NAMI Buffalo & Erie County
National Alliance on Mental Illness

the challenger

vol. 11 - Number 2, Summer-Fall 2018

Mark Your Calendar - Meeting Location Info Below

Family Education Meetings *are held 2nd Thursdays of the month at St. Paul's Lutheran Church, 4007 Main St., Amherst (near Eggert Rd.) 14226 on the 2nd floor (main entrance at back of the church).* ***Family Support Group Meetings: NORTH*** *on 3rd Wednesdays, at St. Paul's Lutheran Church, 1st floor (church entrance at ground level at left rear of the building); and* ***SOUTH*** *on 3rd Thursdays, at the Wesleyan Church of Hamburg, 4999 McKinley Pkwy., Door 5, Rm. 117B, Hamburg, NY 14075.* ***Board meetings*** *are usually at St. Paul's Lutheran Church (location listed above); members welcome. You may wish to call ahead to confirm meeting dates and locations.*

(See box above for board, family education, and support group meeting locations.)

Aug 2018

7 Tues Board Meeting*, 7 p.m.*

9 Thurs Education Meeting, *7 p.m. Library/coffee hour 7:30 p.m. Program: "My Story of Recovery from Bipolar Disorder" Guest: Leslie Wexler, Patient-Family Advocate, BryLin Hospitals*

15 Wed Family Support Group, *NORTH, 7–8:30 p.m.*

16 Thurs Family Support Group, *SOUTH, 7–8:30 p.m.*

Sept

4 Tues Board Meeting, *7 p.m.*

13 Thurs Education Meeting, *7 p.m. Library/coffee hour 7:30 p.m. Program: "New Rehab and Recovery Services at Restoration Society, including crisis diversion and a new community based service site" Guests: Renee Law, manager of the crisis diversion program, and Thanh Nguyen, Coordinated Entry Systems Specialist*

19 Wed Family Support Group, *NORTH, 7–8:30 p.m.*

20 Thurs Family Support Group, *SOUTH, 7–8:30 p.m.*

Oct

2 Premier screening & panel discussion of WNED/PBS documentary, "God Knows Where I am"

9 Board Meeting - Annual Chapter Meeting

11 Thurs Education Meeting, *7 p.m. Library/coffee hour 7:30 p.m. Program: "Office of Consumer Affairs Information on Current Programs, and Services for Intensive Needs" Guest: Robert Dempsey, Regional Advocacy Specialist, WNY Field Office-NYS Office of Mental Health*

17 Wed Family Support Group, *NORTH, 7–8:30 p.m.*

18 Thurs Family Support Group, *SOUTH, 7–8:30 p.m.*

Nov

1 Thurs Special Event - Book Talk with author and advocate DJ Jaffe, Daemen College, *7 p.m.*

7 Tues Board Meeting*, 7 p.m.*

9 Thurs Education Meeting, *7 p.m. Library/coffee hour 7:30 p.m. Program: TBA*

15 Thurs Family Support Group, *SOUTH, 7–8:30 p.m.*

21 Wed Family Support Group, *NORTH, 7–8:30 p.m.*

President's Corner

The July heat wave did not slow this NAMI chapter down one bit.

We now have representatives both on the Erie County Department of Mental Health (ECDMH) Community Advisory Board (Michele Brooks) and on their Mental Health Sub-Committee (Ann Venuto). This is an opportunity for us to bring our concerns in person directly to county officials as well as increase our networking with other community advocates. At the most recent meeting, I expressed the concerns of numerous NAMI members about their frustration with the lack of adequate housing for their family members in contrast to the more optimistic expressed perception of the Erie County Department of Mental Health housing official.

Two issues that our chapter has decided to focus on this year are **housing** and the **criminalization of mental illness**. The Homeless Alliance of WNY reported that 5824 people experienced homelessness in Erie County in 2017. About 54% were male and 94% were single males. Those with a psychiatric diagnosis or substance use disorder were not specified. Gentrification and destruction of obsolete apartment developments has affected median rent which has increased 18% over the last seven years. Social Security Disability rates and other forms of housing help have certainly not increased at nearly the same rate.

We frequently hear complaints about housing from family members of someone with a mental illness. These complaints include lack of available housing, substandard rentals, unsafe neighborhoods, and evictions. To qualify for housing, one must first complete a Single Point of Access (SPOA) intake through the Erie County Department of Mental Health.

The Office of Mental Health is gradually transitioning occupants out of Residential Care Centers for Adults (RCCA) into individual apartments. Many of us are concerned that not all of these chronically ill individuals, who are accustomed to having medications and meals

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

President's Corner *from pg. 1*

provided for them, will succeed when these supports are withdrawn. Call or write your state legislators and express your concerns about this issue.

On July 25th, NAMI was represented at the Erie County Legislature Hearing regarding the report by NYS Commission of Corrections (COC) that India Cummings' death in 2016 in the Erie County Holding Center (ECHC) was pronounced **"homicide by medical neglect."** April Baskin, the Majority Erie County Legislator, tirelessly questioned ECHC officials about details in the heavily redacted report. Frequently the county attorney advised officials that they could not answer many of her questions because the case was in litigation. Sheriff Howard, who left early, responded to questioning with the heated retort: *"Why are you so willing to accept as true what is no more than an opinion?"*

We had the opportunity to have our views about this case aired on WBFO radio and WIVB TV news. India Cummings, a 27 year old woman who had no previous criminal or psychiatric history was arrested after an adverse reaction to synthetic marijuana caused her to become agitated, confused and assaultive. It is our belief that this was a medical emergency and should have been treated as such with immediate evaluation and treatment in an emergency room. Instead she was incarcerated in the ECHC where she died an agonizing and preventable death from untreated injuries. This is hardly an isolated incident with 24 deaths at the ECHC under Sheriff Howard's administration. Please contact your Erie County legislator and ask that they take action on the COC report. Link to Buffalo News coverage of the hearing: https://buffalonews.com/2018/07/25/lawmakers-ask-jail-officials-to-explain-death-of-inmate-india-cummings/

We encourage NAMI members to express their support for April Baskins' legislation to create the **Erie County Corrections Advisory Board** to bring back much-needed oversight of the Erie County Holding Center. This board should include advocates for those with mental illness who are incarcerated in the county jail.

Remember to take good care of yourself, so that you can care for those you love.

Ann Venuto

Violence and Gun Reporting Laws

Editor's note: Gun violence and answers for sensible reform and protection continue to be part of everyday conversation in our communities, and the most recent shooting at the Madden Tournament in Jacksonville, FL makes clear how urgent reform is. We offer here NAMI's position as the question of untreated mental illness continues to be raised as a factor that needs to be taken into account.

Most people with mental illness are not violent. In fact, people with mental illness are more likely to be the victims of violence. Research on the relationship between mental illness and violence shows that there are certain factors that may increase risks of violence among a small number of individuals with mental illness. These factors include:

- Co-occurring abuse of alcohol or illlegal drugs
- Past history of violence
- Being young and male
- Untreated psychosis

The best way to reduce this risk is through treatment. Yet fewer than one-third of adults and half of children with a diagnosed mental illness receive mental health services in a given year.

Where NAMI Stands

We recognize that acts of violence by people with mental illness are usually the result of lack of needed mental health services. Policies and programs must be available and accessible which provide access to:

- Early identification and intervention
- Appropriate treatment and support
- Integrated treatment when there is co-occurring substance abuse
- Family education and support
- Crisis intervention

Creating new federal or state gun laws based on mental illness could have the effect of creating more barriers to people being willing to seek treatment and help

Guns, *continues on pg. 5*

Success is Built with Volunteers!

We appreciate all our volunteers' dedication and recognize especially in this issue: **Mary Regula** who has now catalogued all our member lending books so they could be posted on our website. Look through the list for something to borrow--or suggest we purchase for our collection.

Thanks as well to our teachers for the Fall Family-to-Family classes: **Paula Baumer, Mary Bird**, **Liz Carone, Virginia Eberle, Marcy Rose, and Ellie Worley**. We are happy to continue in the North- and Southtowns, and very excited to add a class in Niagara Falls. We are grateful to our class host sites, too: Niagara Falls Memorial Medical Center, St. Paul's Lutheran Church, Amherst; and the United Church of Christ, West Seneca.

We enthusiastically thank **Bryan Taylor** and **Eric Brooks** for agreeing to head our property committee to handle maintenance and services for our office building.

Finally, a warm shout-out to **Mary Lou Bond** who continues in a year-round "holiday spirit" to sort and pack personal care packages for patients upon leaving ECMC.

If you would like to join a committee (Education, Legislation, Finance, Housing, Outreach and Criminalization of Mental Illness), call the office at 716-226-6264 for more information.

Sending deepest condolences to...

Ruth Cisek and family in the loss of her son Eugene Paul Cisek.

Deborah and **Barbara Hoekstra** mother and aunt of Julia Hoekstra**.** Our hearts are with all the Hoekstra family at this difficult time.

DJ Jaffe whose wife Rose Wagner passed away recently.

Jere Lindstrom, in the loss of her daughter, long-time NAMI member, **Laura Jane Lindstrom.**

Peer Voices

In memory of
Laura Jane Lindstrom,
NAMI Buffalo & Erie
County member.
From her chapbook,
10 Minutes to Poetry,
with family permission

Sick/Well

by Laura Jane Lindstrom

Sick and well
Two terms I'll use
to describe my actions
Unveiling my ruse

My actions looked chosen
Like stopping was a choice
The losing of hope
Took over my voice

One day I shone
The next day I floundered
I overacted so badly
It left my friends confounded

But I wasn't evil
I wasn't good
I was sick trying to get well
Trying to be understood

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Announcing!

Tuesday, October 2

WNED/WBFO, with NAMI Buffalo & Erie County, Crisis Services, Erie County Mental Health Association, the Patrick P. Lee Foundation and others are pleased to offer a **local premier screening and panel discussion of the new documentary feature film,**

"God Knows Where I Am"

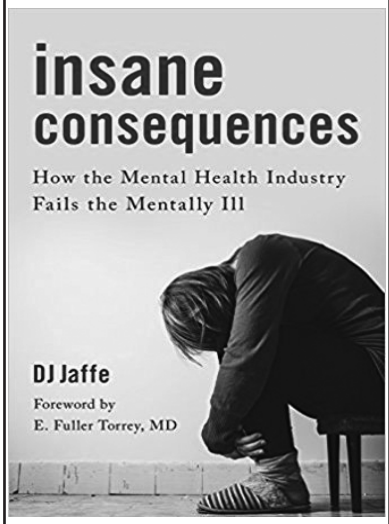
Set to air nationally in October, the film is a moving confrontation of our society's tragic battle with mental health and homelessness. For more information, check wned.org or contact Beth Fronckowiak at bfronckowiak@wned.org

NAMI Buffalo & Erie County
is proud to present
activist/advocate/author

DJ Jaffe

of the Mental Illness Policy Org., on

"How the Mental Health Industry Fails the Mentally Ill"



Thursday,
November 1st, 7 p.m.
Schenk Hall
Daemen College -
Amherst, NY

No admission charge
Light refreshments
RSVP at
www.namibuffalony.org

Please consider naming NAMI Buffalo & Erie County in your will.

Your gift ensures that your support for our mission will continue into the future.

Thank you.

New NAMI President Adrienne Kennedy Begins to Chart A Course

In June, at the national convention, NAMI elected new board president Adrienne Kennedy. Her family's struggles to obtain care for her seriously ill son and her commitment to changing the experience for others reassure that our organization is staying well-focused on the needs of people most seriously affected by severe illness --and their families and caregivers.

Kennedy outlines these ongoing concerns:
Better systems of care and an end to "outdated policies and practices that create unnecessary and, frankly, too often lethal, barriers to care." Ending the Institutions for Mental Diseases (IMD) exclusion, HIPAA misuse or lack of understanding, cross-state differences in "mental health code"; and the need for a balanced, properly supported approach to Assisted Outpatient Treatment (AOT). In addition, she has laid out five priorities for improving mental health care:

- Expand coverage for mental health and substance use disorder care in private insurance, Medicaid, and Medicare.
- Implement first episode psychosis programs on a nationawide basis.
- Decriminalize mental illness.
- Increase supportive housing.
- Continue efforts to educate commnities and the public about mental illness and the importance of compassionate responses.

She concludes in the reviewed blog post, "The realization that my son's life could have been saved had there been greater awareness of his mental illness and effective system changes profundly reinforces my belief in the importance of expanding educational efforts and commnuity awareness canpaigns for compassionate care. We must focus not only on families and peers, but also on providers, credentialed professionals and broader communties."

For more about Kennedy's family's experience and her background, visit Pete Early's blog at:
http://www.peteearley.com/2018/07/16/nami-president-responds-to-parents-blogs-about-serious-mental-illnesses/

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Parent Advocate Tells Fed Panel That HIPAA Often Is Used To Stonewall Families

BY PETE EARLEY

(7-25-18) Mental Health Advocate Doris A. Fuller returned to Washington D.C. recently to testify before the Federal Commission on School Safety at the Departmental of Education about the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and how it often is used to "stonewall" families trying to help a loved one with a serious mental illness. There are three hot button issues, in my opinion, that often are divisive in mental health circles – HIPAA, Assisted Outpatient Treatment, and the Medicaid Institutions for Mental Diseases exclusion.

I am reprinting her testimony to encourage discussion about HIPAA on my Facebook page.

When I first met Doris, she said I was responsible for her moving to Washington D.C. She explained that after she read my book, she felt compelled to find an advocacy job here. Later, I met her daughter – who was the real reason why Doris felt so passionately about our broken system – when Natalie was in a Fairfax County Va. psychiatric ward.

Tragically, Natalie ended her own life. Doris bravely wrote about Natalie's death for The Washington Post and also for my blog. (Her story remains one of the most read and powerful accounts that I've posted. I've included a few paragraphs from it and links at the bottom of this post. Please take time to read it.)

Written Testimony by Doris A. Fuller before the Federal Commission on School Safety

It is a privilege to be here today as a mental health advocate and family member who has observed HIPAA's role in mental health care delivery in a number of settings, including on a college campus.

A few years ago, I was asked to talk about mental illness and violence to the leading organization for student affairs officers on college and university campuses. Mental illness nearly always emerges by the age of 24 – in late adolescence or young adulthood – so these school officials are working daily on the front lines of mental health. In fact, because of the age that serious psychiatric disease typically starts, it is likely that no single other institutional setting in America serves so many individuals with mental health conditions as our high schools and colleges.

During my talk, I extolled the phenomenal communication, support and encouragement my daughter Natalie and I received from state university officials and health care providers when she had her first psychotic break as a college senior. Her symptoms led to a number of extreme behaviors, including painting her naked body blue from head to foot and pressing body prints all over the walls of the school's art building. She was not a typical or easy student to serve. Yet, in significant part because of the university and its health center's active collaboration with me in getting Natalie safely through these episodes, she ultimately returned to campus and graduated.

At the end of my talk to the group I asked if anyone from her university was in the room. Two hands rose timidly in the back.

"Thank you," I said. "My daughter would not have succeeded without you."

After I finished, they came up front to talk to me. By this time, I was working at the Treatment Advocacy Center and regularly hearing from families in crisis because of mental illness in their young adult children. I had learned that few students and families experience the open, collaborative approach Natalie and I did.

Why was that? I asked the officers. How could you talk to me and work with me, as a family member, when other schools around the country won't even return parents' calls?

They told me it was a matter of institutional policy and practice. The university was guided by the conviction that it had the authority under HIPAA, FERPA and applicable state laws to act in the best interests of its students, even if their actions required disclosing personal health information or other confidential matters to families. It was their belief that acting in the best interest of their students was their business.

I heard a similar description of privacy considerations when I attended a 2013 hearing of the House Subcommittee on Oversight and Investigation. The committee was taking testimony into whether HIPAA helps or hinders patient care and public safety. In his written and oral testimony, the director of the Office of Civil Rights for HHS emphasized that the HIPAA Privacy Rule allows communications between health care providers and patient family and friends.

Even so, he acknowledged, "Historically, providers often have been reluctant to share information with patients' friends and family members."

Family members would tell you provider "reluctance" is a gross understatement. "Stonewalling" comes closer to what many experience. I myself have stood in the emergency room of a hospital not 15 minutes from this room, with my daughter bleeding and hallucinating on a gurney beside me, and been told that federal law prohibited hospital personnel from informing or involving me in her care.

This was false.

HIPAA is itself flexible and accommodating, and the

HIPAA cont.'s on pg. 6

Guns, *from pg. 2*

when they need it most. Solutions to gun violence associated with mental illness lie in improving access to treatment, not in preventing people from seeking treatment in the first place.

Federal and state gun reporting laws should be based on these identified traits, not mental illness. NAMI believes that federal standards about people with mental illness being included in the National Instant Criminal Background Check System (NICS) should be changed.

- Inclusion should be based on current scientific knowledge about what may increase risks of violence among persons with mental illness.
- States should be provided with clear guidance about who should be reported and who should not be reported.
- The highly offensive and outdated wording currently in the NICS reporting law, specifically individuals "adjudicated as being mentally defective," should be eliminated.
- Establishing strong safeguards to protect the privacy of individuals whose names are included in federal and state gun reporting databases to make sure that the identities of such individuals are not shared or used for any other purposes.

What NAMI Is Doing

NAMI advocates for the federal government and states should fund programs focused on early identification, early intervention and evidence-based mental health treatments. Investment in research to better identify traits that predict gun violence is also necessary.

How You Can Help

We are a grassroots organization. We rely on people like you to advocate for these services in your community. Connect with your local NAMI to help advocate for funding and create opportunities for partnerships with other community organizations.

From NAMI national, https://www.nami.org/Learn-More/Public-Policy/Violence-and-Gun-Reporting-Laws

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NEW! THREE locations for NAMI Family-to-Family

12-week Classes Begin in September

Register now! Call 716-226-6264 (NAMI)

Open to family members, partners and significant others of individuals living with

Major Depression
Bipolar Disorder
Schizophrenia or Schizoaffective Disorder
Borderline Personality Disorder
Panic Disorder or Obsessive Compulsive Disorder
Post-Traumatic Stress Disorder (PTSD)
Co-occurring Brain and Addictive Disorders

This 12-session class helps caregivers understand and support individuals living with serious mental illness while maintaining their own well-being.

Classes are co-taught by trained NAMI Buffalo & Erie County family member volunteers who know what it is like to have a loved one struggling with one of these brain disorders.

No fee for class; materials are provided.

Classes address diagnosis, medication, privacy restrictions, hospitalization, finding/working with providers and treatment professionals, the criminal justice system, communication, coping with family stress, and more.

Mondays, starting Sept. 10, 6:00-8:30 p.m.:

St. Paul's Lutheran Church
4007 Main St., near Eggert Rd. - Amherst, NY 14226

-or-

United Church of Christ
630 Main St., near Union Rd. - West Seneca, NY 14224

BRAND NEW - FIRST TIME!
Tuesdays, starting Sept. 25, 6:00-8:30 p.m.:

Niagara Falls Memorial Medical Center
621 10th St. - Niagara Falls, NY 14305

Class is for family members and caregivers.
Space is limited. Pre-registration is required.
It is important to attend all sessions.

HIPAA from pg. 4

federal government has made a significant effort to get that message across to medical providers. Since that 2013 House subcommittee hearing, multiple government offices have issued unambiguous guidance that should by now have ended the stonewalling. HHS distributes extremely user-friendly fact sheets for providers and caregivers through its website. Words like "The health provider can share information" in the patient's best interest are repeated over and again.

The 21st Century Cures Act took these efforts a step further by establishing statutory requirements for model training for health care providers to assure they know what is permissible under existing rules.

To date, however, these requirements have not been funded, and they are not being implemented.

It bears repeating that, while medical providers, schools and a host of others routinely claim they withhold information or bar family members from treatment deliberations to avoid liability for violating HIPAA, to my knowledge, there has been no case, ever, of an individual provider being sued for a HIPAA violation and, in fact, there is no statutory provision in HIPAA for such legal action.

It also bears repeating that the mental health treatment narrative for young people in general has moved emphatically to the position that family members play a critical role in recovery.

Family engagement is a cornerstone of the coordinated care model developed by the National Institute of Mental Health for responding to first-episode psychosis. Child and adolescent mental health care has become firmly anchored in a model of leaving children with serious emotional disorders or mental illness in their natural settings – home and school – whenever possible and engaging all the players around them in their mental health development.

We are here today because of concerns about school safety and the impact of mental health on it. It cannot be repeated often enough that most violent acts are not committed by people with mental illness, and most people with mental illness are not violent. We could eliminate all the murders associated with mental illness in this country and 96% of the nation's murders would still occur.

But, statistically, the risk of violence is higher in people with psychiatric disorders that distort reality and impair daily function. That risk is highest early after mental illness symptoms begin – precisely when individuals are most likely to be in high school or on college campuses. It is in the best interest of us all to intervene early and effectively in these diseases.

To this end, nobody knows more about the health histories, risk factors, triggers and other characteristics of teenagers and young adults than the family members and caregivers who live with them and have known them all their lives. Family members possess unique insights into their loved ones facing mental health challenges, and they are uniquely positioned and supremely motivated to overcome those challenges.

When we talk about mental health and the safety of our school children, we should be mindful that the most likely victim of mental health tragedy is the child him or herself. In 2016 and 2017 combined, five children died in seven mass assaults in America's schools, and 17 more were wounded. In the same year, we lost 2,117 teenagers from the age of 15 to 19 to suicide and 3,606 young adults from the age of 20 to 24: 5,723 high school and college-age young people combined.

Despite the productive collaboration I experienced with my daughter's school and with the vast majority of her health care providers, I ultimately lost my Natalie to suicide. One of the things I did to cope with my grief was to participate in a family support group of the National Foundation for Suicide Prevention.

As heartbroken as I was, and remain, over my daughter's death, I could not imagine the grief of several parents I met there whose first knowledge their child had mental health issues came in the call notifying them their son or daughter was dead.

Almost without exception, the child's struggles were known to the school but had been kept from the family to protect the child's privacy. For the child, privacy all the way to the grave. For the parent, a lifetime of agony that they had never been given a chance to save their daughter or son.

As Americans, we all cherish our personal freedoms. We must also be cognizant that family members may not recognize mental health symptoms and some may even be contributing factors in a child's mental health dysfunction. Families are not a replacement for a functional mental health system.

But we should be beyond debating the principle of whether it is in the best interest of young people or their communities to exclude family members from the mental health care team. We don't leave family members out of decisions about the care of aging parents with compromised thinking. We don't shut family out of the ER when their loved ones have a medical crisis or are injured in car accidents. Federal law and clinical practice recognize the family's vital role in mental health care. Anything less than universal embrace should be unacceptable.

Our school children are our future. For their sake and ours, the HIPAA training mandates of the 21st Century Cures Act need to be funded and fulfilled so that inclusion, not exclusion, of families is the default.

http://www.peteearley.com/2018/07/25/13305/

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Substance Use Carries Mental Health Risks—Yes, Even Marijuana

Substance Abuse and Mental Health Services Administration
SAMHSA
www.samhsa.gov • 1-877-SAMHSA-7 (1-877-726-4727)

Each year, SAMHSA [the Substance Abuse and Mental Health Services Administration] holds Prevention Day as an opportunity to share best practices and data with professionals who work day in and day out to end the cycles of substance use disorder sweeping our country. It's usually a chance to learn what "preventionists" on the front lines are experiencing, and how our priorities at SAMHSA and their realities intersect.

I had the honor of addressing these health professionals this year—starting with a status report on the nation's opioid crisis, providing updates and ending with a brief examination of the risks of marijuana consumption. As many of you may know, the opioid fentanyl has had a horrific impact on our nation: Its potency and often-stealthy addition to other drugs have caused the surges in fatal overdoses seen in recent years.

Training medical professionals to deliver proven-yet-underutilized treatments for the opioid crisis sweeping our country is important. These professionals are on the front line, serving as medical resources to people who need them. And our Screening, Brief Intervention, and Referral to Treatment (SBIRT) programs rely on their insight and caring.

As SAMHSA trains medical professionals in the evidence-based practices needed to serve people with substance use disorders (SUDs) and serious mental illnesses, we're also working to combine our resources with experts at the local level. To this end, we recently awarded a $12 million technical assistance grant to the American Academy of Addiction Psychiatry that will put federal resources into the hands of local experts to create community-relevant solutions. This effort is a clear example of SAMHSA working to support communities throughout the nation, moving beyond the valuable work performed by our grantees to assist whoever needs to be trained.

Interestingly, it was the second half of my presentation from Prevention Day that garnered stronger responses from supporters and critics alike. "The Elephant in the Room" dealt with marijuana as a drug that carries risks—risks too seldom discussed.

As a clinical psychiatrist specializing in addiction, as someone committed to treating people with substance use disorders, as a concerned American—I cannot stress enough how understated the risks and consequences tied to marijuana consumption are in our nation's dialogue about the drug and about states' respective moves to decriminalize or legalize aspects of consumption.

America has come a long way from the dramatics of "Reefer Madness," the 1930's cult film that railed against the use of marijuana. But, sadly, today, warnings about the drug often are dismissed as outdated propaganda. Amid discussions of decriminalization or of legalizing medicinal use, the topic rarely includes factual examinations of the harm that can come with marijuana consumption. Data show Americans have grown to perceive the drug as less harmful than alcohol and other drug use.

Also ignored are data that speak to how the drug can adversely affect health, can be associated with a decrease in IQ with chronic use, can lead to a number of undesirable social consequences and can reveal a predisposition to serious mental illness.

To that last point, a study of the data shows the risk of schizophrenia increases as marijuana use increases. The data also shows a higher risk of schizophrenia-like psychosis is directly related to younger ages of first marijuana use. It's important to note that there is a distinction between a substance causing psychosis and one revealing a predisposition—the data I present concern the latter.

We know serious mental illness and SUDs often co-occur. And I believe there is room for researching the medical potential of marijuana's components. But pretending that marijuana is a harmless substance is not the way to help our loved ones. It is time for medical professionals to courageously share what the data say, even if the conclusion is a socially unpopular one. Our people—particularly our young people—are depending on us.

Most important, SAMHSA offers supports for people who grapple with substance use disorders—whether tied to marijuana, alcohol, opioids or other substances. We know that, with appropriate treatment, people recover from SUDs. We're working tirelessly to not only connect Americans to these resources, but to also get them back on the path toward fulfilling, productive lives.

March 26, 2018
Dr. Elinore F. McCance-Katz is the Assistant Secretary for Mental Health and Substance Use, and head of SAMHSA.

Update: Study Suggests Cannabis Compound Can Make Schizophrenia Medication Less Effective

New research in mice reveals how THC, the main psychoactive compound in cannabis [marijuana], can reduce the effectiveness of risperidone, an antipsychotic drug used widely to treat people with schizophrenia. Earlier studies have suggested that cannabis use can reduce the effectiveness of antipsychotic treatments and increase rates of psychosis relapse, but the reason has not been clear.

Exposure to THC did not reduce the effectiveness of clozapine, another common antipsychotic drug, said researchers led by 2009 Young Investigator grantee Jonathon C. Arnold, Ph.D., at the University of Sydney, Australia.

The team's study, published in the journal *Neuropsychopharmacology,* found that THC increases the activity of a protein transporter called P-gp, which shuttles drugs such as risperidone out of the brain. This reduces the level of the antipsychotic drug, to the point where it reduces its therapeutic impact.

Why is clozapine not similarly affected? It is not transported by the P-gp protein and is therefore unaffected by THC exposure. This suggests that clozapine might be a good first-line treatment for patients with schizophrenia who use cannabis, say Dr. Arnold and his colleagues.

Posted in enews@bbrfoundation.org
July 27,2018
by Brain & Behavior Research Foundation
Complete link is https://www.bbrfoundation.org/content/study-suggests-cannabis-compound-can-make-schizophrenia-medication-less-effective
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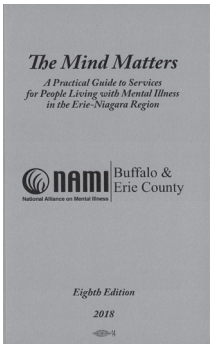

Families and interested others may request a copy of the 2018 ***Mind Matters: A Practical Guide to Services for People Living with Mental Illness in the Erie-Niagara Region*** by calling 716-226-6264 or email your request to namibuffalony@gmail.com. The guide is also available on our website at www.namibuffalony.org

Beef Jerky

Research Weekly: Nitrated Meats and Mania

by Elizabeth Sinclair, Director of Research at the Treatment Advocacy Center (TAC)

New research indicates that nitrates — chemicals used to cure meats such as in beef jerky, hot dogs and other processed meats — may contribute to mania, an abnormal mood state common in patients with bipolar disorder.

(July 24, 2018) Treatment Advocacy Center Board Member Robert Yolken, MD, and colleagues from Johns Hopkins University found that individuals hospitalized for mania had three and a half times higher odds of previously eating nitrated meats than individuals with no history of psychiatric disorders.

Mania is a state of elevated mood and energy that can last anywhere from a week to many months and is generally seen in people with bipolar disorder. Manic states can include delusional thinking and may lead to dangerous risk-taking behaviors.

Eating nitrate-cured meats does not necessarily cause mania, but the results indicate that certain diets and bacteria in the gut may contribute to disorders that affect the brain. The authors replicated the study in rats and found similar results - rats who had been fed nitraterich foods exhibited extreme hyperactivity compared to rats fed a normal diet.

The authors also analyzed ten years of patient records from more than 1,100 patients at Sheppard Pratt Health System in Baltimore, Maryland. While a history of eating cured meats was significantly more likely to result in hospitalization for those with psychiatric disorders and

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manic episodes, eating cured meats was not associated with greater odds of being diagnosed with schizoaffective disorder, bipolar disorder or major depressive disorder.

"We looked at a number of different dietary exposures and cured meat really stood out," says Dr. Yolken. "It wasn't just that people with mania have an abnormal diet."

Nitrates have been previous linked to some cancers and neurodegenerative diseases, but evidence to the validity of the association is mixed.

Dr. Yolken expresses caution in interpreting these results, indicating more research is needed before making any sort of conclusions about dietary changes for individuals with bipolar disorder. However, the research has been gaining publicity already being publicized by national news outlets such as NBC News and The Atlantic. *(emphasis added)*

References:
Khambadkone, S. G. et al. (2018, July). Nitrated meat products are associated with mania in humans and altered behavior and brain gene expression in rats. *Molecular Psychiatry*.

SMRI is a s*upporting organization of the Treatment Advocacy Center, whose mission includes supporting the development of innovative treatments for and research into the causes of severe and persistent psychiatric illness. The Treatment Advocacy Center, which accepts no funding from pharmaceutical companies, also was founded by Dr. Torrey.*

Additional information on this topic may be found at:
Mania Linked to Beef Jerky
http://www.psychiatrictimes.com/bipolar-disorder/mania-linked-beefjerky/page/0/1?rememberme=1&elq_mid=2624&elq_cid=1668134
RESEARCH UPDATE Psychiatric Times Jul 31, 2018

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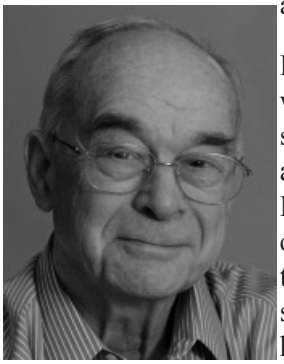
NAMI and Mental Health Advocates Across the Nation Mourn the Passing of Dr. Frederick J. Frese

We are saddened to hear of the death on July 16, 2018 of a former NAMI Board member who has spent his life serving, treating and advocating for those with mental illness.

Buffalo & Erie County chapter members have heard Dr. Frese speak about his journey to recovery and it is an amazing story.



Diagnosed with paranoid schizophrenia as a young Marine Corps officer, he refused treatment and spent years of his life in jails around the country, because of his psychotic state. Finally he ended up in a psychiatric hospital where he not only began his recovery but went on to earn his doctorate in psychology and years later became head of psychological services at that same Ohio psychiatric hospital.

A passionate advocate for those with serious mental illness he believed that a prohibition against "forced treatment" amounted to a sentence to prison, where the seriously ill are often preyed upon.

Frese had a long and distinguished career that included serving two separate six-year terms on the NAMI Board of Directors. He was a major force in bringing the voice of lived experience into NAMI's leadership.

He was also a member of the American Psychological Association Task Force for the Seriously Mentally Ill and was the founding President of the American Psychological Association's Community and State Hospital Section. Fred also served as President of the National Mental Health Consumers' Association.

His is an amazing and inspirational story, and in many ways, he was the living, breathing embodiment of why we advocate for reform of the mental health treatment system; an unfailing voice for the value of treatment and a testament to what can be accomplished by someone with unfailing passion.

Fred was also instrumental in the growth and direction of the Treatment Advocacy Center, serving as a founding board member and on their board for nearly twenty years. From testifying before Congress to appearing on Nightline, he remained a dedicated and hopeful champion for our cause, frequently saying that there is more hope for recovery today than ever before.

His advocacy extended deeply into issues that included support for AOT [Assisted Outpatient Treatment] and CIT [Crisis Intervention Teams], and vigorous opposition to the death penalty in all but the rarest exceptions.

As Dr. E. Fuller Torrey said, "Fred is an extraordinary person who has helped educate a whole generation about schizophrenia as a brain disease and has demonstrated that it is possible to live a full and productive life despite having it."

His voice will be truly missed.

Includes excerpts from
In Memoriam: Board Member, Dr. Frederick J. Frese by John Snook
http://www.treatmentadvocacycenter.org/fixing-the-system/features-and-news/4019-in-memoriam-board-member-dr-frederick-j-frese#.W09xNVyK6D0.facebook
and
NAMI Mourns Fred Frese, Mental Health Champion
https://www.nami.org/About-NAMI/NAMI-News/2018/NAMI-Mourns-Fred-Frese-Mental-Health-Champion

■

"Anosognosia Is Clearly Biological In Origin"
Dr. E. Fuller Torrey Argues That Science Proves It

(3-13-18) An article entitled "The Perplexing Semantics of Anosognosia: Why an obvious phenomena has sparked controversy", written by Dr. Dinah Miller, co-author of COMMITTED: The Battle Over Involuntary Psychiatric Care, drew strong reactions yesterday after I posted it. Among them was this reply from Dr. E. Fuller Torrey, who has been described by The Washington Post as "perhaps the most famous psychiatrist in America."

By E. Fuller Torrey, M.D.

Dear Pete,

Dr. Miller questions the appropriateness of using the term "anosognosia" to describe the lack of awareness of illness in individuals with schizophrenia or other psychosis. In *The Study of Anosognosia* (G.P. Prigatano, ed., Oxford University Press, 2010) anosognosia is defined as "a complete or partial lack of awareness of different neurological… and/or cognitive dysfunctions" which would appear to cover psychoses. She contacted the late Dr. Oliver Sacks who in fact had given an eloquent description of anosognosia in *The Man Who Mistook His Wife for a Hat:*

"It is not only difficult, it is impossible for patients with certain right-hemisphere syndromes to know their own problems – a peculiar and specific 'anosognosia,' as Babinski called it. And it is singularly difficult, for even the most sensitive observer, to picture the inner state; the 'situation' of such patients, for this is almost unimaginably remote from anything he himself has ever known."

Dr. Miller is also incorrect in saying that "we know nothing of the fundamental neural dysfunction" for individuals with anosognosia. Studies of stroke patients have demonstrated that the inferior parietal lobule plays a critical role, especially on the right side. Since 1992, there have been 25 studies comparing the brains of individuals with schizophrenia with and without anosognosia. In all but three studies, significant differences are reported in one or more anatomical structures. Since anosognosia involves a broad brain network concerned with self-awareness, a variety of anatomical structures are involved, especially the anterior insula, anterior cingulate cortex, medial frontal cortex, and inferior parietal cortex. Three of the positive studies included individuals with schizophrenia who had never been treated with medications, discounting the likelihood that the observed brain changes resulted from treatment.

For example, here are descriptions of two recent studies: In Canada at the University of Toronto, 52 individuals with schizophrenia were assessed for awareness of illness (using the relevant item on the Positive and Negative Syndrome Scale (PANSS)) and underwent MRI. Lack of awareness of illness (anosognosia) was strongly correlated with both severity of illness ($p<0.01$) and with total white matter volume ($p<0.01$). Hemispheric asymmetry was evident with the right hemisphere showing less volume than the left hemisphere in patients with impaired awareness of illness, specifically in the anterior end of the inferior temporal lobe ($p=0.05$); the dorsal lateral prefrontal cortex ($p=0.003$); and the inferior parietal lobe (angular gyrus) ($p=0.05$). These findings are consistent with the occurrence of anosognosia in some individuals when stroke occurs in the right hemisphere and suggests that awareness of illness in schizophrenia is likely more associated with to the right hemisphere than to the left.

The authors of the study noted that persons with schizophrenia vary in their degree of anosognosia: "They can have equally bizarre delusions or perceptual disturbances but can be quite dissimilar in their ability to recognize that these experiences arise from their mind rather than a part of objective reality." This combination of insight with profound mental disturbances is one of the most puzzling aspects of schizophrenia for family members." Reference: Gerretsen, P., Chakravarty, M.M., Mamo, D., Menon, M., Pollock, B.G., Raiji, T.K., Graff-Guerrero, A. (2013). Frontotemporoparietal asymmetry and lack of illness awareness in schizophrenia. *Human Brain Mapping,* 34, 1035—1043.

In Canada, researchers at McGill University used magnetic resonance imaging (MRI) to assess 66 individuals with chronic schizophrenia and 33 healthy controls. The Scale to Assess Insight (SAI-E) was used to assess insight into symptoms. Patients with low awareness of symptoms had significantly thinner right insula cortex. The insula is increasingly thought to be a key structure for self-perception. Ref: Emami, S., Guimond,

S., Chakravarty, M.M., Lepage, M. (2016). Cortical thickness and low insight into symptoms in enduring schizophrenia. *Schizophrenia Research,* 170, 66—72.

Thus anosognosia is clearly biological in origin, in contrast to denial which is psychological in origin.

Dr. Miller is correct about one thing—anosognosia is merely a neurological observation and, by itself, has no implications for treatment, involuntary or otherwise. Decisions regarding treatment should be made separately. Thus a woman with Alzheimer's disease and anosognosia who wants to walk outside in the winter without shoes or socks can be allowed to do so or can be involuntarily prevented from doing so. The fact that she has anosognosia does not, by itself, dictate a course of action. Similarly a woman with paranoid schizophrenia and anosognosia may or may not be treated involuntarily depending on other factors.

Dr. E. Fuller Torrey needs no introduction. He is the author of Surviving Schizophrenia: A Family Manual, an early leader and supporter of the National Alliance On Mental Illness, and the founder of the Treatment Advocacy Center.

■

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The Annual Meeting of NAMI's Board of Directors will be held on Tuesday, October 9th at St. Paul's Lutheran Chrch, 4007 Main St., Amherst, NY 14226 at 7:00 p.m. for the purpose of electing new members to the Board of Directors and adoption of new by-laws. The board will also elect new Officers.

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There comes a point where we need to stop just pulling people out of the river. We need to go upstream and find out why they are falling in.
~ Desmond Tutu

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author, advocate, and activist
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