

the challenger

A Publication of the NATIONAL ALLIANCE on MENTAL ILLNESS in Buffalo & Erie County

Vol 1 No. 3
June-July 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).

May

NAMI Family Support Meeting, Wednesday, May 27th, 7 PM.

June

NAMI Board Meeting, Thursday, June 4th, 7:30 PM. You're welcome to join us and observe your Board in action.

NAMI Educational Meeting, Thursday, June 11th. Library and coffee hour 7:00 PM Presentation 7:30 PM. Guest speaker: Joanne Baggs, BuffaloGeneral Hospital, "What's Dialectical Behavioral Therapy and How Can It Help?"

NAMI Family Support Meeting, Wednesday, June 24th, 7 PM.

July

NAMI Board Meeting, Thursday, July 2nd, 7:30 PM.

NAMI Educational Meeting, Thursday, May 7th. Library and coffee hour, 7:00 PM. Presentation 7:30 PM. Guest speaker: Patrick Welch, Erie County Director of Veterans Affairs on "Post-traumatic stress disorder; not just a veteran's problem." PTSD affects up to 40% of people with serious mental illness. What it is, how it develops, how to treat it.

NAMI Family Support Meeting, Wednesday, July 23rd, 7 PM.



August

NAMI Board Meeting, Thursday, August 6th, 7:30 PM.

NAMI Educational Meeting, Thursday, August 13th. Library and Coffee Hour: 7:00 PM. Presentation 7:30 PM. Guest speaker: Celia Spacone, MD, on new programs at Buffalo Psychiatric Center.

Broken Promises

History is full of instructive lessons, too often ignored. Twenty years ago, Buffalo Psychiatric Center and other state hospitals converted hundreds of beds, to RCCA's—Residential Care Centers for Adults—which were in essence "step-down" beds that would not have to meet the expensive regulations and restrictions imposed on hospital beds. RCCA's were touted as long-term residences that would be "home" for as long as patients chose to remain. They would not require that patients "move on" to other (cheaper) settings such as apartments if they were content in the RCCA.

NAMI Buffalo fought the conversion of those beds long and hard, the only voice in opposition. We had learned not to trust the system and decision makers who had too often sold us a bill of shoddy goods. And we were right. That solemn promise that patients could stay as long as they wanted in RCCA's has now been broken.

The loved one of one of our NAMI families has just received a letter informing her that she must meet with a discharge planner and select an alternative to her RCCA residence, regardless of her wish to remain. She is now in a state of acute anxiety and uncertainty, remembering other unhappy "community placement" experiences. Her family is anxious and troubled, fearing her return to psychosis and upheaval.

We have learned that the decision to "move 'em out" of the RCCA was not made locally—that the cavalier decision to turn people's lives upside down was made in Albany, by bureaucrats far removed from the consequences of their decisions. So much for promises from politicians and bureaucrats, so much for "patient-centered" care and "patient choice". For us NAMI families, it's hard to be right. ■

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Toxoplasmosis Parasite May Trigger Schizophrenia and Bipolar Disorders

Scientists have discovered how the toxoplasmosis parasite may trigger the development of schizophrenia and other bipolar disorders.

The team from the University of Leeds' Faculty of Biological Sciences has shown that the parasite may play a role in the development of these disorders by affecting the production of dopamine — the chemical that relays messages in the brain controlling aspects of movement, cognition and behaviour.

Toxoplasmosis, which is transmitted via cat faeces (found on unwashed vegetables) and raw or undercooked infected meat, is relatively common, with 10-20% of the UK population and 22% of the US population estimated to carry the parasite as cysts. Most people with the parasite are healthy, but for those who are immune-suppressed — and particularly for pregnant women — there are significant health risks that can occasionally be fatal.

Dr Glenn McConkey, lead researcher on the project, says: "Toxoplasmosis changes some of the chemical messages in the brain, and these changes can have an enormous effect on behaviour. Studies have shown there is a direct statistical link between incidences of schizophrenia and toxoplasmosis infection and our study is the first step in discovering why there is this link."

The parasite infects the brain by forming a cyst within its cells and produces

an enzyme called tyrosine hydroxylase, which is needed to make dopamine. Dopamine's role in mood, sociability, attention, motivation and sleep patterns are well documented and schizophrenia has long been associated with dopamine, which is the target of all schizophrenia drugs on the market.



The team has recently received \$250,000 (£160,000) to progress its research from the US-

based Stanley Medical Research Institute, which focuses on mental health conditions and has a particular emphasis on bipolar illnesses.

Dr. McConkey says: "It's highly unlikely that we will find one definitive trigger for schizophrenia as there are many factors involved, but our studies will provide a clue to how toxoplasmosis infection - which is more common than you might think - can impact on the development of the condition in some individuals.

"In addition, the ability of the parasite to make dopamine implies a potential link with other neurological conditions such as Parkinson's Disease, Tourette's syndrome and attention deficit disorders, says Dr. McConkey. "We'd like to extend our research to look at this possibility more closely." ■

Science Daily
March. 11, 2009



News in Brief



New York State

■ The current budget crisis will result in the layoffs of more than 1,000 staff from the New York State Office of Mental Health and the closure of 450 state psychiatric center beds. 300 will be permanent closure, 150 beds will be moved to transitional placement.

■ The state legislature rejected an OMH proposal for state hospital directors to serve as representative payees, where patients' Social Security funds would be used to pay state hospitals for services, rather than be available at discharge to establish patients in the community. Retroactive to 2002, if you had a loved one hospitalized during this time period he/she may have funds due them from a state psychiatric center.

■ New York State is implementing a new prescription saver card that lowers the cost of prescriptions by as much as 60% on generics and 30% on brand name drugs at participating pharmacies. NYS residents are eligible if they are not already receiving Medicaid, are age 50 to 65, are determined disabled by the Social Security Administration, and have household incomes up to \$35,000 (single) or \$50,000 (married). The card cannot be used with any other pharmacy discount (such as EPIC) but will cover prescription purchase in the Medicare "donut hole".

How To Apply

Applications are being accepted online at the Prescription Saver Web site, <http://nyprescriptionsaver.fhsc.com>, or by phone at 800-788-6917. TYY users can call 800-290-9138. Forms will be available at pharmacies and community organizations.

Approved participants should receive their cards in the mail about two weeks after filing an application.

Information on the drug discounts, participating manufacturers and pharmacies, and a pharmacy locator is available at the Prescription Saver Web site, <http://nyprescriptionsaver.fhsc.com>.

■ NYS Office of Mental Health has recently published a new HIPPA booklet. It is available through the NYS Office of Mental Health website to download or call Tom O'Clair at 518-474-4888 for a paper copy.

■ The legislature rejected proposed cuts in the budget and delaying implementation of the SHU bill. The SHU law bans solitary confinement of inmates with serious mental illness.

■ The legislature also voted not to cut the state share of SSI benefits for people with disabilities.

■ Lawmakers also rejected proposals requiring prior approval for certain anti-depressants, and a proposed 1 percent cut in funding for mental health programs.

National

■ The recently signed American Recovery and Reinvestment Act of 2009 provides for the one-time payment of \$250 to individuals who get

SSI or Social Security benefits. Payments should be received by late May 2009. No action is required on the part of the recipients. Individuals receiving benefits from the U.S. Dept. of Veterans Affairs may also be eligible. This one-time payment will not jeopardize benefits such as Medicaid, rental caps, Food Stamps, or other benefits.

■ Thanks to the efforts of NAMI, MHA, and thousands of advocates, the federal Mental Health Parity and Addiction Equity Act of 2008 has been passed and will go into effect on January 1, 2010. 113 million people across the country will have the right to non-discriminatory mental health coverage, including 82 million enrolled in self-funded plans, who cannot be assisted by State parity laws.

~
Please Remember
NAMI
Buffalo
&
Erie County
in your Will
~

When a Family is Left Wondering Why

For many families with a loved one suffering from a mental illness, the stories of care denied can hit close to home. You know your son, daughter, or even a parent is sick and needs help. You do all you can to get them to the emergency room or even a psychiatric hospital. You think you've made progress. Then the staff tells you your loved one will be discharged—even though it's clear to you that they are still symptomatic.

Confused and frustrated by the decision, you hope and pray something doesn't happen.

Sadly, tragedy can strike.

About two months ago, the Pak family of Norcross, Georgia was pleading with a state facility not to release 32-year-old Na Yong Pak from its care because she was so clearly sick. She refused to sign discharge papers and stated that she would not take her medication.

"My daughter should stay in the regional hospital a couple more months, but they say 'that's ok, take her home,'" father Gold Pak told the *Atlanta Journal-Constitution*. He added with what was described as a mournful wail, "Noooo...that's not right."

The hospital still sent her home. On February 11th, Na Yong was in a delusional state and set her mother on fire. Myong Hui Pak died as a result.

Problems at the Georgia facility are well documented. They were part of a two-year problem by the U.S. Department of Justice and the subject of numerous media stories.

Yet, the state Department of Human Resources still tried to skirt responsibility and put the blame on a patient who



was clearly ill and not going to maintain treatment in the community.

"I'm sure there is a lot of confusion and if someone's loved one has been hurt or killed, then people are trying to make sense of that," Dena Smith, spokesperson for the department told the

Atlanta Journal-Constitution. "But not at the expense of the rights of people who have mental illness. Personal responsibility of managing mental illness should definitely be brought into consideration. It's only fair to people who every day manage and live in the community with mental illness."

In a letter to the Governor of Georgia, sent by the Department of Justice just three weeks before the tragedy, they cited the hospital for failing "to provide adequate discharge planning." The Department even noted that this failure was a violation of a patient's constitutional rights and in violation of several federal statutes, including the Americans with Disabilities Act and the Civil Rights Act of 1964.

What's most glaring is 1) the state's failure to adequately treat the patient, 2) their excuses and 3) their blaming the patient for acts which led to her mother's death even though she was so ill she should have been in the hospital.

What's truly tragic is that this situation could occur anywhere in this country to a family and their mentally ill loved one, and we'd hear the same excuses from treatment facilities and professionals.

Adapted from an article in the Treatment Advocacy Center's newsletter. ■

Some Humanity, Mr. Paterson

Albany Times Union Editorial
February 13, 2009

Governor Paterson needs to look almost everywhere in state government if he's going to eliminate, or even reduce, a budget deficit that's projected to be as high as \$14 billion next year. But even the most dire of fiscal crises have boundaries. Sadly, Mr. Paterson has crossed one of them.

The word comes from the Paterson administration that the state can't afford to comply with a law liberating seriously mentally ill prison inmates from the psychological torture chamber known as The Box.

The inhumane practice of confining inmates with psychiatric disabilities to 23 hours a day of solitary confinement, ostensibly for disciplinary purposes, was supposed to end by 2011. For that, thank Gov. Eliot Spitzer. He signed legislation last year that Gov. George Pataki had vetoed and Mr. Paterson prefers to wait until 2014 to implement. Both Mr. Pataki and Mr. Paterson objected to the cost of compliance.

Several hundred mentally ill inmates would be moved out of The Box and into special residential treatment units under this law. But by waiting three years to do that, the Paterson administration says it can delay filling 388 jobs at the Department of Corrections and hiring another 86 people at the Office of Mental Health. Doing that, the administration says, would save \$11 million this year and \$15 million next year.

Talk about wrong-headed thinking. Advocates for the inmates whose lives would be immeasurably improved by taking them out of solitary confinement contend that those jobs don't have to be filled immediately. A state prison system with a declining inmate population has ample space to house some of the most vulnerable prisoners of all.

As long as the Paterson administration insists that money is indeed the overriding issue here, then it had best be even more diligent and frugal in controlling state spending. No more extravagantly expensive rugs for the governor's mansion, for example. And no other excessive perks. A state government that can put a price tag on ending cruel and unusual punishment ought to be able to save money in the most creative and, yes, humane ways imaginable.

Meantime, maybe some of the governor's crack budget-cutters can calculate the cost of keeping a few hundred already damaged human beings in The Box for a few more years. Isn't there a price to be paid ultimately for the loss of social contact and the inadequate food and medical care these inmates must further endure, not to mention symptoms so terrifying that they frequently lead to suicide attempts?

It's state spending that needs to be reined in, not any sense of decency and compassion in state government.

The issue: The governor thinks a good way to save money is to keep mentally ill prison inmates in The Box.

The Stakes: The most vulnerable become the most expendable in such an approach to cutting spending.



On the Frontiers of Science

Childhood Predictors of Complete and Severe Suicide Attempts: Findings from the Finnish 1981 Birth Cohort Study

A recent study of 5302 Finish citizens indicates that males who completed suicide and/or made serious suicide attempts in adolescence or early adulthood had psychiatric problems by the age of 8, including living in a nonintact family, psychological problems as reported by a primary teacher, or conduct, hyperkinetic and/or emotional problems. Male suicides were predicted most strongly by children identified as having both conduct difficulties and internalizing their problems. No predictive associations among the study variables were found among the females.

A. Sourender, et.al

Archives of General Psychiatry

April 13, 2009

Yi-Gan San as Adjunctive Therapy for Treatment-Resistant Schizophrenia: An Open-Label Study

Recent studies indicate that the traditional Japanese herbal medicine yi-gan san may be safe and useful in treating behavioral and psychological symptoms in patients with dementia and borderline personality disorder, as well as treatment-resistant schizophrenia. A significant decrease in both positive and negative symptoms measured on the PANNS scale was observed, but not in the control group.

Tsuyoshi Miyaoka, MD, et.al.

Clinical Neuropharmacology, Vol. 32, pages 6-9

January-February 2009

The CATIE Schizophrenia Trial

The massive, government-sponsored CATIE study has some discouraging news regarding maintaining pharmacological treatment in schizophrenia. Only 26% of patients completed the 18-month trial on the medicine they were originally prescribed. Patients receiving olanzapine stayed on their medication a slightly longer time, despite its association with metabolic disturbance, especially weight gain.

Perphenazine (Trilafon) an older antipsychotic, unexpectedly showed comparable levels of effectiveness and produced no more extrapyramidal side effects than the newer medications. Despite elevated prolactin levels, risperidone was the best tolerated medication.

Ziprasidone ((Geodon) was associated with weight loss and with positive impact on lipids and blood glucose. Olanzapine and risperidone showed greater effectiveness in tolerability.

Clozapine demonstrated better effectiveness compared to other agents for patients who discontinued their first medication because it wasn't effective.

T.C. Manschrek, et.al.

Harvard Review of Psychiatry

March 13, 2009

Add-on Mirtazapine Enhances the Antipsychotic Effect of First Generation Antipsychotics

In a recent double-blind, placebo-controlled trial, mirtazapine outranged placebo on almost all measures. The PANSS (Positive and Negative Syndrome Scale) score for positive symptoms decreased by 17.2% with mirtazapine vs. 1.6 with placebo, and the PANSS score for negative symptoms decreased by 12% for mirtazapine and 3% for placebo.

G. Joffe et. al.

Schizophrenia Research

March 25, 2009

AHRQ: Research Summaries

Most Office-Based Psychiatrists are Providing Medication Rather Than Psychotherapy to Their Patients

The use of psychotherapy has declined markedly among U.S. office-based psychiatrists, reveals a new study. For instance, the percentage of visits to psychiatrists that included psychotherapy dropped from 44.4 percent during 1996-1997 to 28.9 percent in 2004-2005. Similarly, the number of psychiatrists who provided psychotherapy to all of their patients fell by nearly half from 19.1 percent to 10.8 percent during that time. The researchers attribute the decline in psychotherapy to a drop in the number of psychiatrists specializing in psychotherapy and a corresponding rise in those specializing in drug therapy. They note that these changes were likely sparked by reimbursement policies favoring brief medication management visits over psychotherapy and the introduction of new psychotropic medications with fewer adverse effects in recent years. The study was supported in part by the Agency for Healthcare Research and Quality (AHRQ).

www.ahrq.gov/research/feb09/0209RA24.htm

Social Security Clogged with Disability Claims

TAMPA, Florida — For all the talk of an impending crisis in Social Security, one already exists: The system is clogged with hundreds of thousands of disputed disability claims, a backlog so big that some people wait years for a hearing.

Social Security officials blame underfunding, understaffing, a dramatic rise in cases and an increasing number of claims involving hard-to-prove ailments, such as back pain, depression and anxiety.

Even with a \$500 million infusion from the federal stimulus program, it could take years to clear the backlog. In the meantime, many of those who have applied for benefits struggle to make ends meet.

Social Security benefits are available to people who can no longer work because of a disability, regardless of whether it was suffered on the job or off. The monthly checks average \$1,063. Someone seeking benefits must first send an application and wait an average of 106 days for a decision, according to the Social Security Administration. The agency denies nearly two-thirds of the applicants, who then can request a hearing to appeal.

Then the real wait begins. Those who received a hearing last fiscal year had waited nearly a year and half on average — twice the wait time in 2000, according to the SSA. More than 765,000 people — about double the number in 1998 — are now waiting for a hearing.

Sixty-one percent of applicants who go through an appeal hearing are ultimately approved for disability benefits.

Since 1990, the number of Americans receiving Social Security disability has more than doubled, to 7.4 million, while the number of staffers to process the claims — and sort out the fakers from the truly disabled — has dropped by around 5 percent.

“Workloads have gone up, resources did not go up proportionately, and the agency was too slow to embrace new technologies,” said Social Security Commissioner Michael Astrue, explaining the backlog. “It’s a combination of all those things.”

Also, Astrue noted that at the start of the disability program in 1957, the vast majority of applicants were blue-collar

workers, generally with a single disability from a traumatic accident. That is no longer the case.

Recipients receive benefits if they are deemed mentally or physically unable to work and the condition is expected to last at least a year or will lead to the person’s death.

People injured on the job can often collect workers’ compensation, though it generally runs out after a certain amount of time, while Social Security benefits continue as long as the disability persists.



Rep. Kathy Castor, D-Fla., introduced a bill that would require a hearing be held no more than 75 days from the time it is requested, and a final verdict no more than 15 days after that. Castor represents Tampa, one area where the backlog has been particularly bad. “It’s crushing, especially during the economic crisis,” she said.

Astrue said Castor’s proposal does not take into account the time applicants need to prepare their cases. He has set a goal of a nine-month maximum wait for a hearing.

“The long waits aren’t acceptable,” Astrue said. “But it’s not something you can fix overnight.”

Applicants increasingly have found they are unable to navigate the system on their own — 85 percent of them, by Astrue’s estimation, hire a lawyer or obtain other representation to help prepare their paperwork, gather medical records and ready them for a hearing.

The Social Security Administration is approaching the problem from multiple angles — experimenting with electronic records to speed up medical reviews, hiring more judges and other staff, and adding offices — but the efforts only go as far as the funding.

The recently passed budget gave the Social Security Administration \$126.5 million more than President Barack Obama requested, and many see the increase, combined with the stimulus relief, as the best chance the agency has had to relieve the backlog.

*Matt Sedensky
Associated Press
April 01, 2009*

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Put him in a prison cell and you have a John Bunyan.
Bury him in the snows of Valley Forge and you have a George Washington.
Have him born in abject poverty and you have a Lincoln.
Put him in the grease pit of a locomotive roundhouse and you have a Walter P. Chrysler.
Make him second fiddle in an obscure South African orchestra
and you have a Toscanini.
The hardships of life are sent not by an unkind destiny to crush,
but to challenge

Exhaustion: Causes and Treatment (Rodale)

