted, Wrapped and Delivered to Help Make the Holidays Bright in 2016!

***Christmas is for Kids!* and *Christmas is for Adults, Too!* were wonderful successes this year.**
Did you know? Part of the children and families we reach—almost a quarter—are veterans' families.

We've been giving to the children and families of vets in treatment since 2009. This year we helped 142 such families. Pictured below, *Christmas is for Kids!* co-chair Tom McNulty delivered gifts to WNY Heroes with founder Chris Kreiger for 142 families! Chris served four tours and sustained serious injuries on each tour. He was given a Purple Heart by Louise Slaughter at the opening of a Sabres game a few years ago.

Our gifts of clothing, books, and treats for adult inpatients at ECMC were also received with happiness and appreciation.

Thank you, Christmas for Kids volunteers!
We couldn't do it without you all.

Tom and Chris making the holidays happen for 142 veterans' families. Great job, guys!

WHAT'S AT STAKE FOR MENTAL HEALTH CARE

KEEP WHAT WORKS

The 114th Congress passed important mental health reforms as part of the 21st Century Cures Act to address the mental health crisis in our nation. This brings hope to the 60 million Americans living with mental illness, but these reforms are in peril if mental health coverage is not preserved.

The Affordable Care Act includes provisions that improve coverage for mental health care and promote independence and self-sufficiency for people who live with mental health conditions. With fair and equal mental health coverage and Medicaid expansion, more Americans are getting treatment when they need it—helping them to stay in school, on the job and in recovery.

Insurance Safeguards and Mental Health Care

· Today, individual and small group health insurance plans are required to cover mental health conditions—and at the same level (parity) as other health conditions—due to insurance safeguards, or legal requirements, in the Affordable Care Act.

· Families can now cover their children on their health insurance plan until age 26, an important protection because 75% of mental illness begins by age 24.

· 45 million Americans with a mental health or substance use condition are protected from losing or being denied coverage because of safeguards for people with pre-existing conditions.

Medicaid Expansion and Mental Health Care

· Nearly 1 out of 3 people covered by Medicaid expansion live with a mental health condition.

· With Medicaid coverage, people have access to critical services, like Assertive Community Treatment and First Episode Psychosis programs, that improve lives and keep people out of hospitals, off the streets and out of jails.

· States that expanded Medicaid have significantly reduced costs for uninsured hospital visits and uncompensated care.

· Medicaid expansion is important because it

What's At Stake, cont's. on pg. 5

Coming July 1, 2017, New Dues Structure for NAMI Membership

Effective July 1, 2017, NAMI membership rates will change to:

Single	$ 40
Household* (new)	$ 60
Open Door	$ 5

Your NAMI in Buffalo & Erie County membership creates our strong voice as we advocate for needed changes and improvements in policies, programs, funding and services for people who live with and strive for recovery despite serious persistent mental illness.

*Household membership must list all members of a household at the time it is taken, and will count as only a single membership vote for elections. It entitles all listed household members to NAMI conference and on-line store discounts. Multiple individuals at a single address still have an option to take an individual membership and open door membership for additional voting memberships. Renewals made before July 1 can be done at current rates, $35 for Individuals, $3 Open Door. All membership types include and will continue to include local, state, and national levels.

You can renew on line, however we remind everyone that donations are only kept local if donated through our office at NAMI Buffalo & Erie County, PO Box 146, Buffalo, NY 14223. Contact the office at 716-226-6264 if you have any questions about donation or membership.

▪

Giving-Wise

We are pleased to have several new employer and designated giving donors these past few months from programs like Thrivent Choice, JC Penney and Bank of America Cybergrants, and DoTopia. There are many ways to give to NAMI in Buffalo & Erie County.

Thank you for checking with your employers for matching gifts; and your favorite vendors, like Amazon Smile, where you can specify a portion of your purchase to be donated to us. We also remain grateful to our friends who pledge through United Way and SEFA.

Please consider naming NAMI in Buffalo & Erie County as your charity of choice. If you would like to know more about such giving opportunities, call our office at 716-226-6264.

▪

IS SOMEONE YOU KNOW BEING DENIED TREATMENT FOR A MENTAL DISORDER?

Timothy's Law, New York's mental health parity law of 2006 requires that insurers provide coverage for the diagnosis and treatment of mental health disorders at least equal to coverage offered for other health conditions.

The federal Mental Health Parity and Addiction Equity Act of 2008 prohibits health plans from imposing greater costs or treatment limitations on mental health or substance use disorder benefits than on medical or surgical benefits.

In May 2016, N.Y. Attorney General Eric T. Schneiderman alerted individuals seeking treatment or facing obstacles with their health insurer to call their office's Health Care Helpline at 1-800-428-9071.

Schneiderman stated: "My office has taken an aggressive approach to enforcing these laws and will continue to take on those who ignore the law and, by doing so, reinforce the false and painful stigma often associated with substance abuse and mental health conditions."

Over the past two years, the Attorney General's Health Care Bureau has signed agreements with five major companies (Cigna, MVP, EmblemHealth, ValueOptions/ Beacon, and Excellus), representing millions of members across New York State, after determining that these companies were not in compliance with federal and state mental health parity laws. The settlements required the companies to implement a host of reforms to comply with state and federal law, and gave members the opportunity to appeal medical necessity denials. The Attorney General's office also recovered $2.9 million in penalties, and secured $1.6 million in consumer reimbursements for out-of-pocket treatment costs. Since the agreements were signed, ongoing monitoring has for most plans shown fewer barriers to treatment, including lower denial rates and more consumers accessing needed care.

Any resident who is denied substance abuse treatment should:

- Check the denial letter for accuracy and inform plan of mistakes.
- Ask the health provider to submit a letter of medical necessity, including facts that show that you meet the

relevant medical necessity criteria, point-by-point.

- Request a written, detailed explanation of the denial from the insurer.
- Look for common improper denial flags, such as "fail first" requirements, reduced payments for out-of-network providers, insufficient or incorrect information in denial letters, refusing to provide medical necessity criteria or using criteria that do not match the health condition, and failure to consult with the health provider or consider medical evidence supplied.

"If your health plan denies the treatment your provider recommends, remember, you have rights under New York State law," said Avi Israel, President of the addiction recovery non-profit Save the Michaels of the World. "Your loved one shouldn't have to 'fail first' and you have the right to appeal the plan's denial. Don't simply take no for an answer and walk away.

Call Attorney General Eric Schneiderman's Health Care Helpline at 1-800-428-9071. and ask for help."
Excerpted from nyag.pressoffice@ag.ny.gov May 11, 2016

Joseph Malczewski
Deputy Director of Intergovernmental Affairs for Upstate New York
New York State Attorney General Eric T. Schneiderman
Main Place Tower, Suite 300 A
350 Main Street
Buffalo, New York 14202
p: (716) 853-8488
m: (347) 515-2126

▪

What's At Stake, from pg. 4

covers single adults with mental illness who fall through the cracks, including:

- Young adults with first symptoms of a serious mental illness who are not ill enough to meet disability criteria (and Medicaid eligibility). Without Medicaid expansion, many young adults will not get the early intervention they need to manage symptoms and avoid a lifetime of disability.
- People whose mental health symptoms are so severe they cannot navigate the complex federal SSI/SSDI disability determination system (which leads to Medicaid eligibility).
- People with serious mental illness whose symptoms have been stabilized with psychiatric hospitalization and therefore are frequently ineligible for traditional Medicaid at discharge because they do not meet disability criteria.

Without mental health treatment covered by Medicaid expansion, people's conditions frequently worsen and result in costly and avoidable hospitalizations, homelessness and incarceration. With Medicaid expansion, young adults with first symptoms and adults living with serious mental illness can get the treatment they need to get well and stay well.

▪

Donald Trump Should Drain the Swamp at SAMHSA and CMHS

DJ Jaffe Executive Director, Mental Illness Policy Org

12/14/2016 04:42 pm ET

The 21st Century Cures Act signed by President Barack Obama contains smart, well-designed mental-health provisions. But unless President-elect Trump and Tom Price, his nominee for Health & Human Services (HHS) "drain the swamp" at the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Center for Mental Health Services (CMHS)—divisions of the federal Department of Health and Human Services—many of the new law's useful provisions could be negated or undone by the permanent bureaucracy.

SAMHSA and CMHS are largely responsible for overseeing and implementing federal mental-health policy, and will remain so under the Cures Act. Unfortunately, those agencies are failures, as SAMHSA's former chief medical officer, Elinore McCance-Katz, revealed in an op-ed, after she left the agency in disgust in 2015.

"SAMHSA does not address the treatment needs of the most vulnerable in our society. There is a perceptible hostility toward psychiatric medicine, a resistance to addressing the treatment needs of those with serious mental illness, and a questioning by some at SAMHSA as to whether mental disorders even exist—for example, is psychosis just a 'different way of thinking for some experiencing stress?'

SAMHSA and CMHS virtually ignore skyrocketing rates of homelessness, arrest, incarceration, suicide, and hospitalization that occur when the seriously mentally ill are allowed to go untreated. Instead, they wrap the provision of social services in a mental-health narrative and divert funds to unrelated or ineffective programs. These agencies encourage states to spend part of the $500 million that they receive in federal mental-health block-grant funding on people who don't even have mental illness and on "prevention," though serious mental illnesses, such as schizophrenia and bipolar disorder, can't be prevented. Nonprofit groups that depend on SAMHSA funding have lobbied states to close psychiatric hospitals, thereby making treatment more difficult. Recently, SAMHSA-funded groups convinced New York City to divert $8 million of city funds to Mental Health First Aid, a SAMHSA-promoted educational program that trains people to "better recognize the signs, symptoms and risk factors of mental illness and addiction and more effectively provide support." The program does nothing to help the mentally ill because no treatment is made available, even when symptoms are identified.

SAMHSA and CMHS are failed agencies that have almost no support from anyone other than those whom they fund. Thanks to the leadership of Pennsylvania Republican congressman Tim Murphy, the mental-health provisions of the Cures Act attempt to refocus SAMHSA and CMHS on the seriously ill—as opposed to the worried well—and to rely on science rather than pop psychology. The Cures Act replaces the SAMHSA administrator with an assistant secretary for mental health and substance-use disorders. The person who fills this important job will be responsible for both SAMHSA and CMHS, and for coordinating mental-health policy with other federal agencies. Trump should appoint a top psychiatrist like McCance-Katz or others who are committed to focusing on the seriously ill and ending the funding of nonsense. Or he could appoint a judge who is committed to reducing incarceration of the seriously mentally ill.

Murphy, along with powerful Texas Republican senator John Cornyn, included in the bill many provisions that are designed to force SAMHSA and CMHS to focus on the seriously ill. In the past, however, these agencies have ignored congressional direction, especially as it relates to Assisted Outpatient Treatment (AOT). Known as "Kendra's Law" in New York and "Laura's Law" in California, AOT is court-ordered, out-patient treatment of the most seriously ill, who may be so sick that they are unaware of their own symptoms. AOT is reserved for a tiny group of patients who have historically failed to comply with treatment. By keeping such patients out of jails and hospitals, and ensuring that they take prescribed violence-preventing medications, AOT has improved outcomes and reduced the costs of care.

The Cures Act extends and modestly expands federal AOT funding through 2022. The last time Congress funded AOT, however, CMHS bureaucrats hijacked the grant-funding process, giving preference to states whose AOT teams employed a "peer-support worker." In other words, the agency required state mental-health agencies to hire people with mental illness. There is no evidence that this improves outcomes, but it clearly increases costs.

SAMHSA-funded groups succeeded in watering down the final bill. Early iterations of the Cures Act contained provisions that would have allowed parents to access medical information about their seriously mentally ill adult children, as well as provisions to increase the number of hospital beds available to the seriously ill and reign in federally funded anti-treatment lawyers. But the bill is still a major step forward. It provides funding for mental-health courts, which can divert nonviolent, seriously mentally ill

33rd Annual Awards & Dinner Celebration
Keynote Speaker Announced:
Former NFL Player Keith O'Neil,
Advocate for Ending Stigma Around Mental Illness

Keith O'Neil is a former NFL football player having played for the Dallas Cowboys, Indianapolis Colts and New York Giants. During his professional career, he served as team captain and was a member of the Colts Super Bowl XLI Championship team. Keith is currently writing a book and speaking to audiences in the sports and mental health communities. Keith is also the President and Founder of the 4th and Forever Foundation which brings awareness to mental health and funds research for mental illness.

Keith played in the NFL with an undiagnosed mental illness, bipolar disorder, and is extremely passionate about helping others who suffer with mental health issues. He is devoted to erasing the stigma of mental illness in our society through his own personal experience. He is utilizing his book along with motivational speaking engagements to create awareness of mental illness.

The reason Keith is going public about his experiences is that he wants to inspire those with similar challenges. He believes, "with the proper diagnosis, medical attention and determination, anyone can achieve anything. If I can make it in the high stress environment of playing in the NFL with bipolar disorder, anything is possible!"

Keith lives in Pendleton, NY with his wife Jill and two sons Connor and Tanner. Keith's father, Ed O'Neil was an All-American linebacker at Penn State University, and a first round draft pick in the 1974 NFL Draft. His brother Kevin, played linebacker at Syracuse University and played in five major bowl games.

We hope to see you at the dinner! On Thursday, April 6, 2017 at Salvatore's Italian Gardens. RSVP by March 30. For more information or to request a reservation, please call 716-226-6264.

Drain the Swamp, cont'd. from pg. 6

offenders to mandated treatment instead of jail. It provides funds to train police on how to de-escalate interventions with the seriously ill. It provides for the collection and dissemination of data on the number and types of crimes committed by mentally ill individuals, the involvement of mental illness in deadly incidents involving law-enforcement officers, and the costs of imprisoning the seriously ill.

For too long, we have spent too much on trying to improve "mental wellness"—whatever that is—rather than delivering treatments that can reduce homelessness, arrest, incarceration, suicide, and hospitalization among the seriously mentally ill. We've sent the least ill to the head of the line and the most-seriously ill into the shadow mental-health system of jail and prison. Bullying and stress have been treated; schizophrenia and bipolar have been ignored. This bill attempts to end that insanity.

And if the right person is appointed as assistant secretary, it will likely work.

# # #

A version of this appeared in *City Journal* published by the Manhattan Institute and in Real Clear Politics.

DJ Jaffe is Executive Director of Mental Illness Policy Org

DJ Jaffe is an advocate for the most seriously mentally ill and has served multiple terms as a director of the New York City, state, and National Alliance for the Mentally Ill. He co-founded the Treatment Advocacy Center in Arlington, VA with the prominent psychiatrist and author, Dr. E. Fuller Torrey before creating Mental Illness Policy Org. in New York.

DJ's mental illness op-eds have appeared in the New York Times, Washington Post and he is regularly quoted by the media. DJ's work is focused exclusively on the 4% who are the most severely mentally ill, including those with schizophrenia and bipolar disorder. Most of the mental health industry is focused on the 18% with some form of often mild illness, or the 100% who can have their mental "wellness" improved. DJ focuses on those who are often homeless, incarcerated or institutionalized. He delves into politically incorrect, but important, topics like reducing violence, preserving psychiatric hospitals, making it easier to civilly commit those who need help.

His book, "Insane Consequences: How the mental health industry fails the mentally ill" will be published in April, 2017 by Prometheus Books. http://mentalillnesspolicy.org

Schizophrenia's Strongest Known Genetic Risk Deconstructed

Suspect gene may trigger runaway synaptic pruning during adolescence – NIH-funded study

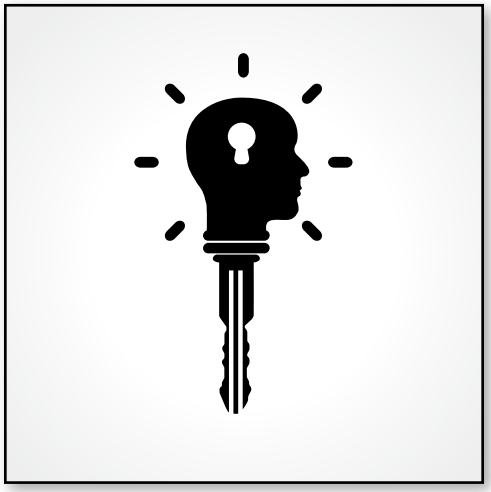
Versions of a gene linked to schizophrenia may trigger runaway pruning of the teenage brain's still-maturing communications infrastructure, National Institutes of Health (NIH)-funded researchers have discovered. People with the illness show fewer such connections between neurons, or synapses. The gene switched on more in people with the suspect versions, who faced a higher risk of developing the disorder, charac-terized by hallucinations, delusions and impaired thinking and emotions.

"Normally, pruning gets rid of excess connections we no longer need, streamlining our brain for optimal performance, but too much pruning can impair mental function," explained Thomas Lehner, Ph.D., director of the Office of Genomics Research Coordination of the NIH's National Institute of Mental Health (NIMH), which co-funded the study along with the Stanley Center for Psychiatric Research at the Broad Institute and other NIH components. "It could help explain schizophrenia's delayed age-of-onset of symptoms in late adolescence/ early adulthood and shrinkage of the brain's working tissue. Interventions that put the brakes on this pruning process-gone-awry could prove transformative."

The gene, called C4 (complement component 4), sits in by far the tallest tower on schizophrenia's genomic "skyline" of more than 100 chromosomal sites harboring known genetic risk for the disorder. Affecting about 1 percent of the population, schizophrenia is known to be as much as 90 percent heritable, yet discovering how specific genes work to confer risk has proven elusive, until now.

A team of scientists led by Steve McCarroll, Ph.D., of the Broad Institute and Harvard Medical School, Boston, leveraged the statistical power conferred by analyzing the genomes of 65,000 people, 700 postmortem brains, and the precision of mouse genetic engineering to discover the secrets of schizophrenia's strongest known genetic risk. C4's role represents the most compelling evidence, to date, linking specific gene versions to a biological process that could cause at least some cases of the illness.

"Since schizophrenia was first described over a century ago, its



underlying biology has been a black box, in part because it has been virtually impossible to model the disorder in cells or animals," said McCarroll. "The human genome is providing a powerful new way in to this disease. Understanding these genetic effects on risk is a way of prying open that black box, peering inside and starting to see actual biological mechanisms."

McCarroll's team, including Harvard colleagues Beth Stevens, Ph.D., Michael Carroll, Ph.D., and Aswin Sekar, report on their findings online Jan. 27, 2016 in the journal Nature.

A swath of chromosome 6 encompassing several genes known to be involved in immune function emerged as the strongest signal associated with schizophrenia risk in genome-wide analyses by the NIMH-funded Psychiatric Genomics Consortium over the past several years. Yet conventional genetics failed to turn up any specific gene versions there linked to schizophrenia.

To discover how the immune-related site confers risk for the mental disorder, McCarroll's team mounted a search for "cryptic genetic influences" that might generate "unconventional signals." C4, a gene with known roles in immunity, emerged as a prime suspect because it is unusually variable across individuals. It is not unusual for people to have different numbers of copies of the gene and distinct DNA sequences that result in the gene working differently.

The researchers dug deeply into the complexities of how such structural variation relates to the gene's level of expression and how that, in turn, might relate to schizophrenia. They discovered structurally distinct versions that affect expression of two main forms of the gene in the brain. The more a version resulted in expression of one of the forms, called C4A, the more it was associated with schizophrenia. The more a person had the suspect versions, the more C4 switched on and the higher their risk of developing schizophrenia. Moreover, in the human brain, the C4 protein turned out to be most prevalent in the cellular machinery that supports connections between neurons.

Adapting mouse molecular genetics techniques for studying synaptic pruning and C4's role in immune function, the researchers also discovered a previously unknown role for C4 in brain development. During critical periods of postnatal brain maturation, C4 tags a synapse for pruning by depositing a sister protein in it called C3. Again, the more C4 got switched on, the more synapses got eliminated.

In humans, such streamlining/pruning occurs as the brain develops to full maturity in the late teens/early adulthood – conspicuously corresponding to the age-of -onset of schizophrenia symptoms.

Future treatments designed to suppress excessive levels of pruning by counteracting runaway C4 in at risk individuals might nip in the bud a process that could otherwise develop into psychotic illness, suggest the researchers. And thanks to the head start gained in understanding the role of such complement proteins in immune function, such agents are already in development, they note.

"This study marks a crucial turning point in the fight against mental illness. It changes the game," added acting NIMH director Bruce Cuthbert, Ph.D. "Thanks to this genetic breakthrough, we can finally see the potential for clinical tests, early detection, new treatments and even prevention."

https://www.nimh.nih.gov/news/science-news/2016/schizophrenias-strongest-known-genetic-risk-deconstructed.shtml

▪

The High Cost of Untreated Mental Illness

Without treatment, mental illness exacts a high cost on individuals, families and our economy.

□ Suicide is at a 30-year high. Every day, an average of 117 people die by suicide.

□ Mental health conditions cost the economy an estimated $193 billion dollars in lost earnings each year.

□ Mental health conditions are the number one cause of disability and workplace absenteeism.

□ 1 out of every 8 emergency department visits involves a diagnosis of mental health or substance use condition.

□ Mood disorders are the 6th most common hospital stay and resulted in $5.2 billion in hospital costs in 2013.

□ Up to 25% of people who are homeless live with a serious mental illness.

□ People with serious mental illness are over-represented in our jails and are booked into custody at nearly 4 times the rate of other individuals."

From "What's at Stake for Mental Health Care", NAMI.org

The Criteria of Emotional Maturity:

- *The ability to deal constructively with reality*
- *The capacity to adapt to change*
- *A relative freedom from symptoms that are produced by tensions and anxieties*
- *The capacity to find more satisfaction in giving than receiving*
- *The capacity to relate to other people in a consistent manner with mutual satisfaction and helpfulness*

- *The capacity to sublimate, to direct one's instinctive hostile energy into creative and constructive outlets*
- *The capacity to love*

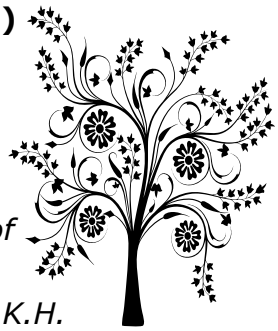
~ William C. Menninger

Thank You for Generously Supporting Our Fall Fundraiser

***Future Fund* - Circle of Hope ($500-999)**

Susan Minotti

Fall Benefactors ($100-249)



Anonymous - T.F.
Antoinette Ezzo
Susan Friedhaber-Hard
Dan & Mary Lavis
Grace Martorana, *in memory of Phillip A. Martorana, Jr.*
Dorothy Pappas, *in honor of P.K.H.*
Richard & Marcy Rose, *in memory of Roger Watkins*

Fall Friends (up to $99)

Sherwood & Andrea Antman
Bob & Grace Chambers, *in honor of D.S.*
Barbara Milliken
Jill Pariso
Patricia Sturgess

New and Renewing Members

Anonymous ~ C.L.
Lara Almquist
Elizabeth Anderson
Allison Andrews
Helen Aronoff
Melissa Berger
Shoureen Berner, *in honor of, prayers for H*
Melissa Bolz
Michele Brooks
Elizabeth Carone
Bob & Grace Chambers
Robert Cochran
Rita Congdon
Mary Delaney
Marlene Donohue
Patsy Foster
Janice Gagliardi
Judy Goldstein & Jackie Jaszczynski
Darlene Gorski, *in honor of C.A.M.*
Wanda Haak
Dr. David Heffler
Mrs. Se'Vaughn Herrera
Margaret Hickey
Catherine Laughlan
Linda Lipp
Deborah Lowry
John & Linda Mallia
Debbie Manfredi
Karen Maricle
Lynn Matthews
Tom McNulty
Carol Moscati, *in memory of Christopher Moscati*
Judy Olsen
Elizabeth Schreier
Jim & Carol Seifert
Nancy K. Smith, *in memory of Nancy D. Smith*
Sheila Summers
Karen Welgoss
Kathleen Whelehan
Walter Wilczak
William & Denise Woods
Carolyn Young

Thank you to our generous donors! You make our work possible. . .

Dorothea Dix Circle ($5,000/+)

Catherine Sandford-Kopp Foundation
Noble Family Charitable Foundation

President's Circle ($1,000-4,999)

Robert & Valerie Funk

Builders ($250-999)

Friends at East Aurora American Legion Post 362

Benefactors ($100-249)

Friends at 1st Presbyterian Church of Clarence
Elizabeth Anderson, *in memory of Peter Anderson. Thank you for everything you do to help so many people and families.*
Friends at Clarence Contemporary Club
Ellen Todd Cooper
Karla Jaeger, *in honor of P.F. & M.F.*
Laura Lindstrom, *in memory of Hugh M. Lindstrom & H. Randall Lindstrom. Thank you for your support to all those still walking their journey.*
Matt & Joanne Meier, *in memory of Willie Edwards*
Joan Snyder, *in memory of Peter Snyder*
Friends at United Way Buffalo & Erie County
Carolyn Young

Sustainers ($50-74)

Anonymous
Patsy Foster
Lynn Matthews, *in memory of Tyler Matthews*
Elizabeth Schreier , *in memory of Billy Schreier*

Advocates ($30-49)

Friends at JC Penney
Carrie Rose
Jo Sheahan - *Thank you very much for your good work.*
Pam Termer
Friends at Thrivent Choice Program
Sharman Staschak

Friends (up to $29)

Friends at Barnes & Noble Booksellers (Amherst)
Friends at DoTopia
Judy Goldstein & Jackie Jaszczynski, *in memory of Reva*
Marilyn Green, *in memory of Roger Watkins*
Mary Kirkland, *in memory of Roger Watkins*
Doris Sielski, *in memory of Roger Watkins*
Nancy K. Smith, *in memory of Nancy D. Smith*
Marian Summa, *in honor of J.S.D.*
Rosemarie Sweeney, *in memory of Roger Watkins*

Donations for *Christmas is for Kids!*

With sincerest thanks:

Star Circle ($1,000/+)
Katherine Evans

Circle of Light (250-499)
Friends at O'Connor Medical Group

Santa's Circle ($100-249)
David Barrett
Marjorie Blondell
Julie Chirico
Douglas Easton

Friends (up to $99)
Katherine Collins
Lisa Cruz
Mary Dendy
Antoinette Ezzo
Lori Geisler
John & Eileen Grimaldi
Harry & Marie Guildford
Anju Gupta & Hari Gopal
Barbara Milliken
Dr. Kathleen Vertino - *God bless you*
Lori Wagoner – *Thanks for all you do for the kids.*

. . .and *Christmas is for Adults, Too!*

Friends (up to $99)
Mary Dendy

NAMI in Buffalo & Erie County
Board of Directors

Officers

Ann Venuto, President

Liz Carone, Vice President

Michele Brooks, Treasurer

Alana Madrid, Recording Secretary

♦

Mary Lou Bond

Judy Capodicasa

Patsy Foster

Colleen Frey

Barbara Hoekstra

Lynda Regan

Marcy Rose

Patricia Seifert

Jackie Thompson

Barb Utter

We invite you to join

NAMI in Buffalo & Erie County

in helping us make a difference for people who have mental illness, and their families.

Mail to:

NAMI in Buffalo & Erie County
PO Box 146, Buffalo, NY 14223

Name _____

Address _____

City _____ State_____ Zip_____

Phone _____

E-mail_____

☐ Membership $35 - OR -

☐ "Open Door" Membership - $3 for those in financial need, or to add a voting spouse/partner

-or-

☐ Donation; amount: $ _____

☐ Include Membership in this donation

☐ In memory of **- OR —** in honor of:

_____

☐ **Please keep my membership/ contribution anonymous.**

I'd like to help with the following (check your interest/s):

☐ Fund/friend Raising
☐ Office & Clerical
☐ Legislative Advocacy
☐ Write Support Letters
☐ Speakers Bureau
☐ Other_____
☐ Please put me on the phone tree/email list to receive legislative or other alerts.

Please send a copy of the newsletter to:

_____

_____

_____

NAMI in Buffalo & Erie County is a 501(c)3 not-for-profit. You will receive a receipt for your tax purposes.

Buffalo & Erie County
PO Box 146
Buffalo, NY 14223

Non Profit Org.
U.S. Postage
PAID
Buffalo, NY
Permit No. 2037

Return Service Requested

"Do a little bit of good where you are;
it's those little bits of good put
together that overwhelm the world."
~ Archbishop Desmond Tutu

33rd Annual Awards & Dinner Celebration
Thursday, April 6, 2017