

# the challenger

A Publication of the NATIONAL ALLIANCE on MENTAL ILLNESS in Buffalo & Erie County Vol 1 No. 5  
October - November 2009

## Mark Your Calendar

All regularly scheduled monthly meetings are held at St. Paul's Evangelical Lutheran Church, 4007 Main Street, Amherst (near the intersection of Main and Eggert Rd.). Board meetings and monthly educational meetings are held on the second floor (main entrance at the back of the church). Support group meetings are held on the first floor (church entrance at ground level at left rear of the building).

### October

**NAMI Board Meeting**, Thursday, October 1st, 7:30 PM. All members welcome!

**NAMI Educational Meeting**, Thursday, October 8th. Library and Coffee Hour: 7 PM. Presentation: 7:30 PM. Guest speaker' Nancy Singh, Restoration Society, on new programs and program changes.

**NAMI Family Support Meeting**, Wednesday, October 28th, 7:00 PM.

### November

**NAMI Board Meeting**, Thursday, November 5th, 7:30 PM. All members welcome indeed.

**NAMI Educational Meeting**, Thursday, November 12th. Library and Coffee Hour: 7 PM. Presentation 7:30 PM. Guest speaker Beth Ladd, Clinical Director of Mental Health Services at Buffalo General Hospital, on a new model for inpatient care and other program changes.

**NAMI Family Support Meeting**, Wednesday, November 25th, 7 PM.

### December

**NAMI Board Meeting**, Thursday, December 3rd, 7:30 PM

**NAMI Monthly Educational Meeting**, Thursday, December 10th Library and Coffee hour 7 PM. Presentation 7:30 PM. Guest speakers: Harmony Hurtgen, Court Clerk, Tonawanda Mental Health Court, and Kelly Gotham-Audin, Attorney-at-Law, Tonawanda MH Court on procedures and options families need to know if a loved one is arrested.

**NAMI Christmas is for Kids Wrapping Session**, Hope House 432 Amherst St., Buffalo, 10 AM. Volunteers needed!

**No Family Support meeting in December.**

### January

**No NAMI Board Meeting.**

**NAMI Monthly Educational Meeting**, Thursday, January 14th. Library and Coffee Hour at 7 PM. Presentation at 7:30 PM. Guest speaker: Michael Cummings, MD, Community Psychiatry Liaison for ECOM and the UB Dept. of Psychiatry.

**NAMI Family Support Meeting**, Wednesday, January 27th, 7 PM.



## State plan threatens treatment for behavioral issues

The World Health Organization predicts depression is reaching epidemic proportions. Depression is the leading cause of absenteeism and low productivity in the workplace. New York State spends more per psychiatric patient than any other state, more than any other country and ranks second in suicides. More low and middle-income families than ever are in need of low-cost, high-quality mental healthcare.

The outlook for behavioral health care is not bright, and may be getting worse for New Yorkers under a reform plan proposed by the state Office of Mental Health and Health Department. Perhaps driven by the state's budget crisis, they are aggressively pursuing a reform plan that will provide access to care only to Medicaid recipients. The unintended consequence is that this will leave low- and middle-income families in the lurch.

The timing could not be worse as employers and managed care companies aggressively move people into high deductible health plans. When faced with paying your mortgage or \$70 per therapy session for your son or daughter's care for an emotional disturbance, which would you choose if you have a modest income?

Many private psychiatrists are not taking new patients. Private psychotherapists, with rare exceptions, do not provide the labor-intensive work necessary to properly serve children and families struggling with serious emotional disturbances.

Clearly, there must be a two-step approach to behavioral health care reform to achieve bet-

**Continued on page 2**

**Continued from page 1**

ter outcomes and improve access. First, providers must lower cost and improve services. Then, Medicaid, Medicare and commercial insurers must pay fair rates. Government plays a pivotal role in both steps.

Of more than 1,400 health insurance plans, a New York State Medicaid claim is the most costly in the nation to adjudicate. Many millions in unnecessary administrative costs would be saved if New York streamlines its Medicaid billing processes.

As long as employers and health insurers are on the same team to cut costs while patients and doctors are on the team to deliver the best care, there will be conflicting goals. Perhaps government can play some role in reconfiguring the reimbursement system so everyone's goals are aligned.

A performance-based reimbursement system would attract more of the best psychiatrists, social workers and psychologists to treat New York's most seriously mentally ill residents. Integrating New York's fragmented primary health, mental health and substance abuse systems should be a top priority.

The bottom line: It is in the interest of anyone who pays taxes or insurance premiums to build a health care system that will achieve a more productive work force and improve children's academic performance.

*by Jerry Bartone  
TheBuffalo News*

*Jerry Bartone is the executive director at Community Concern of WNY Inc., a provider of state-licensed mental health services in Derby. ■*

## **State Reform Plan Will Invest More In Programs**



Jerry Bartone's Another Voice published Sept. 15 outlines the importance of behavioral health services very effectively. However, the "reform plan" being refined by the New York State Office of Mental Health is attempting to save and strengthen these essential programs. This is a plan that will invest more — not less — in mental health care. However, there are very real threats and opportuni-

ties in the wind. Concerned individuals should weigh in on these issues to ensure that crucial programs are sustained.

In the past two years, the agency has taken a number of strong initial steps to strengthen mental health counseling and clinic programs. The reimbursement rates of the lowest-paid providers were raised almost 20 percent last year. "Standards of care" were developed to reinforce the basics of good treatment. An agreement was reached among state agencies that modest amounts of mental health, addiction treatment or health care treatment could be provided in any clinic licensed by any one of the relevant state agencies without seeking "double licensure."

Even with these changes, problems persisted. The agency's reimbursement approach was inequitable, with rates for equivalent services by different providers varying by hundreds of dollars. It was not tied to the reasonable costs of care, and the approach was inconsistent with federal laws.

The reform program was developed based on a yearlong effort involving dozens of clinic providers, local government officials and consumer/family advocates. It will be phased in slowly over a four-year period, giving providers time to adjust. All current agency funds will be invested in the new approach that will focus on rehabilitation and recovery, support a new range of services including outreach and engagement and complex care management, and allow for multiple services in the same day. In addition, the State Department of Health will launch, with federal approval, an "uncompensated care" reimbursement program — brand new to behavioral health — to cover some of the costs of caring for the uninsured

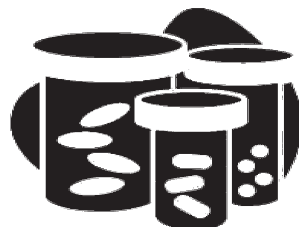
Despite all of these steps and protections, there are still some reasons to be concerned, and Bartone identifies several. There has been a long-term trend in New York State to replace state funds with Medicaid reimbursement whenever possible. This has been good in that care has been expanded, while the federal government has covered half the cost. But support measured simply by state appropriations has not kept pace. This must be a long-term concern of advocates. However, in the worst economic downturn in a generation and a serious multiyear state budget crisis, it is not realistic to expect the state to spend more in the short term.

The Office of Mental Health reforms will continue New York's support for essential services. Advocates should monitor changes, but insist that mental health is included in overall national health reform.

*By Michael F. Hogan  
The Buffalo News*

*Michael F. Hogan is commissioner of the New York State Office of Mental Health. ■*

## Clinical Trials: What to Know Before You Sign Up



You've read the news stories about medical studies that have unveiled a promising new arthritis drug or procedure. And you may have asked yourself, "How can I get in on that?" Perhaps next time you can, by volunteering for a clinical trial.

A clinical trial is a research study which involves the use of new drugs or devices that are not yet approved by the U.S. Food and Drug Administration (FDA) or the comparison of different types of approved treatments, drugs, or devices. A clinical trial may be sponsored by a government agency, a drug company, a foundation, or a medical institution.

All clinical trials have inclusion and exclusion criteria, depending on what is being investigated. For example, since arthritis becomes more prevalent with age, studies generally focus on older people with the disease.

Study sites are overseen by institutional review boards, or IRBs, which are made up of scientists, physicians, and community members who review trials to ensure that the rights and welfare of all subjects are protected. Once IRB approval is granted, researchers may recruit volunteers for the trial.

"Informed consent" is the process by which you learn the facts about a clinical trial that enable you to decide whether to participate. Researchers will interview you to determine whether you meet the inclusion criteria. All research involves risk, which can range from the loss of confidentiality in completing questionnaires to more serious types of risk, such as side effects from a study drug or device.

Prior to the start of a trial, you must be informed of all known risks, benefits, and costs associated with the study. Most important, be sure you're right for the trial, that you know where to get information if you have additional questions, and what help is available if you suffer an adverse event. ■

## Abigail Van Buren

### *Father Thankful for Kindness*

Dear Abby: My 20-year-old son, "Gabriel," is suffering from the onset of psychosis. His mother and I have been working with local mental health officials to have him committed to a hospital so he can receive the treatment he so desperately needs.

While my wife was driving him to the hospital, Gabe jumped out of the moving vehicle and took off. He wasn't found for 10 days. When he was returned, we were able to have him committed, and he is now undergoing treatment.

Since then, Gabe has begun talking about his "adventure," which involved walking more than 200 miles. At the time he fled, he was wearing only a shirt, shorts, slippers and a hat. He had \$10 on him. He said he made his way through swamps and woods, and was covered with mud and ticks.

After walking for two days, a woman began walking beside him and asked if she could help. Her name was Gay. She took my son into her home, where he was welcomed by her husband and daughter. They also gave him some food and money when he left.

Our son could have died had it not been for Gay and her family. Since we don't know the last name or exact location of these Good Samaritans, a letter in your column is the only way we have to express our deep gratitude. Thank you, and may God bless each of you for your kindness.

— Grateful Dad, Alexandria, Va.

*Dear Grateful Dad I'm pleased to print your letter. Not only does it convey your feelings, it also serves as a reminder that the mentally ill people we see living on our streets and in our alleys — instead of in hospitals where they should be receiving treatment — are ALL somebody's children. And even if their families are not involved, they are still children of God.*

Abigail Van Buren

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## **Changes! Changes! Buffalo General Hospital, Behavioral Health Outpatient Services**

**BGH has moved its outpatient services from 80 Goodrich to 1010 Main Street (where Goodrich intersects with Main) and has reopened its Partial Hospital Program. Partial Hospital Program is a medically supervised program that provides active treatment designed to stabilize and reduce acute symptoms, to serve as an alternative to inpatient hospitalization, or to reduce the length of a hospital stay. The new telephone numbers are:**

**Intake 716-859-4706**

**Adult Outpatient Counseling 716-859-4772**

**Chemical Dependency 716-859-4744**

**MICA/Trauma Treatment Services 716-859-4795**

**Partial Hospital Program 716-859-4817**

**General Information 716-859-4700**

### **Buffalo Federation of Neighborhood Services (BFNC)**

**The Program Coordinator for CSS Case Management Services is Chandra Banks M.S, who can be reached at 716-853-0600 (telephone) or 716-885-1470 (fax). Case Management Services are usually limited to those individuals enrolled in other services in the agency, but referrals may be made by a current provider or through the Erie County Single Point of Entry (SPOE).**

### **National Grid Consumer Advocates**

**This utility service has identified two consumer advocates for customers residing in Erie County.**

**Miguel Santos 716-440-7916 (cell) 716-845-9811 (fax)**

**Mark Johnson 716-239-0958 (cell) 716-857-4722 (fax)**

### **Medicaid Eligibility**

**As of April 1, 2008, the asset limitations have been raised to \$13,050 for individuals and \$19,200 for married couples. NYS expects the computer programs to be changed by Fall. All new applications are using the new limits. Individuals on Family Health Plus may now qualify for Medicaid which will provide more comprehensive coverage with few co-pays or deductibles.**

## **On the Frontiers of Science**

For older adults being treated for depression, SSRI's pose danger.

Numerous studies in the last five years have documented a serious potential side effect of antidepressants for those seniors using SSRI's such as Lexapro, Zoloft, Paxil, Prozac and Celexa. While such drugs successfully treat depression in seniors—a group with the highest suicide rate, 20 percent, and as high as 80% for those in nursing homes—there is a real risk of weakened bones.

Individuals taking such medications should get 1,000-2,000 IU of vitamin D3 and 1,500 mg of calcium per day through food or supplements; exercise at least 30 minutes every day; participate in some type of resistance training (weight lifting) every other day, three times a week; don't smoke, and limit alcohol intake to no more than two drinks a day. Patients should also have a bone density scan scheduled at least every two years.

You might also discuss switching antidepressants to one of those without this side effect, such as Zyban, Wellbutrin XL, Cymbalta and Effexor.

### ***Arthritis Advisor August 2009***

#### ***Macular Degeneration and antipsychotic drugs***

Macular degeneration, a progressive, incurable condition, can result in severe vision loss and blindness in people over 60. The condition is clearly related to age and hereditary factors, but can also be induced by drugs, including use of phenothiazines, antipsychotic medications including Thorazine (chlorpromazine), Mellaril (thioridazine), Prolixin (fluphenazine), Trilafon (perphenazine), and Stelazine (trifluoperazine).

Patients 50 years old or older taking these medications should have regular eye exams by an ophthalmologist. Patients can also self-check for some indications. Have the patient cover one eye and look at a wall at a point where it meets the ceiling. Normally, that line will appear straight. If it's wavy, the person should see an ophthalmologist.

Regina Spires, RN,BSN  
www.rnweb.com Vol. 69, No. 2

# We Can't Turn Our Backs On Mentally Ill Homeless

Working in the Allentown area of Buffalo for almost 25 years, I have had ample opportunity to make the acquaintance of many residents of this neighborhood, including the mentally ill homeless who wander its streets. These tortured souls subsist by salvaging through garbage and relying on the aptly named and heroic acting "Friends of the Night People."

It is widely agreed that the mentally ill came to live on our streets in large numbers due to the confluence of two events: the cost-cutting-inspired emptying of large mental hospitals and the catastrophic success of patients' rights advocates in winning the right for a mentally ill person, acting alone, to decide whether hospitalization, or even medication, was required.

The terrifying effects of this are felt every day. We have experienced an explosion of severely mentally ill people on the streets, desperately trying to survive in a world that expects them to manage their own recovery. It's a dilemma straight out of *Catch-22*; how do you know you need help, if your only means for determining that need has been compromised?

Our society can no longer pretend to ignore this confounding riddle. The National Institute of Mental Health says that almost 10 percent of the U.S. population suffers from a serious mental illness. We are blessed to have a "functioning paranoid-schizophrenic" in my family. Blessed? Unlike many schizophrenics who never recover, my stepdaughter has a normal life, an understanding husband and a loving son. She has beaten the odds, but not without some titanic struggles along the way and some critical assistance.

Getting help, the first step to mental health, is both the most important and the most difficult thing to do. Gone is any notion of having an adult person "committed for observation." Persuading my stepdaughter to seek help was just the beginning, next we had to hope that the hospital would accept her. Erratic behavior and rash actions, of great concern to friends

and family, might not constitute mental illness to the discerning doctor performing the evaluation.

Fortunately, she was admitted to the hospital and the process of recovery, however tenuous, had begun. But it was far from a straight line from hospitalization to functioning schizophrenic. There was the inevitable push back against "having a mental illness" and reluctance to "take pills for the rest of my life." A turning point came with the intervention of an overburdened but dedicated social worker. The ability to locate and benefit from social services made all the difference.

Supplemental Security Income enables my stepdaughter a life with some dignity despite the fact that the illness prevents her from holding down a regular job. Medicare ensures that medical bills will not interfere with recovery by inducing a financial crisis. Most importantly, regular visits with a doctor enabled her to receive the right medication in the right dose. Finally, group therapy provided a community within which the road to recovery could be found. What provided her a chance for a "normal" life was the much-maligned "government health care system."

Sadly, this opportunity is not available to all who suffer. Our society faces a moral Rubicon regarding the mentally ill. Have we lost the compassion to care for those who cannot provide care for themselves? When we avoid the shabbily dressed man, loudly talking to himself, we lose a piece of our humanity. When we look away from the bag-lady pushing a shopping cart full of her meager worldly belongings, we abdicate our responsibility to care for the less fortunate. Our society's compassion is measured by how we treat our most vulnerable. ■

*Dave Hxy  
The Buffalo News  
August 9, 2009*

## *News in Brief*

### **Work, SSI and SSDI**

Buffalo Employment and Training Center holds monthly sessions from 10 to 11:30 each month at 77 Goodell St., Buffalo 14202 covering SSI's formula for counting wages; how to work and keep Medicaid; SSI's trial work period, SSI's PASS plan and more. All presentations are by certified benefits advisors from Neighborhood Legal Services staff. Pre-registration encouraged, but walk-ins are welcome. For more information, call 847-0650, ext. 271.

### **Medicaid Buy-in for Working People with Disabilities**

Neighborhood Legal Services also can assist working people with disabilities in applying for the Medicaid Buy-in option which could save them a great deal of money while keeping their insurance and medication coverage. For information email [McDonald@nls.org](mailto:McDonald@nls.org) (put MBI-WPD in the subject line).

If you have a loved one who has been in the Erie County Holding Center, and his/her treatment was unsatisfactory, the New York Civil Liberties Union would like to know about your relative's experiences there. All reports will be kept strictly confidential. Contact them at 716-332-4658 or send an email to [ECHC2009@gmail.com](mailto:ECHC2009@gmail.com)

### **UBDept of Psychiatry Grand Rounds**

Jeffrey Anker, MD, Asst. Professor of Psychiatry, UB, on "A 'Secure Room' is Better than a 'Seclusion Room'". December 11, 8 AM, Buffalo Psychiatric Center.

### **New Meds for Schizophrenia**

Invega Sustenna (paliperidone palmitate), is a recently approved injectable drug used to treat schizophrenia/psychosis. Relapse in a clinical trial was 10% for patients on Invega, and 34% of patients on placebo, suggesting a very good tolerability profile.

lloperidone is a new atypical antipsychotic approved in May. Clinical trials suggest that for some patients, the side-effects may be more tolerable than those of other antipsychotics.

## The People's Pharmacy Treating Mental Illness

Hundreds of years ago, people with mental illness might be burned at the stake or locked away in a dungeon. In the early 20th century, some patients with schizophrenia were lobotomized with an ice pick to blunt emotions and reduce agitation.

Other treatments included padded cells, strait jackets, cold wet sheets and electroshock therapy. Mental institutions in the first part of the 20th century were sometimes referred to as "snake pits."

It was in this barbaric context that the first antipsychotic drugs were developed. In 1952, when Thorazine (chlorpromazine) was first introduced, it was hailed as a breakthrough.

Other drugs such as Stelazine (trifluoperazine), Mellaril (thioridazine) and Haldol (haloperidol) followed. Although these antipsychotic medications were popular with psychiatrists, patients often thought of them as chemical straitjackets.

Such drugs helped reduce hallucinations and agitation. But there was a high price to pay for the apparent benefits. The drugs made people feel sedated and slowed them down, resulting in a zombie-like shuffle.

Other side effects included dizziness, slurred speech, seizures and a variety of movement disorders such as severe neck muscle spasms causing head twitches or uncontrollable rhythmic movements such as sticking out the tongue. Urinary retention, constipation and sexual difficulties also contributed to the drugs' unpopularity with patients, who often discontinued their medicines as soon as they were discharged.

A newer generation of schizophrenia drugs was introduced in the early 1990s with great fanfare. Drugs like Clozaril (clozapine), Risperdal (risperidone), Zyprexa (olanzapine), Seroquel (quetiapine), Geodon (ziprasidone) and Abilify (aripiprazole) are known as atypical antipsychotics.

Psychiatrists hoped that these medications would be better tolerated and much more



effective than older antipsychotics. Some even believed the new drugs would help schizophrenic patients return to normal.

More than \$13 billion is spent on antipsychotic medications each year. They are prescribed for a range of conditions beyond schizophrenia, including Alzheimer's and dementia, bipolar disorder, insomnia, autism, obsessive-compulsive disorder, ADHD and major depression.

Despite the initial enthusiasm, there is growing consternation about the safety and effectiveness of these powerful mind medicines. A few years ago, a study found that the newer and far pricier drugs were no more effective or less likely to cause troublesome side effects than an older antipsychotic (*New England Journal of Medicine*, Sept. 22, 2005). A new study in the same journal (Jan. 15, 2009) reported an alarming rate of sudden cardiac death linked to the newer drugs.

It's no wonder that patients and families are nervous about these medicines, especially when you consider that they can cause other complications such as dramatic weight gain, diabetes, strokes and irregular heart rhythms. Children and older people may be particularly vulnerable.

People with mental illness deserve much better treatment than they have received to date. Although lobotomies and straitjackets are no longer used, modern medications leave a lot to be desired.

January 22, 2009  
The Buffalo News  
Joe and Teresa Graedon

## NAMI New and Renewing Members

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Walter Wilczak  
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Grace Neureuther *in honor of*  
Kathleen Kirkland  
Nancy J. Monin *in memory of Dr.*  
Louis Monin & Matt Monin

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*No one will be denied membership due to financial hardship. If you are on a limited, fixed income, contact Mary at 832. 4035*

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*Moral courage is a rarer commodity than bravery in battle or great intelligence. Yet it is the one essential, vital quality for those who seek to change a world that yields painfully to change.*

Robert F. Kennedy

