

# the challenger

A Publication of the NATIONAL ALLIANCE on MENTAL ILLNESS in Buffalo & Erie County Vol 1 No.6  
January - February 2010

## Mark Your Calendar

All regularly scheduled 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).

### January

**No NAMI Board Meeting.**

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

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

### February

**NAMI Board Meeting,** Thursday, February 4, 7:30 PM.

Come meet your NAMI Board members!

**NAMI Monthly Educational Meeting,** Thursday, February 11. Library and Coffee Hour 7 PM. Program: "Minds on the Edge" a spectacular new documentary video, following by open discussion.

**NAMI Family Support Meeting,** Wednesday, February 24th, 7 PM.

### March

**NAMI Board Meeting,** Thursday, March 4, 7:30 PM.

All NAMI members are welcome to attend.

**NAMI Educational Meeting,** Thursday, March 11, Library and Coffee Hour: 7 PM. Presentation: 7:30 PM. Guest speaker: To Be Announced.

**NAMI Family Support Meeting,** Wednesday, March 24, 7 PM.

### April

**NAMI Board Meeting,** Thursday, April 1, 7 PM.

If you're a NAMI member, you're welcome to join us.

**NAMI Educational Meeting,** Thursday, April 8. 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 Family Support Meeting,** Wednesday, April 22, 7 PM



## Christmas is for Kids

Mrs. Santa, aka President Mary, was making the lists and checking them twice and three times as we prepared for Christmas liftoff, and NAMI's major winter project to brighten the lives and gladden the hearts of nearly 600 mentally ill or seriously emotionally disturbed children and teens this holiday season.

Youngsters in Bry-Lin, Erie County Medical Center, homeless shelters, group homes, foster care...all those places that house and treat, but don't love, the "throw-away" kids. Little ones living in poverty with a parent who may also be mentally ill—or in jail, in the hospital, away at war, or dead.

So Mary collects the wish lists, shops all year, and like a philharmonic conductor, orchestrates and organizes a mighty effort to ensure that no child in need is forgotten. With the collaboration and invaluable aid of Tom McNulty, the staff of MHA, and Tom's own very special family in gathering gifts and resources, NAMI is poised once again to provide toys and teddy bears, pajamas and socks and blankets, dolls and dreams to "our" children across Erie County and as far away as Fredonia. Wrapping and sorting took place Saturday, December 12th. Along with "our" kids, we wish all of you a very Happy New Year!

Mailing Address • 302 Parkhurst Blvd. • Buffalo, NY 14223 • 716.832.4035  
WEB SITE: [www.NAMI BuffaloNY.org](http://www.NAMI BuffaloNY.org) E MAIL: [namibuffalo@aol.com](mailto:namibuffalo@aol.com)

# Heart Disease A 'Silent Killer' in Patients with Severe Mental Illness

A large new study confirms that people with severe mental disorders — such as schizophrenia or other psychotic disorders — are 25 percent to 40 percent more prone to die from heart disease than people without mental illness are.

Moreover, smoking and physical inactivity — behaviors that individuals potentially can change — significantly contribute to this increased risk of death, found researchers led by Amy Kilbourne, Ph.D.

They looked at results from the 1999 Large Health Survey of Veteran Enrollees in conjunction with the VA's National Psychosis Registry and the National Death Index of the Centers for Disease Control and Prevention (CDC). Including responses from more than 147,000 veterans, the study is the largest of its kind to ever take place. Most of the respondents were men and about two-thirds were 50 or older.

Kilbourne, associate director of the VA Ann Arbor National Serious Mental Illness Treatment Research and Evaluation Center in Michigan, and colleagues from Dartmouth Medical School conducted the study, which appears in the November-December issue of the journal *General Hospital Psychiatry*.

Patients with mental disorders who also had a diagnosis of diabetes — a known risk factor for heart disease and a side effect of some antipsychotic medications — were at high risk for heart disease-related mortality, as were patients with a diagnosis of dementia.

Smoking and lack of exercise, both common behaviors in people with mental disorders, contributed

to the heart disease-related deaths considerably.

"These are devastating illnesses that lead to a lot of functional impairment, so many of these individuals have difficulty staying motivated to exercise to begin with, or finding places where they feel comfortable exercising," Kilbourne said.

However, even when considering factors such as diabetes and lifestyle, researchers found that patients with schizophrenia or other psychotic disorders were still more likely to die from heart disease. "This suggests that we are either missing some factor, or there is something inherent about having these disorders that puts patients at greater risk for heart disease-related mortality," Kilbourne said.

Eric Goplerud, Ph.D., director of the Center for Integrated Behavioral Health Policy in Washington, said that results of this study and others suggest that people with serious mental illnesses are far less likely to receive medical screening and general preventive care. He said that lack of coordinated care has serious consequences: "Serving their mental needs in one stovepipe and their medical needs in another is probably associated with premature mortality."

"The issue of cardiovascular disease in this population is huge," Goplerud said. "As we look at national health reform, it is absolutely critical that people with mental illness and addictions be included — they are dying of preventable medical conditions."

*Kilbourne AM, et al. Excess heart-disease-related mortality in a national study of patients with mental disorders: identifying modifiable risk factors.*

*Gen Hospital Psychiatry 31 (6), 2009.*

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People with mental illnesses such as depression and anxiety are the heaviest smokers in the country, but their doctors are afraid to ask them to quit. They assume that if their patients try to quit smoking, their mental disorders will get worse.

That is a myth, according to Brian

Doctors erroneously believe mental disorders will worsen if they take away a person's tobacco. "Not a single study shows that symptoms get worse," Hitsman said. He examined 13 randomized clinical trials that measured psychiatric symptoms during smoking cessation treatment. Seven studies showed that psychiatric symptoms actually improved during smoking cessa-

People with mental disorders do have a harder time quitting than the general population, Hitsman acknowledged, but said newer studies show it is possible to enhance the chance of success with this approach. Even if patients simply reduce their smoking, they are much more likely to quit successfully at a later date.

## DOCTORS FEAR ASKING MENTALLY ILL TO QUIT SMOKING



Hitsman, a tobacco addiction specialist and assistant professor of preventive medicine at Northwestern University Feinberg School of Medicine. He also is a member of the Robert H. Lurie Comprehensive Cancer Center of Northwestern University.

This population's tobacco use and dependence need to be treated, he said. Hitsman has designed and published the first comprehensive, evidence-based plan for psychiatrists, psychologists and other mental health providers to help their patients quit smoking. His paper appeared in a recent issue of *The Canadian Journal of Psychiatry*.

"These doctors and mental health specialists focus on their patients' psychiatric health and lose track of their physical health," said Hitsman, who is a health psychologist. "Tobacco cessation gets a lot of attention, but we leave out a population that smokes the majority of all the cigarettes."

Between 40 to 80 percent of people with mental illness are daily smokers, depending on the disorder, compared to less than 20 percent of people who don't have problems with mental illness, according to research. The mentally ill also smoke more cigarettes per day — often up to two packs. They have a disproportionately high rate of tobacco-related disease and mortality, such as cardiovascular disease or cancer, with a correspondingly heavy financial burden to the health-care system.

The mentally ill receive tobacco treatment on only 12 percent of their visits to a psychiatrist and 38 percent of their visits to a primary care physician, Hitsman said.



tion treatment, and six showed no changes.

Another problem is mental health professionals believe tobacco is not a real addiction compared to other drug addictions.

"The perception is patients need tobacco because it's their only source of pleasure and helps them feel better," Hitsman said. "There is very little evidence, though, that smoking cigarettes serves to self-medicate emotional symptoms."

There is evidence from a few studies, however, that when mental health providers insert smoking cessation treatment into the mental health treatment plan, they can help their patients quit or cut down.

"They find if you take advantage of the relationship with the counselor and insert smoking cessation counseling into treatment that you enhance quit rates," Hitsman said.

His tobacco cessation plan combines cognitive behavioral therapy, pharmacotherapy and motivational counseling to help the patient quit. Hitsman also has identified several treatment medications that may further facilitate quitting for this population.

To help motivate the patient, the counselor highlights the benefits of quitting, the personal costs of smoking and the barriers to cessation success. "It gets the person in a problem-solving mode, at the basis of which is a solid relationship with the counselor," Hitsman said.

Tobacco dependence also needs to be treated as a chronic disease, Hitsman believes. "We know that treatment provided for a longer duration substantially increases the abstinence rates of people without mental disorders," he noted. "Smokers with mental illness may be especially likely to benefit from extended or maintenance tobacco treatment."

Hitsman's colleagues on the paper are Tony George, M.D., professor and chair of addiction psychiatry at the University of Toronto, Taryn Moss, a psychology student at the University of Toronto and Ivan Montoya, M.D., medical director of the division of pharmacotherapies and medical toxicity at the National Institute on Drug Abuse.

*Science Daily*  
September 9, 2009



## Pay Psychiatric Patients to Take Meds?

A team at Queen Mary Hospital in London has begun a study of the effectiveness of paying individuals with schizophrenia and bipolar disorder to take their medication.[1] The study will include 136 patients who "have a very poor track record for taking their medication" and who are all on long-acting antipsychotics, which they receive by injection every two weeks or so. Half of them will be paid £15 (about \$24) each time they come in for their injection, and half will receive no money and will thus be controls. Both groups will then be followed to see whether the payments make a difference in preventing relapses and rehospitalizations.

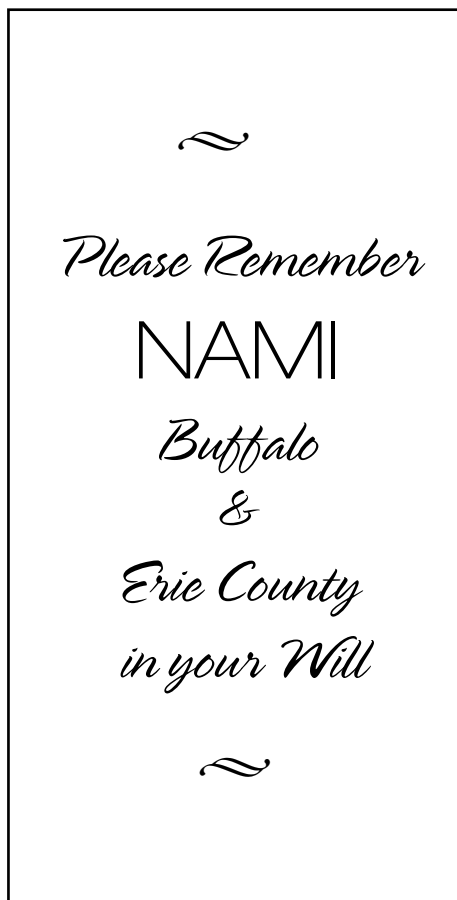
Paying patients to take their prescribed medication or to otherwise follow up their medical care, immunizations, etc., is not a new idea but has been little used in psychiatry. A 1997 article in the British Medical Journal analyzed 11 such studies published between 1976 and 1996; in 10 of the 11 studies, the individuals who received payments did significantly better than those who did not.[2] For example, in a study of hypertension, patients were paid on a sliding scale from \$4 to \$16 depending on how close their blood pressure was to the target number. Payments have also been demonstrated to be effective in patients with tuberculosis, thus reducing rehospitalizations.

Objections to such studies have focused mostly on ethical issues such as, is it coercive? MIND, a politically correct British mental health charity, opposes the Queen Mary Hospital program because they claim "it runs counter to informed decision making." Most patients involved in the study are in it, of course, because they have anosognosia and do not know they are sick; thus, they are anatomically unable to carry out "informed decision making." But groups like MIND do not pay attention to such issues. Arguments in favor of payment programs include the fact that

patients in such programs are likely to lead much better-quality lives and spend less time homeless, incarcerated, or rehospitalized. It is thought that the modest cost of such programs will be more than offset by savings in decreased rehospitalization alone.

We need more data on such programs for individuals with severe psychiatric disorders. Theoretically, the federal Substance Abuse and Mental Health Services Administration (SAMHSA) should be supporting such demonstration projects, but this is a hopelessly politically correct agency and is unlikely to do so. We will have to wait for the braver Brits to show us the way.

*E. Fuller Torrey, M.D.  
Treatment Advocacy Center  
October 2009*



## Study May Prompt Rethink On Schizophrenia Drugs

- Fewer deaths with clozapine than newer drugs
- Call to consider cheap generic as first-line treatment
- Finnish study fuels debate on atypical antipsychotics

LONDON, July 13 (Reuters) - Schizophrenia patients given a cheap older drug are less likely to die prematurely than people on newer treatments, despite the older product's well-known adverse side effects, Finnish researchers said on Monday.

The finding may lead to wider use of clozapine — sold by Novartis as Clozaril, but also available as a generic — instead of newer drugs like AstraZeneca's Seroquel, the current market leader.

Clozapine was the first of a new generation of schizophrenia drugs, known as atypical antipsychotics. But its use has been restricted by health authorities because of safety concerns and patients taking it require regular blood tests.

Despite this, an analysis of 10 years' records for 67,000 patients in Finland found that, compared to treatment with the first-generation drug perphenazine, the risk of early death for patients on clozapine was reduced by 26 percent.

By contrast, mortality risk was 41 percent higher for those on Seroquel, known chemically as quetiapine; 34 percent higher with Johnson & Johnson's Risperdal, or risperidone; and 13 percent higher with Eli Lilly's Zyprexa, or olanzapine.

"We know that clozapine has the highest efficacy of all the antipsychotics and it is now clear, after all, that it is not that risky or dangerous a treatment," study leader Jari Tiihonen of the University of Kuopio said in a telephone interview.

# Spontaneous Mutations Widespread in Non-familial Schizophrenia

People with schizophrenia from families with no history of the illness were found to harbor eight times more spontaneous mutations - most in pathways affecting brain development - than healthy controls, in a study supported in part the National Institutes of Health's (NTH) National Institute of Mental Health (NIMH). By contrast, no spontaneous mutations were found in people with schizophrenia who had family histories of the illness.

"Our findings strongly suggest that rare, spontaneous mutations likely contribute to vulnerability in cases of schizophrenia from previously unaffected families," said Maria Karayiorgou, M.D., of Columbia University, who led the research team. "This may also shed light on why the illness has frustrated efforts to implicate gene variants with major effects, and seems to defy natural selection by persisting in the population even though relatively few of those affected have children." (Karayiorgou and her colleagues report on their whole genome study online in *Nature Genetics*. May 30, 2008.)

"Such abnormal deletions or duplications of genetic material are increasingly being implicated in schizophrenia and autism, explained NIMH Director Thomas R. Insel, M.D. "Now we have a dramatic demonstration that genetic vulnerabilities for these illnesses may not be inherited from parents, at least in the sense that these vulnerabilities were not present in the parental genome. This line of research holds promise for improved treatments - and perhaps someday even prevention of developmental brain disorders."

Although it's known that genetics plays a major role in the transmission of both autism and schizophrenia, most cases are sporadic rather than familial.

Echoing findings of another recent study (<http://www.nimh.nih.gov/science-s/2008/rates-of-rare-mutations-soar-three-to-four-times-Wgher-m-scluzopluenia.shtml>), Karayiorgou and her colleagues determined that most of the suspect mutations were not random, but found in genes and pathways involved in brain development. However, whether a mutation was spontaneous or inherited was not determined for most of the subjects included in the earlier study.

To pinpoint the sources of the glitches, the researchers in the new study compared genetic

data from 369 subjects with data from their biological parents - in a total sample of 1,077 individuals drawn from the European ancestry Afrikaner population in South Africa. Including parental genes makes it possible to definitively determine what's inherited.

Scans of each person's genome detected the spontaneous mutations in 15 of 152 individuals (10 percent) with non-familial schizophrenia, and only in two of 159 people (1 percent) without the illness - the eightfold difference. Such sporadic cases were only 1.5 times more likely than controls to harbor inherited mutations.

The researchers also found three deletions of genetic material at a site on chromosome 22 previously implicated in schizophrenia, confirming it as the only known recurrent such mutation linked to schizophrenia. In addition to NIMH, the current study also cites support from the NIH's National Cancer Institute, National Institute of Diabetes and Digestive and Kidney Diseases, National Eye Institute, and the Lieber Center for Schizophrenia Research at Columbia University.

The National Institute of Mental Health (NIMH) mission is to reduce the burden of mental and behavioral disorders through research on mind, brain, and behavior. More information is available at the NIMH website, <http://www.nimh.nih.gov>. The National Institutes of Health (NTH) - The Nation's Medical Research Agency - includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases.



Continued from page 4

## Thousands Of Premature Deaths

Tiihonen estimates clozapine is given to around one fifth of Finnish schizophrenia patients, but less than 5 percent in the United States.

Clozapine's side effects include agranulocytosis, a potentially fatal decline in white blood cells, and current rules stipulate the drug can only be used after two unsuccessful trials with other antipsychotics.

Tiihonen and colleagues wrote in the *Lancet* medical journal that these restrictions should be reassessed in the light of their findings, since not using the drug may have caused thousands of premature deaths worldwide.

Seroquel, Zyprexa and Risperdal are among the world's top-selling drugs, with a combined sales of \$12.5 billion in 2008, although Risperdal now faces generic competition.

Worries about the safety profile of all the atypical antipsychotics have loomed large since 2002, however, following evidence of increased rates of diabetes and cardiovascular disease.

The Finnish study found no pronounced differences in heart deaths between the different atypicals, but patients on clozapine had a substantially lower risk of suicide while those on Seroquel were more likely to kill themselves.

An AstraZeneca spokeswoman said the Anglo-Swedish company was comfortable that Seroquel was safe, effective and an important treatment for mental illness.

*Ben Hirschler  
Reuters  
July 13, 2009*

## NAMI's Future Fund Will YOU help?

Hundreds of mental health agencies in Erie County and across the state, have already suffered crippling budget cuts, affecting programs and even their very survival, which means cuts in services and access, longer waiting times, or even no services at all for some of our mentally ill loved ones. Buffalo Psychiatric Center has cut fifty inpatient beds. There is little or no money for new residential opportunities for those in need. Other hospitals such as ECMC and BGH are facing looming cuts in reimbursement for mental health inpatient and outpatient services. Cuts in transportation funds, case management, vocational programs, psychiatrist reimbursement rates are threatened by New York State's billion-dollar financial shortfall. And all reports indicate that things are simply going to get worse in 2010.

NAMI has always been here to help families find the best services; direct families in filing complaints regarding inadequate or poor care; provide support, sympathy, and empathy to families in pain or crisis through our monthly support meetings; provide knowledge and understanding, and common ground through our monthly educational meetings, our library, and the wonderful Family2Family 12-week classes.

Our dedicated volunteers teach our classes, attend meetings and sit on committees and task forces to represent the family point of view. Volunteers compile our newsletter, respond to hundreds of requests for information every year, answer more than a thousand phone calls, help families write letters, keep current on new medications, and program development.

If we had to pay for all the donated time, expertise, and effort so generously given the bill would run to tens of thousands of dollars. But so many NAMI families step up to the plate and help to shoulder the work that we're home free—well, almost free....

There are printing costs, and phone bills, office equipment and supplies, library purchases, postage, utilities, Christmas is for Kids, and lots of other expenses. Will you help?

And there's tomorrow.... The day looms when NAMI will have to have some paid staff to manage our organization, to keep it going for all the families today and tomorrow for those struggling with mental illnesses in their families. The Future Fund is our way of ensuring that NAMI Buffalo & Erie County will be here to answer the call, comfort those in need, teach those hungry for knowledge about mental illness, and provide a safe and welcoming haven for every family struggling with mental illness.

Please find your Future Fund contribution envelope (or call Mary at 832-4035 if you've misplaced it) and make as generous a contribution as you possibly can. AND, consider volunteering for some of the tasks that have to be done to keep us going!

## NAMI's Future Fund

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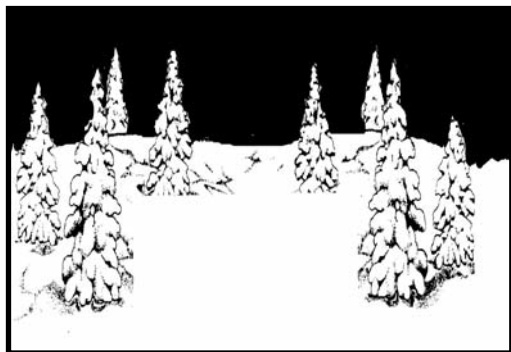
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*If you also want to be a member of NAMI New York State, add \$3.00 to your membership dues. If you want to be a member of the National NAMI, add \$10.00 to your dues.*

*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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*The best way to cheer yourself up is  
to try to cheer somebody else .*

*Peace is not a season, but a state of mind*

