the challenger

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

vol. 7 - Number 3
December 2015

Mark Your Calendar

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. There are two family support meetings on the 3rd Wednesday of the month: one at St. Paul's, on the 1st floor (church entrance at ground level at left rear of the building) and the other, at Lake Shore Behavioral Health, 3176 Abbott Rd., Orchard Park, 14127. Board meetings are held at 636 Starin Ave., Buffalo, 1st floor; members are welcome.

December

NAMI Board Meeting, Tues.,1st, 7 pm
No NAMI Monthly Educational Meeting
Christmas is for Kids Gift Wrap, Sat., 5th
NAMI Family Support Meetings, Wed., 16th, 7 pm
NAMI Awareness & Anti-stigma gift wrap at Barnes & Noble, Niagara Falls Blvd., Sun., 20th, 10am - 2pm

January

NAMI Board Meeting, Tues., 5th, 7 pm
NAMI Monthly Educational Meeting, Thurs., 14th Guest: Nicole Blackwell, Paralegal; Legal Services & Advocacy (LSA) Outreach Coordinator, Mental Health Association of Erie County, Inc. on "Legal Services from the MHA"
NAMI Family Support Meetings, Wed., 20th, 7pm

February

NAMI Board Meeting, Tues., 2nd, 7 pm
NAMI Monthly Educational Meeting, Thurs., 11th Library/Coffee Hour: 7 pm. Program, 7:30 pm Guest: Eileen Trigiboff, DNP on "Stress Management: how to support your loved one without losing who you are"
NAMI Family Support Meetings, Wed., 17th, 7 pm

March

NAMI Board Meeting, Tues., 1st, 7 pm
NAMI Monthly Educational Meeting, Thurs., 10th Library/Coffee Hour: 7 pm. Program, 7:30 pm. Guest: Olivia Retallack, MA, Coordinator Suicide Prevention Coalition of Erie County on "One Hour Suicide Prevention Training: QPR - Question, Persuade, Refer"
NAMI Family Support Meetings, Wed, 16th, 7 pm

President's Corner

With the season of giving upon us, I want to thank those of you who responded to our NAMI Fall Fundraiser. Our generous members and volunteers help make NAMI Buffalo successful and able to offer help when advocacy and compassion are needed. It is the message of Thanksgiving, the spirit of the holidays, and the hope of a new year.

We are engaged in a new effort for the holidays to provide socks, underwear and sweat pants and tops, and Christmas candy treats for inpatients at ECMC this year. If anyone desires to provide a monetary donation or new items as mentioned above, please contact our office. This is a small project for this year and we could expand it next year. We still have the Christmas is for Kids project, but are realizing that the adult population with mental illness needs to be remembered as well.

Rep. Tim Murphy's bill (HR2646), just passed in special committee and will be presented to Congress soon.

Please keep your letters encouraging your legislators to pass this federal legislation. There are other mental health bills pending and we will keep you informed as they come up, through our email bulletins or this newsletter. It is critical that you state what you want specifically and a bit of information why you want it.

I attended a Treatment Advocacy Center (TAC) conference call on November 5, during which Murphy's bill was discussed as well as a TAC study that is on their website (www.treatmentadvocacycenter.org), called "Going, Going, Gone", which is their study by the Stanley Foundation about the effects of the loss of inpatient beds. This is

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

President's Corner *from pg. I*

obvious to us all, but the study needs to be used to influence public policy. On December 15, there will be a report on their study of the recent police shootings and mental illness.

They have information on site about research on evidence-based practices in treatment of mental illness. You may sign on to receive e-news action alerts at this site. The Stanley Foundation is Dr. E. Fuller Torrey's group and known for reliable information. It is another way to become an informed advocate.

I wish all of you happy and peaceful holidays, and good health for the new year.

Marcy Rose,
President
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Sympathy

Our thoughts are with **Ravinder Dua** who we recently learned lost his wife, **Veena**, early this year. Our thoughts go out also to **Josephine Sheahan** and **Mary Regula** who lost their husband and father, Dan Sheahan, in May.

We wish peace and comfort to the family of **Nancy Mariani** in the loss of her son, Michael.

Get well wishes go out to Donna Matecki as she recovers from a mishap; and to **Judy Capodicasa** who has been under the weather.

Did you know?

Acts of Charity Help the Giver, Too

Studies show over and over that there are many benefits to those who give charitably to others from documented results for the giver called "helper's high" or "giver's glow". These benefits can last a lifetime, and include:

- An improved sense of well-being
- Lower stress levels
- Better physical health
- Enhanced emotional health
- Enriched sense of purpose

Thoughts of helping activate the area in the brain associated with happiness--the mesolimbic pathway. This in turn releases dopamine, a neurotransmitter that regulates the brain's centers for reward and pleasure. In addition, the act of giving helps people fight depression and head off illness by increasing the body's protective antibodies. Who knew that giving could do us such good?

Excerpted from:
"Acts of Charity help the giver, too"
Bruce Deboskey
Tribune News Service, Oct. 18, 2015
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Member Notes

Hearty thanks to:

Deb Gabriel, who has stepped down from the NAMI NYS board. We appreciate her service and representation for our chapter at the state level. We are very pleased to have **Lynda Regan** now coming onto our NAMI state board to serve with our president **Marcy Rose** whose term continues.

Judy Capodicasa, retiring from her service in managing membership renewal mailings. It's an important job and she has done it for three years.

Board Treasurer **Jerry Keppel** and Finance committee member, **Richard Rose**, for assisting with accounting operations when our "regulars" were not available.

Welcome to new board of directors member, **Val Coniglio,** and thank you for standing in as mistress of ceremonies at the November education meeting.

Jeanne Figurel for useful, timely write-ups for the newsletter--they are greatly appreciated!

New Family-to-Family Class Set to Begin in January Sign up Now!

The next Family-to-Family Class will begin on Saturday, January 16th at Elma United Methodist Church, 2991 Bowen Rd., Elma. Class will run from 9-11:30 am.

Pre-registration is required for the 12-session class and you need to attend all 12 sessions. Space is limited. To reserve a spot, contact the office at 226-6264.

A Timely Update on the Erie County Medical Center CPEP Unit and Services

Donna Gatti, Director of the Erie County Medical Center Comprehensive Psychiatric Emergency Program (CPEP), recently provided an update on changes at CPEP to our **Family Education meeting (Sept. 2015)**. While she recognizes that there are still several problems that need to be addressed, the changes she outlined were welcome news to those present at the meeting.

CPEP is now located in a new building which is separate from the medical emergency services. Therefore CPEP now has its own Medical Doctors who do the physical assessment which formerly was required to be done in the regular emergency room. Following that, an individual is assessed by a psychiatric nurse, a social worker and a psychiatrist. Social workers are now available 24/7 as part of the Team. She also indicated that Social Workers will soon be assigned to inpatient units for expanded hours as well.

Additional services are available from Mental Health Association Family Advocates, Department of Social Services, Mental Health Peer Connection, Crisis Services, and pastors. These organizations have staff on site at CPEP for up to eight hours a day, five days a week. Family Advocates are providing information, printed material, group meetings, and one on one discussions with family members in the waiting area. Social Services provides assistance with housing, food and other supports for individuals who do not need to stay at the hospital. Peers provide individual and group meetings with people who want to talk with someone who has experienced mental illness and provide information on peer services within the community. Crisis Services (Mobile Outreach) provides community support, monitoring and assistance with necessary links in the community for up to 90 days for individuals who are not admitted but who are unstable and lack natural supports in the community. Pastoral counseling is available upon request.

Extended Observation Beds (EOB) continue to be for individuals who meet the criteria for admission, but are expected to stabilize within three days. The Mobile Outreach Team supports 5 male Crisis beds at the City Mission and 2 female Crisis beds at Cornerstone Manor. As the Crisis abates, individuals can use the resources available at the Mission/Cornerstone for food, clothing, financial assistance, job seeking and linkages to community services and supports. Efforts are also underway to establish Rose House, a national model of peer operated crisis beds, for 5-7 beds in separate residence.

While medications are dispensed in CPEP, medication prescriptions cannot be written in CPEP. Individuals may be seen in the Medication Administration Program (MAP) for a prescription of thirty days of medication if they are unable to get a MD appointment or do not have a psychiatrist. ECMC has decided to use Nurse Practitioners as staff extenders to address the problems in recruiting and retaining psychiatrists. MAP will expand to a community location (1010 Main St.) shortly.

The meeting included a lively discussion of the issues that most concerned family members present at the meeting. Ms. Gatti was responsive to those concerns while helping the audience understand the complexity of some of the problems. Ms. Gatti is aware that there are problems at CPEP that may not be addressed to everyone's satisfaction including the long time spent in CPEP. While there are now over 13,000 admissions to CPEP each year, only 30% become inpatient admissions. Therefore, the question arises as to how many individuals could have received service in another setting. She noted that the admissions from Cheektowaga have declined as the Police Department has fully implemented the Crisis Intervention Teams (CIT) training and supports. Likewise the problems with the current physical space--a noisy gymnasium size layout with beds lining the walls--must balance the need for less chaos and some privacy against the need to have eyes on up to 50 people at a time. Efforts are being made to improve the waiting space for family members including comfortable chairs, available food, TV and other amenities. This is welcome news, but given the hours that family wait there, Ms. Gatti was encouraged to use some of that time to have a Social Worker talk with family and obtain information.

Contributed by NAMI member Jeanne Figurel

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Sunday, December 20th is a NAMI Awareness and Anti-Stigma Barnes & Noble Gift Wrapping Event 10 am - 2 pm

Again this year, NAMI and some of our partner organizations will volunteer for gift wrapping at Barnes & Noble at 1565 Niagara Falls Blvd., Amherst. It's a fun time to get to know each other and tell the story of NAMI's mission and work. You are welcome to join us!

Previous experience is not required, though an ability to wrap and tape is useful. You can sign up for a 4- or 2-hour block of time.

If you don't wrap, you can still come out and support our efforts--and get your books and gifts wrapped! We can verify hours of service for young people who have a community service graduation or merit requirement, too.

To sign up, call Liz at 668-4741 by December 15th.

My Son and Bipolar Disorder. Where is My Casserole?

When my son was diagnosed with bipolar you could've swore I told people he had the plague. No one brought casseroles to my house or offered their support. Yet I got a lot of "I'm sorry" and very pitiful looks, as if my son had been diagnosed with a terminal illness. Mental illness is a lifelong battle but it is treatable and not terminal.

Why does society view it so differently? Why are they so afraid of it? Why are people with mental illness treated like outcasts? Society is definitely afraid of what they do not understand. Just because you can't see it doesn't make it any less important. Why is there such a stigma attached to it and how to we dispel it?

If I were to tell those same people my son had cancer I am sure their reaction would've been much different. I am sure my neighbors would be dropping off casseroles and offering their support. I am sure I would have a list of doctors I could choose from. I am sure I wouldn't have to wait weeks or months to see a specialty doctor. I am sure we wouldn't have to spend hours upon hours in an emergency room waiting to get treatment or find an open bed. I am sure we would have options for hospitals stays and they would cater to sick children. I am sure my insurance company would let my son get treatment and not given me a certain number of days in a calendar year or an expenditure cap. I am sure someone would be throwing me a benefit or a go fund me page to help defer the rising costs of treatment. I am sure there would be lots of funding for research. I am sure there would be fundraising events for research and people would be raising awareness. I am sure the community would be rallying for his recovery. I am sure people would care!

So why don't people care that my son has bipolar? He was just 10 years old when he was diagnosed. A sweet young innocent boy who had no control over his mood swings. A victim of his own brain. I wasn't a bad parent, he wasn't raised in a bad environment, it is NOT a behavior problem and he DOES NOT choose to be this way!!! Just because he looks "normal" doesn't mean he isn't sick. You can't see diabetes or epilepsy, multiple sclerosis, or cancer for that matter and still they don't get the bad wrap mental illness does.

Is it the name? Mental? Does society view it as something you should have control over? The more I am submerged in this world the more I am noticing the number of people who don't suffer from some type of mental illness seems to be minimal. If the statistics show that 1 in 4 people suffer from a mental illness it would seem we have an epidemic on our hands and yet we haven't progressed with education, awareness, or research funding. It's been 12 years since my son was diagnosed and the struggles parents are going through today hasn't changed much since he was diagnosed. That is very sad to me.

I want someone to bring me a casserole. I want people to send me well wishes. I want my son to get fair treatment for his illness. I want him to be in a hospital without white walls and bars on the windows. I want him to not have to be strip searched for his stay in the hospital. I want him to have a doctor it doesn't take weeks to get in when he is sick. I want him to have insurance coverage that doesn't have a bunch of red tape. I want research funding and fundraisers. I want him not to be afraid to tell people about his illness.

I want fair treatment and recovery.

I want him not to be judged.

I want him to have a fair chance in society without stigma!

Julie Joyce is a Chicago Police Officer and the mother of an adult son who suffers from Bipolar and ADHD disorders. Over the years Julie has been a strong advocate and volunteer with National Alliance for Mental Illness, (NAMI), The Balanced Mind Foundation (TBMF), and has assisted with the creation and implementation of the Advanced Juvenile Crisis Intervention training (CIT) for Chicago Police officers. She is certified by the Federal Bureau of Investigation Hostage Negotiation Team as a Crisis Negotiator, has conducted presentations on mental illness for Attorney General Lisa Madigan's Office and has had the opportunity to speak to legislatures on the need for special education funding. Julie has also conducted educational presentations for DCFS on interventions for kids with mental illness. Along with her son, she was interviewed on NPR, WBEZ, for the "Out of the Shadows" series which focused on juveniles and mental illness. Currently, Julie spends her time raising awareness and advocating for people living with mental illness.
Copied with permission from bp Magazine's Blogging Community at www.bphope.com

Blogger: Julie Joyce October 5, 2015
URL to article: http://www.bphope.com/blog/my-son-and-bipolar-disorder-where-is-my-casserole/

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bp MAGAZINE Welcome to bphope! .com HOPE AND HARMONY FOR PEOPLE WITH BIPOLAR

Speaking out against media stigma

Thank you, Dr. Borenstein

Dear Marcy,

I want to share with you a recent email exchange I had with the New York Times. On Monday, September 28 I sent a letter to the editor and the public editor about the inappropriate use of the word schizophrenic in this article - The Daily News Layoffs and Digital Shift May Signal the Tabloid Era's End. Unfortunately they have not published my letter. I did however receive a response from the office of the Public Editor and I am quite pleased that they acknowledged my letter.

I am hopeful that the misuse of words for mental illness will not happen again in the New York Times. Should you come across anything similar in any print or online publication please do not hesitate to let me know.

Sincerely,

Jeffrey Borenstein, M.D.

To the Editor:

A story about the possible demise of tabloid journalism (The Daily News Layoffs and Digital Shift May Signal the Tabloid Era's End, September 27th) referred to the The Daily News' "… schizophrenic mix of titillating crime reportage and hard-hitting coverage of public issues."

For those of us who deal with the devastating effects of schizophrenia—psychiatrists, patients, families and caregivers —the use of this medical term as a negative metaphor is both deeply offensive and inaccurate. Schizophrenia is a severe, chronic brain and behavior disorder that causes mental disturbances that disrupt normal thoughts, speech, and behavior.

While it is common to hear terms such as "schizophrenic" and "bipolar" used to describe erratic behavior, it doesn't make their flippant usage any less objectionable. It also underscores a need to educate the public—including reporters and editors—about how to speak respectfully about people with mental illness, which affects one in four people.

Though it may seem trivial to some, we must be vigilant about how we speak about mental illness. When the New York Times misuses the word schizophrenia, it reinforces the kind of negative stereotypes and stigma that lead people to suffer in silence rather than seek help.

Prejudice against the mentally ill hampers efforts to fund research, improve diagnosis and access to treatment, and, ultimately, find cures.

The English language is full of words that would more accurately describe the stories that appear in The Daily News. Please make this the last time that the term schizophrenia is used in this inappropriate way.

Sincerely,

Jeffrey Borenstein, M.D.

President & CEO

The Brain & Behavior Research Foundation

This is the response I received:

Dear Mr. Borenstein,

Thank you for taking the time to write. I understand your concerns, and have also forwarded your email to The Times's standards desk, which monitors the paper's word choices, usage and style. As our office has no role in determining the letters that are selected for publication, you've done the right thing by contacting The Times's letters editor.

Again, thank you for writing and raising our awareness about this. Our office will certainly keep your points in mind.

Best regards,

Joumana Khatib

Office of the Public Editor

The New York Times

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Special thanks to Parkview Health Services for new support for the upcoming Mind Matters. We hope to have the new edition ready in early 2016.

Changes Announced for Monitoring Clozapine to Improve Delivery of Treatment, Increase Access

What makes clozapine a unique and effective antipsychotic? As I detailed in my recent Advocate piece, Clozapine is the only FDA-approved medicine for treatment resistant schizophrenia. It's been found to be effective in treatment resistant schizophrenia and in reducing the risk of suicide in people who have schizoaffective disorder or schizophrenia. I feel it is underutilized, and have seen many good outcomes on this medication. The one caveat of this medication is that it requires vigilance to monitoring of medical side effects.

A recent announcement by the FDA stated that beginning October 15 it will change the approach to monitoring clozapine. There are two key areas that are being changed, which both strike me as substantial improvements. The changes address a rare but serious side effect of clozapine, which is the reduction of a specific type of white cells called neutrophils. For those taking clozapine, having their blood drawn on a structured schedule monitors their neutrophil counts (the schedule is not changing as a result of these changes). Greatly reduced neutrophil counts can lead to risk of infection or death, which is why monitoring for this risk is incredibly important. This is especially true during the first six months of treatment when the risk is greatest.

Here are the announced changes to monitoring clozapine:

1. There will only be one centralized clozapine registry, called the Risk Evaluation and Mitigation Strategies (REMS). REMS will keep track of a person's neutrophil counts to be sure no one who has too low of a count gets the medicine. Currently there are six different registries, and this can cause delays as well as increasing the chance for error. This change to one registry will streamline the monitoring component of clozapine. If you have any questions, ask your local pharmacy or staffer who runs your clozapine clinic.

2. Clinically, the new changes will allow for more physician and patient discretion in some situations that involve a low neutrophil count. Some individuals have low counts even before they start the treatment, which has shown to be more common in some ethnic groups. This is called Benign Ethic Neutropenia or BEN. The FDA is allowing these individuals to review the risks and benefits of taking the medicine with their doctor. In short, it allows for more clinical flexibility and shared decision making than the more absolute structure of the older system. Questions? Ask your prescribing doctor.

NAMI National Blog by Ken Duckworth, M.D. | Sep. 25, 2015

Blog at: https://www.nami.org/Blogs/NAMI-Blog/September-2015/Changes-Announced-for-Monitoring-Clozapine-to-Impr#

http://www.nimh.nih.gov/news/science-news/2015/our-brains-secrets-to-success.shtml

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Our Brain's Secrets to Success?

Unique support system promotes cortex growth, connectivity linked to prowess

Discoveries about how the human brain contributes to our success – both as a species and as individuals – are among the first fruit of projects funded under the National Institutes of Health Brain Research through Advancing Innovative Neurotechnologies® (BRAIN) Initiative program as well as the Human Connectome Project . One study may help to explain the mystery of how our primate brain's outer mantle, or cortex, was able to expand as much as 1000-fold through evolution, compared to other mammals. The other reveals that the more successful we tend to be – score higher on commonly considered positive personal qualities, such as education and income levels and life satisfaction – the more key parts of our brain tend to talk with each other when we're not doing anything in particular.

A team of BRAIN Initiative-supported scientists, led by Arnold Kriegstein of University of California, San Francisco, reported in Cell, Sept. 24, 2015, on what may be the secret to the human cortex's exponential growth. Another team led by Stephen Smith of University of Oxford, UK, and David Van Essen, Washington University, St. Louis, explains findings linking brain connectivity to measures of personal success Sept. 28, 2015 in the journal Nature Neuroscience. The studies were funded, in part, by the National Institute of Mental Health (NIMH) and other NIH components.

Kriegstein and colleagues found that the human cortex harbors a unique support system for neuron-producing factories during early brain development — in outlying cellular neighborhoods that barely exist in lower animals. The researchers discovered the molecular underpinnings of this unique group of stem cells that churn out thousands of neurons and support cells where their mouse counterparts produce only 10-100. They also discovered that the secret to this prolific output seems to lie in these cells' ability to carry with them their own self-renewing "niches," — support systems that enabled them to thrive in far flung circuit suburbs. The results add to a deeper understanding of the human brain's parts list and enhance scientists' ability to perform disease-in-a-dish experiments relevant to uniquely human disorders like autism and schizophrenia, which are difficult to model in rodents.

Smith's group mined Human Connectome Project data on 461 individuals to find out whether any patterns of brain connectivity are associated with specific sets of correlated demographics and behavior. In addition to images of their resting state structural and functional brain connections, the Project collected data on 280 such subject measures,

Support System *cont's. pg. 7*

Support System *cont'd from. pg. 6*

including psychological factors such as IQ, language performance, rule-breaking behavior and anger. A set of such measures statistically related to each other emerged as strongly correlated with connectivity between certain brain structures prone to talking with each other during the brain's default mode, or resting state. This set was mostly composed of positive personal qualities, such as high performance on memory and thinking tasks, life satisfaction, years of education, and income. The set turned out to have a more than three-fold stronger correlation with increased brain connectivity than any of 99 other sets of measures examined. The brain regions associated with the set, which may be related to general intelligence, have been linked to higher-level human thinking – e.g., memory, imagination, sociability, value-guided decision-making and reasoning.

"It may be expected that these aspects of cognitive function would have an influence on life in a complex society," note Smith and colleagues. "It is great to see data from large investments like the Human Connectome Project and the BRAIN Initiative result in such interesting science so quickly," said Greg Farber, Ph.D., director of NIMH's Office of Technology Development and Coordination. "Both efforts seem very well positioned to continue to provide the research community with new tools and results to enhance our understanding of the brain."

Press release from National Institutes of Health/National Institute of Mental Health, Sep. 28, 2015

References:

Molecular Identity of Human Outer Radial Glia during Cortical Development. Pollen AA, Nowakowski TJ, Chen J, Retallack H, Sandoval-Espinosa C, Nicholas CR, Shuga J, Liu SJ, Oldham MC, Diaz A, Lim DA, Leyrat AA, West JA, Kriegstein AR. Cell. 2015 Sep 24;163(1):55-67. doi: 10.1016/j.cell.2015.09.004. PMID: 26406371

A positive-negative mode of population covariation links brain connectivity, demographics and behavior. Smith SM, Nichols TE, Vidaurre D, Winkler AM, Behrens TEJ, Glasser MF, Ugurbil K, Barch DM, Van Essen DC, Miller Kl. Nature Neuroscience, September 28, 2015.

N.B. Research and studies like these provide a foundation for future efforts to address brain disease or dysfunction, and to determine whether higher level brain activity can be stimulated or increased to improve individuals' ability to make decisions or reason out solutions to problems. With better understanding of early brain development, and how different parts of the brain are connected and work together, science may provide more effective ways to help people who have conditions like autism and schizophrenia.

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Special Ops commander tries to lessen the stigma of getting help

By Laura Koran
Updated 7:21 AM ET, Tue October 6, 2015 (Excerpt)

Fort Bragg, North Carolina (CNN) The head of the U.S. military's most elite forces doesn't just talk the talk of ending the stigma of seeking mental health help. He has walked the walk -- into the counselor's office himself.

Army Gen. Joe Votel, commander of U.S. Special Forces Command, has used the support programs offered by the U.S. military for his own family. "We went down and took advantage of some family-life counselors that were available to us," he told CNN in a recent exclusive interview, though he didn't elaborate further. "It was right there available to everybody, and we took advantage of it."

The 35-year veteran of Special Operations has a message for his troops: "Is it is absolutely normal and expected that you will ask for help."

His time in the military has taught Votel that the demands of constant training and prolonged deployments can take a toll on troops and their families. "The injuries that our people deal with aren't always physical ones," said Votel. "These are hard-charging people. They suppress stuff and

Special Ops *cont's on pg. 8*

BPC Announces
New Rapid Access
and Central Intake

Buffalo Psychiatric Center (BPC) is pleased to announce that they now offer Centralized Intake for their eight outpatient mental health centers located throughout Western New York. Central Intake allows for rapid access to mental health clinical services at any of their locations with early morning and evening appointments available.

Their staff's goal is to treat individuals affected by the full spectrum of mental health disorders including serious mental illness.

BPC has a variety of services available to patients at their sites; including mobile services and a Wellness Center, fully equipped with state of the art fitness equipment, full court gym, and swimming pool.

To refer a patient to one of their locations:
please call 716-816-2218

What Can We Do About Stigma?

A study by Allerby and colleagues focuses on stigma experienced by relatives of individuals with mental illness in the Swedish COAST Study. Stigma's mark—shame and disapproval—extends beyond individuals who struggle with mental illness, touching their families as well. So-called "associated stigma" affects family members or close friends. Blame and "contamination" are particularly salient dimensions of associated stigma. It was not long ago that the "refrigerator" mother was thought to cause schizophrenia, underscoring the fact that even early causation theories pointed a blaming finger at parents. Families also experience "anticipated stigma" in which they avoid circumstances or events, concerned about others' stigmatizing attitudes and beliefs.

What are the impacts of associated stigma? The COAST study showed that stigma contributed to worse quality of life and increased burden. At the National Alliance on Mental Illness (NAMI)–NYC Metro, we hear from family members who feel stress and worry that others—friends, family, and associates—judge their family's private life, medical treatment choices, and genetic traits. Many say that stigma delayed them from helping their relative seek treatment and interferes with their family relationships and ability to pursue support. They acknowledge frustration and sadness when trying to explain the cause of illness to others. Embarrassment can ensue when people find their relative's behavior socially unacceptable. These experiences cause family members to withdraw from social situations and even publicly minimize or conceal their relative's condition. They feel discouraged and may give up hope for a good quality of life and choose to withdraw from their ill relative, even though being a part of a well-functioning family is important to recovery.

Is associated stigma still a problem? Has society become more enlightened and accepting? Advocates, consumers, and family members have undoubtedly made progress in combating stigma and associated stigma. The COAST study showed that only 18% of family members of individuals with schizophrenia reported experiencing stigma. The authors give possible reasons for this finding: family members were recruited from outpatient clinics rather than from family-oriented advocacy groups or family network meetings, and less than one-tenth of participants lived with their ill relative. It is also likely that the culture and services provided in Sweden helped to minimize stigma. If stigma is measured only among family members of individuals receiving services, then those whose experience of stigma is severe enough to inhibit service use have no voice. Many studies have demonstrated far higher rates of associated stigma than found in the COAST study; undoubtedly, the prevalence of

***Stigma** cont's on pg. 9*

***Special Ops** cont'd from pg. 7*

it comes out later, and so we have to have the capability to take care of that."

He particularly wants his troops to know that even with the stigma that has historically attached to seeking help for post-traumatic stress in the military, going to a counselor won't hinder their careers.

"If you hurt yourself doing (physical training) in the morning, you go to the doctor and be taken care of ... and it's the same way if you're having stress or emotional issues," Votel said. "We want you to come forward." Special Operations Command does not maintain statistics on post-traumatic stress cases because of privacy prohibitions, but a 2012 Department of Veterans Affairs study found that 30% of service members who fought in Iraq or Afghanistan received the diagnosis.

Votel noted, "I'm as vulnerable to it as anybody." Suicide is of particular concern because the Special Operations community has historically experienced it at a higher rate than conventional forces. In recent years, the command invested in offering support resources for its personnel to tackle the issue. Votel's predecessor, Navy Adm. William McRaven, created the Preservation of Force and Family initiative for exactly this reason, and the effort seems to be paying off.

While suicide rates fluctuate, they trend downward in the Special Operations community. While they stood at 23 among Special Operations personnel in 2012, they have decreased each year since then to total just 12 so far in 2015. Despite this progress, Votel says his command will remain vigilant when it [the suicide rate] comes [out], addressing all-too-prevalent emotional and mental conditions, both for his men and for himself. "My command psychologist always comes in and gives me a rundown on the things that are happening in the command, and things that she is seeing."

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***Stigma** cont'd from pg. 8*

associated stigma is influenced by many issues, such as culture and education. It is not surprising that in the community of individuals served by NAMI, rates of associated stigma seem to be far greater.

What can we do about associated stigma? We should continue to call attention to it and educate the public on how stigma, including associated stigma, impedes help seeking and treatment participation. NAMI works to reduce the emotional, mental, and economic toll caused by damaging stereotypes, prejudicial beliefs, and discrimination. NAMI's local affiliates offer free evidence-based programs, such as the 12-week Family-to-Family education program for family caregivers of individuals with mental illness. NAMI–NYC Metro has recently completed an evaluation that replicates initial findings about the effectiveness of Family-to-Family. NAMI offers a host of other programs, including Ending the Silence, Provider Education, and In Our Own Voice.

Beyond services and support, NAMI is initiating an action-based campaign, Stigmafree, to eliminate barriers and stereotypes that so often prevent people from getting needed help. Individuals, companies, campuses, community groups, and faith communities will be challenged to take the pledge to be stigma free and agree to learn about mental health; to see the person and themselves, not the illness; and to take action. NAMI–NYC Metro has initiated an award-winning social media–based mental health campaign called #IWillListen (www.IWillListen.org) to create awareness of the prevalence of mental illnesses and reduce the stigma associated with them. #IWillListen encourages people to listen to their friends, family members, and colleagues with an open mind and without judgment when it comes to mental health. Many schools, businesses, and communities have used the #IWillListen program at their campuses, offices, and locales to raise awareness of mental health. We cannot afford complacency.

Barbara Ricci, B.A., Lisa Dixon, M.D.
Psychiatric Services
Volume 66 Issue 10, October 01, 2015, pp. 1009-100

Ms. Ricci is board president and Dr. Dixon is on the board of NAMI-NYC Metro. Dr. Dixon is also director of the Division of Mental Health Services and Policy Research, New York State Psychiatric Institute
■

With thanks to renewing members and a warm welcome to new ones:

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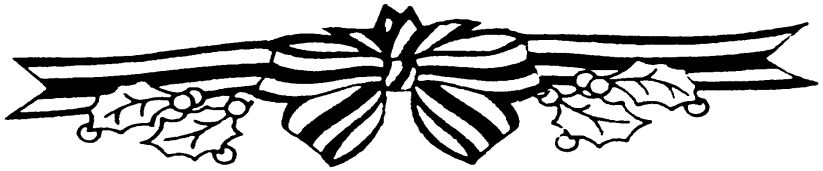

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