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.

January
NAMI Board Meeting. Tuesday, January 6th, 7 p.m.
NAMI Monthly Educational Meeting, Thursday January 8th
Library and Coffee Hour: 7 p.m. Program: 7:30 p.m.
Speaker: Jennifer Seib, LMHC, CASAC, Director of Chemical Dependency at BryLin Topic: Adolescent Substance Abuse
NAMI Family Support Meetings, Wednesday, January 21st, 7 p.m.

February
NAMI Board Meeting, Tuesday, February 3rd, 7 p.m.
NAMI Monthly Educational Meeting, Thursday, February 12th
Library and Coffee Hour: 7 p.m. Program: 7:30 p.m.
Guests: Tara Karoleski, Coordinator of SPOA and Lisa McNeil, Assistant Coordinator of SPOA. Topic: Adult SPOA (Single Point of Access), ACT, AOT & housing and an overview of services & linkages provided by the Erie County Department of Mental Health
NAMI Family Support Meetings, Wednesday, February 18th, 7 p.m.

March
NAMI Board Meeting. Tuesday, March 3rd, 7 p.m.
NAMI Monthly Educational Meeting. Thursday, March 12th
Library and Coffee Hour: 7 p.m. Program: 7:30 p.m.
Guest: Jack Guastaferro, CEO, Restoration Society. Topic: Overview of Services including Incarceration Diversion Program for Homeless
NAMI Family Support Meetings, Wednesday, March 18th, 7 p.m.

April
NAMI Board Meeting, Thursday, April 7th, 7 p.m.
NAMI Monthly Educational Meeting. Thursday, April 9th
Library and Coffee Hour: 7 p.m. Program: 7:30 p.m. Guest: Michael Ranney, Dir. Intensive Svcs. Erie County Dept. of Mental Health. Topic: Mental Illness & the Correctional System in Erie County
NAMI Family Support Meetings, Wednesday, April 15th, 7 p.m.
NAMI 31st Annual Dinner and Awards, Thursday, April 30th, 6:00 p.m. Sean Patrick’s, 3480 Millersport Hwy., Getzville

President’s Corner:

I am gladly relinquishing the space reserved for the President’s Corner in this issue to a consumer who writes poignantly about his reasons for wanting Representative Tim Murphy’s Bill to pass. Keep in mind that even though the bill was called H.R. 3717 in 2014, it will be assigned a new number very soon for 2015. Please look for legislative reminders about this in your emails from NAMI Buffalo. If you want to receive these notices, be sure to send our NAMI office your email address. (716-226-6264 or namibuffalony@gmail.com). Your advocacy is very important!

Reasons to Support the Mental Health Crisis Act
By Dustin DeMoss


H.R. 3717 currently has 115 House co-sponsors, of which 77 co-sponsors are Republican and 38 co-sponsors are Democrats. Importantly, Rep. Eddie Bernice Johnson (D., Tex.), a liberal Democrat, member of the Black Caucus and former psychiatric nurse, has co-sponsored the legislation. The latest action on this bill was on April 3, 2014, when Rep. Murphy chaired a subcommittee hearing.

After the first anniversary of the Newtown, Connecticut tragedy, it has become incumbent upon lawmakers in the next Congress—the 114th Congress—to pass H.R. 3717, which Rep. Murphy is expected to reintroduce with a different bill number but same bill name:

(See H.R. 3717, cont’d on pg. 2)
Expanding these veteran court programs is not only a great preventative measure, but it will be certain to assist in decreasing the number of suicides—22 a day—that is becoming a painful statistic for our nation. There are many times when I could have had contact with the law, because of things I was doing as a result of my mental illness untreated. This program could help any veteran that comes in contact with the law. I know many of the veteran court program cases deal with addiction treatment. It will help veterans seek mental illness treatment as well.

Additionally, the bill helps many people who are in our prisons with serious mental illness. It expands treatment for those in prison. It seeks “to enhance the capabilities of a correctional facility to identify, screen, and treat inmates with a mental illness, as well as develop and implement post-release transition plans for them.”

Those in U.S. prisons don’t get adequate mental health care. The fact that severe mental illness often leads to prison requires that we adequately treat prisoners. Additionally, they must be treated with dignity and respect.

While H.R. 3717 doesn’t fix everything that is wrong with our broken mental health care system, it tackles some important issues. It’s time to get this bill on President Obama’s desk. We need House of Representative members to pass H.R. 3717. We need senators to pass the legislation on the Senate side. And we need President Obama to sign the bill, to help families everywhere. Please contact your legislators in moving this bill forward.

Follow Dustin DeMoss on Twitter: www.twitter.com/DustinDeMoss

Posting: 01/05/2015 1:58 pm EST
Updated: 01/05/2015 1:59 pm EST

A Big Thank you!
...to co-chairs Mary Kirkland and Tom McNulty as well as the many, many people and organizations that collected gifts, moved them, and wrapped and delivered this year’s Christmas is for Kids project, once again helping bring the holidays to over 600 children in care in WNY. Special thanks to Lake Shore Behavioral Health for the assist with van transport.

...to Liz Carone, for coordinating a very successful gift wrapping/ awareness event with Barnes & Noble, Amherst. NAMI members Brenda Lehman, Stephanie & Julia Maines, Fran Smith, Sherry Byrnes, and several folks from Lake Shore Behavioral Health also assisted, as well as Patti Voight.

...to Liz Carone and Marilyn Green for their help in developing sponsors for our next edition of “The Mind Matters”

...to Mary, Jim, and Suzanne Kirkland for help on mailings.

...to Lynn Matthews for facilitating the southtowns family support group.

...to Linda Mallia for her excellent work as chair of the legislative committee.

Remembering...
the families of those who have recently lost a loved one:

Dr. Abel Fink, Joe & Mickey Rugnetta, Deborah Riches in the loss of her son, Jacob; and Doris Sielski in the loss of her husband, Steven; and the family of Karen and Rudy Kristich in the loss of Karen’s sister Diana Houseknecht, wife of Erie County Mental Health Association Executive Director, Ken Houseknecht. NAMI is sorry for your families’ losses.
Every parent and family member wants to insure the financial stability of their disabled adult child. Too often, however, their efforts can threaten the important public benefits that assure medical care, prescriptions, housing, income and supplemental food support. The disabled individual wants to be employed, but shares his family’s concerns about the barriers or risks to these benefits. With expert legal advice, both of these issues can be addressed; the former with a carefully designed Trust and the latter with the Social Security Redbook and development of PASS Plans.

In December 2014, Congress passed a Bill, Achieving a Better Life Experience (ABLE) Act of 2014 which simplifies the process of reducing assets which are a barrier to qualifying for benefits. The ABLE Act allows individuals with disabilities identified before the age of 26 to create a tax exempt savings account that can be used for maintaining health, independence, and quality of life. As Michael Morris, Executive Director of the National Disability Institute (NDI) notes, “this is the first time...policy on disability recognizes that there are added costs to living with disability.”

Each individual with a significant disability, that which meets the criteria for SSI or SSDI, and whose disability was established before age 26, is eligible to open an ABLE account. If the person is not actually receiving SSI/SSDI, there will be procedures for proving that he meets the functional limitations of SSI. Once eligibility is established, the individual may open an ABLE account. Individuals, their family members, and friends may contribute up to $14,000 (the gift tax exempt amount 2015) annually. The maximum cap for the account is the current cap for State 529 college savings account. In New York, that is $375,000 for 2014, but many states are imposing a state limit of $300,000 for ABLE accounts regardless of the state cap on 529 Plans. Once the ABLE account reaches $100,000, the individual would be suspended from SSI benefits and no longer receive that monthly income. The individual, referred to as the beneficiary of the account, would continue to be eligible for Medicaid.

The funds in an ABLE account are not considered assets for the purpose of qualifying federal benefits such as TANF, Medicaid, food stamps and subsidized housing. The contributions to the account are not tax deductible, but any earnings or interest on the funds are tax exempt.

The US Department of the Treasury will issue regulations during 2015. These regulations will specify how to apply for an account which may differ by state and may further specify what the funds may be used for. In general, allowable expenses are “qualified disability expense” meaning any expense related to the disabled beneficiary as a result of living with a disability. This is expected to include education, housing, transportation, personal support services, health care and financial management. No accounts can be opened until the regulations are fully approved. More information on the ABLE Act is available in writing and also in a video on YouTube (Ten Things you need to know about ABLE Accounts). Additionally, see: www.omh.ny.gov/omhweb/resources/newsltr/2015/january/january-omh-newsletter.pdf

The ABLE account can be accessed by the state, upon death of the beneficiary, to repay Medicaid expenses paid by the state. Since this is not true of certain Trusts, the individual and his family may want to use both tools for the most control over the funds. ABLE accounts provide the most flexibility for the beneficiary to make individual decisions about how to use the funds.
Ziprasidone
(Marketed as Geodon and Generics):
May Cause
Rare But Potentially Fatal Skin Reactions

The FDA is warning that the antipsychotic drug ziprasidone (marketed under the brand name, Geodon, and its generics) is associated with a rare but serious skin reaction that can progress to affect other parts of the body. A new warning has been added to the Geodon drug label to describe the serious condition known as DRESS. DRESS may start as a rash that can spread to all parts of the body. It can include fever, swollen lymph nodes, and inflammation of organs such as the liver, kidney, lungs, heart, or pancreas. DRESS also causes a higher-than-normal number of a particular type of white blood cell called eosinophils in the blood. DRESS can lead to death. Patients who have a fever with a rash and/or swollen lymph glands should seek urgent medical care. Health care professionals should immediately stop treatment with ziprasidone if DRESS is suspected.

The FDA reviewed information from six patients in whom the signs and symptoms of DRESS appeared between 11 and 30 days after ziprasidone treatment was started. None of these patients died. Ziprasidone is an atypical antipsychotic drug used to treat schizophrenia and bipolar I disorder.

(FDA Safety Announcement 12/11/2014)

B vitamins to enhance treatment response to antidepressants in middle-aged and older adults: Results from the B-VITAGE randomised, double-blind, placebo-controlled trial

The study aimed to determine whether vitamins B6, B12 and folic acid enhance response to antidepressant treatment over 52 weeks. Findings revealed that B vitamins did not increase the 12–week efficacy of antidepressant treatment, but enhanced and sustained antidepressant response over 1 year. Replication of these findings would mandate that treatment guidelines adopt the adjunctive use of B vitamins as a safe and inexpensive strategy to manage major depression in middle–aged and older adults.

Methods
- Randomised, double-blind, placebo-controlled trial of citalopram (20-40 g) together with 0.5 mg of vitamin B12, 2 mg of folic acid and 25 mg of vitamin B6 for 52 weeks.

Participants were community-dwelling adults aged 50 years or over with DSM-IV-TR major depression.

The authors measured severity of symptoms with the Montgomery-Åsberg Depression Rating Scale (MADRS).

The primary outcome was remission of the depressive episode after 12, 26 and 52 weeks.

Secondary outcomes included reduction of MADRS scores over time and relapse of major depression after recovery by week 12.

Results
- In total, 153 people were randomised (76 placebo, 77 vitamins).
- Remission of symptoms was achieved by 78.1 and 79.4% of participants treated with placebo and vitamins by week 12, by 76.5 and 85.3% at week 26 and 75.8 and 85.5% at week 52 (effect of intervention over 52 weeks: odds ratio.
- Group differences in MADRS scores over time were not significant.
- The risk of subsequent relapse among those who had achieved remission of symptoms at week 12 was lower in the vitamins than placebo group.

Almeida OP, et al
The British Journal of Psychiatry, 12/10/2014

Continues next column
Writing about involuntary treatment is harder than you might think

There are many controversies in psychiatry, but the most controversial issue continues to be that of involuntary treatment. Over the past year, I have been working on a book on forced care, along with Dr. Annette Hanson, the forensic psychiatrist who also writes this Shrink Rap News column. The work I’ve been doing for the manuscript – identifying and interviewing the people with a stake in the issue – has placed me in a funny role of being more journalist than physician. It’s a role I mostly love, and if you’ve hit the midpoint of your career and have an opportunity to dedicate some of your time to doing something completely different, I highly recommend shifting gears for a little while.

One of the things I have found most surprising is the reactions of people when I ask to include them. While most people are willing, almost all hesitate a little. Some are quite eager to participate, and one group in Richmond who uses involuntary electroconvulsive therapy heard of my project and extended an invitation for me to come visit, interview them, watch the procedure, and speak with one of their patients. Many people are proud of the work they do and eager to showcase it; they want to have their viewpoint included. With others, I have needed to ask repeatedly, listen to their concerns, and offer reassurances. I’ve taken to telling people they can read a draft of what I write about them – I learned early in the process that without this offer, few people would be willing to speak to me.

I wish I could say that I’ve noticed a pattern to who is comfortable speaking and who is not. Many of the psychiatrists and researchers I’ve approached have given their time willingly without hesitation (or at least without that much hesitation), including Dr. E. Fuller Torrey; Dr. Paul Appelbaum; Jeffrey Swanson, Ph.D.; Dr. Steven Sharfstein; Dr. Daniel Fisher; Vermont Psychiatric Society President Margaret Bolton; Dr. Bruce Hershfield; and American Psychiatric Association President Paul Summergrad, to name just a few of the many people who have shared their

(Shrink Rap cont’s on pg. 6)

Save the Date!
Thursday, April 30th for
NAMI’s Annual Dinner and awards
at Sean Patrick’s restaurant, Getzville.

Our keynote speaker this year is Maj. Charles S. “Sam” Cochran (ret.). Sam is nationally known for founding the Memphis, Tennessee CIT (Crisis Intervention Teams) training model. Sam began that work in 1988, after a police officer shot and killed a man who had a mental illness. He has worked with police departments as well as NAMI state organizations and chapters across the country to implement CIT in hundreds of communities to keep everyone safe in moments of crisis answered by first responders. He’s a both dynamic and educational speaker.

This will be a “don’t-miss” event!
Invitations will go out soon.
For more information, contact the office at 716.226.6264

Please remember
NAMI in Buffalo & Erie County
in your will and estate planning.
Your gift will support better lives for families and individuals who live with mental illness far into the future.
time, experiences, and wisdom with me. It was not as easy for me to find a psychiatrist I could observe working on an inpatient unit, and the project might have been halted in its tracks if not for the enthusiasm of Johns Hopkins psychiatry chair Raymond DePaulo, who allowed me to shadow his team while they tended to inpatients. It was surprisingly easy to find a Crisis Intervention Team police officer to ride with, a little more effort to engage a mental health court judge.

Those who oppose forced treatment initially were more difficult to engage, but with perseverance, I was able to persuade the leadership of MindFreedom International to speak with me, and well, I ambushed a barely willing Scientologist while I was in New York for APA last May. In terms of patient participation, this hesitation did not hold true – many people volunteered to speak with me about how involuntary treatment harmed them, and it was much more difficult to find patients who felt helped by the treatment that was thrust upon them. Two absolutely wonderful women gave generously of themselves so that this project would have real voices to it: both “Lily” and “Eleanor” relived difficult experiences for me and allowed me to obtain their medical records and to speak with their families and their doctors. None of this was easy for them, but it did provide me with an education I would have gotten no other way as they reflected back on the meaning it had to them to have been committed to psychiatric units.

The subject of involuntary outpatient commitment has been particularly difficult to research, in part because I live in Maryland, a state which has no provision for this. I spoke with one family member in Arizona who initially was eager to be interviewed, along with her adult child who has come to feel that involuntary care has been very helpful. When I called back, the mom had changed her mind about participating: “You’re writing a book with a balanced view. There no balance or controversy here for me; it’s a medical problem that needs treatment.” Unless I could promise to support, unequivocally, the views she held without qualification, she was not interested in participating in our book, even if it would provide an avenue to express her beliefs about the value of outpatient commitment. For similar reasons, I had to approach Ron Honberg, J.D., at the national office of the National Alliance on Mental Illness (NAMI); the Maryland NAMI members did not want me to speak with me (sic) after two articles I wrote for this Clinical Psychiatry News column suggested that I was not wholeheartedly in favor of outpatient commitment. I was told the topic was “too sensitive” for their members to discuss with me. So while I’ve learned that the topic inspires a great deal of emotion, there are still surprises with every step.

I am continuing to look for people to interview who are the subjects of mandated civil outpatient treatment orders, as well as their family members. If you would like to participate, by all means contact me at DinahMiller@yahoo.com.

Dinah Miller, M.D.
12-30-2014

Clinical research note:
Effectiveness and safety of clozapine in elderly patients with chronic resistant schizophrenia

The authors aimed to evaluate the effectiveness and safety of clozapine monotherapy in a diagnostically homogeneous group of elderly patients suffering from schizophrenia (DSM-IV-TR criteria). The Of 527 elderly patients suffering from schizophrenia 43 patients, mean age 69.4 ± 8.7 years, were treated with clozapine.

- There were 19 women and 24 men, mean disease duration was 38.8 years.
- All had been exposed to at least three first- and second-generation antipsychotics prior to clozapine treatment.
- Clozapine was very well tolerated by the patients and mortality rate (8/43 (18.6% vs. 87/484 (18%)) was equal to that of other first- and second-generation antipsychotics (p < 0.18).
- Re-hospitalization rates with clozapine were significantly lower than rates for the five-year period prior to exposure to clozapine (0.41 vs. 3.8; p < 0.001).

International Psychogeriatrics, 12/23/2014
Pridan, S., et al.
St. Joseph University Parish’s Mental Health Committee is hosting a free movie night on Tuesday, March 17th at 7 p.m., featuring Academy Award winner film Silver Linings Playbook.

A romantic comedy, sometimes bittersweet story, about a man living with bipolar disorder, and the effects of his illness on his family.

They will also hold:

**A Celebration of Mental Wellness**

an annual Interfaith Service

on Tuesday, May 19th at 7 p.m.

in honor of Mental Health Awareness Month

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We invite you to join NAMI Buffalo & Erie County in helping us make a difference for people with mental illness and their families.

Mail to:

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

Name____________________________________
Address___________________________________
City_______________State_____Zip____________
Phone_____________________________________
E-Mail _____________________________________

- ☐ **Membership** $35
- ☐ “Open Door” Membership - $3 (for those in financial need, or to add a spouse/partner)
- OR -

- ☐ **Donation:** amount $ ___________
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☐ Please put me on the phone tree/e-mail list to receive legislative or other alerts.

Please send a copy of the newsletter to:

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Memberships, contributions, and donations are tax deductible.
Does Schizophrenia Run in Your Family? 
Research Study Participation Opportunity

Research shows that in families with a history of schizophrenia, there is a strong genetic link associated with the disease. A genetic link means that it may be possible for medical science to find the gene or sequence of genes causing this debilitating disorder. This information could then be used to develop new treatments for managing symptoms and to hopefully one day find a cure.

The VA Boston Healthcare System has launched a study using the latest research technology in human DNA analysis to help determine the underlying genetic variables responsible for schizophrenia.

To qualify for this study, there must be at least 3 available members of the extended family who are diagnosed with one of these disorders:
- Schizophrenia
- Schizoaffective Disorder
- Schizotypal Personality Disorder
- Bipolar Disorder with Psychotic Features

The study also seeks 3 “healthy” members of the family who are willing to participate. All family members must be at least 18 years old. The study involves a clinical interview and a blood draw.

See study details next column >
IRS-certified accounting students from the UB School of Management will again provide free tax preparation services to individuals and families with annual incomes below $53,000. The initiative is being led by the UB chapter of Beta Alpha Psi, an international honors organization for accounting and finance students, with help from the UB Accounting Association.

### Dates, Times and Locations

#### South Campus

Free tax preparation will be offered from 9:30 a.m. to 5 p.m. on a first-come, first-served basis in 100 Allen Hall on Feb. 7, 8, 14, 15, 21, 22 and 28, and March 1.

#### Downtown Campus

For the first time ever, free tax preparation will be offered on UB’s Downtown Campus in the UB Downtown Gateway, 77 Goodell St., Suite 201, from 9:30 a.m. to 5 p.m. on a first-come, first-served basis on March 7 and 8.

To access the UB Downtown Gateway, you must enter through UB’s Educational Opportunity Center (EOC) at 555 Ellicott St., next door, and follow the signs.

#### North Campus

Free tax preparation will be offered from 9:30 a.m. to 5 p.m. on a first-come, first-served basis in 106 Jacobs Management Center (The John H. Shellum Room) on March 28 and 29, and April 4, 5, 11 and 12. (NOTE: For March 28 ONLY, services will be in 214 Jacobs.)

Participants must bring the following:

- Proof of identification (government-issued ID for each adult, such as driver’s license, state-issued ID card, passport, military ID card, etc.);
- Original Social Security card for each filer and dependent (not a photocopy);
- Date of birth for self, spouse and dependents;
- Wage and earning statements (Forms W-2 and 1099) from all employers;
- Interest and dividend statements (Form 1099);
- New this year: Forms 1095-A, B or C (Affordable Health Care Act Statements)
- Total paid for day care provider and provider’s tax ID number or Social Security number;
- A copy of last year’s federal and state tax returns, if available;
- Bank routing numbers and account numbers for direct deposit; and
- If married filing a joint return, both spouses must be present to sign the required forms.

The free tax preparation service is only available to filers choosing to take the standard deduction rather than itemized deductions.

Volunteers will prepare tax filings for 2014 only.

Send requests for more information to mgt-freetax-prep@buffalo.edu or call 716-430-0761. A student volunteer will reply within 48 hours.

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(Schizophrenia Study details)

The researchers will travel to the Buffalo/Western New York area to meet with families located here. Participants who complete the study receive $130. Study is not restricted to veterans, but is open to the general public.

To learn more, contact:
Email GeneticsResearchVA@gmail.com
Paul Nelson, M.Ed.
Study Coordinator
or call 845-981-9514
Lynn E. DeLisi, MD
Study Investigator
VA Boston Healthcare System
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Thank you all!

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 Katherine Evans

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 Suburban Psychiatric Associates

 Circle of Light ($250-499)
 O’Connor Medical Group

 Santa’s Circle ($100-249)
 BryLin Hospitals
 BryLin Medical Staff
 Dr. Jeffery Grace
 Ed & Marilyn Green
 Phillip & Joyce Orlowski
 Candace Taplin; Hard Hats & High Heels
 Dr. Kathleen Vertino

 Christmas Friends (up to $99)
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 Mary Dendy

 Janice Gagliardi, in memory of Gerrie Cruz
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Anonymous ~ C.P.
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Dr. Helen Aronoff
Brenda Battleson White
William & Mary Lou Bond
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Never doubt that a small group of thoughtful, committed citizens can change the world.
Indeed, it’s the only thing that ever has.

~ Margaret Mead

Thursday, April 30th
Annual NAMI Dinner & Awards
More information inside.