PATHways

Newsletter of NAMI QUEENS/NASSAU *and* NAMI NASSAU AFFILIATES

February/March 2010

The Zucker Hillside Hospital
Sloman Auditorium
76 Avenue & 266 Street
Glen Oaks, NY

7:30 p.m.
(Caring & Sharing at 6:00 P.M.)

FEBRUARY 17, 2010

Friendship Network

Alice Cohen, Director
Nancy Schlessel, Social Worker, LMSW

Friendship Network, sponsored by NAMI Queens/Nassau, is a unique socialization program that introduces adults recovering from mental illness to each other for friendship. This is your opportunity to learn more about the program, who is eligible and how to apply. We will also share several stories and articles written by our members about their experiences in Friendship Network. Attend this worthwhile meeting and you will walk away smiling!

MARCH 17, 2010

Recovery: What Are We Really Talking About?

Barbara Tedesco, Director of Consumer Link, the Peer Support and Advocacy Division of Mental Health Association of Nassau County, and Adjunct Professor at Hofstra University

Twenty years ago, this was a word that we rarely, if ever, heard when we were referring to individuals diagnosed with mental illnesses. Now we hear the word every which way we look, but there still seems to be a lot of confusion. What are we really talking about? Come listen, learn and share your thoughts.

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NAMI Queens/Nassau, an affiliate of the National Alliance on Mentally Illness and NAMI/NYS, gratefully acknowledges the continuing support of the FLB Foundation

NAMI Queens/Nassau Donation & Membership Form

Yes! I want to join NAMI Queens/Nassau to receive useful information and to help improve conditions for those with mental illness. I will receive newsletters from NAMI Queens/Nassau, NAMI, and NAMI-NYS.

MEMBERSHIP DUES: ___ $40 Individual ___ $50 Family
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(A portion of the dues goes to NAMI and NAMI-NYS)

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Nassau County NAMI Affiliates Meeting Info

Affiliate	Location	Date/Time	Contact
NAMI LAMP/ SW Nassau	Peninsula Counseling Center 50 W. Hawthorne Ave, Room 211 Valley Stream	2nd Wed. of Month 6:30 p.m. Support 7:30—9:00 p.m.	Sydelle Wolfsohn (516) 623-7871
NAMI Long Island Regional Council, Inc.	North Shore University Hospital 888 Old Country Rd. Plainview	3rd Thursdays 7:00 p.m. Support 7:30 p.m. Business 8:00 p.m. Speaker	Barbara Roth (516) 694-7327
NAMI North Shore	North Shore Hospital Building 400, Rm. 74 Community Drive	3rd Tuesday 7:30 p.m.	Al Dunlop (516) 671-3957
South Oaks NAMI	South Oaks Hospital 400 Sunrise Highway Amityville	4th Thursdays 7:00—9:00 p.m.	Una Ward (631) 264-4000 Ext. 1-2004
NAMI Nassau University Medical Center	2201 Hempstead Tpke. Conference Rm, 14th Fl East Meadow	1st Wednesday of Month 7:00 p.m.	Angela Liesau (516) 731-0128

From the President

Greeting the New Year with Determination to Lick Stigma

By **JANET SUSIN**

New Year's morning, when I walked out my front door to get the newspaper, I was greeted by an unfamiliar sight: a silver balloon tied with gold ribbon had found its way to our walkway. Still fully inflated, it stayed around for days after, and although strong winds moved it a few feet this way and that, it held its ground and stubbornly refused to leave our property.

I'm not generally superstitious, but I can't resist the temptation to see this as an omen. After the terrible aughts, the zeros or whatever other moniker you might want to attach to the first decade of the 21st century, I hope you'll indulge me in a little optimism. I think this is the decade when we will lick stigma or at least take a giant step forward in that direction. A startling statement I know, but suddenly everyone seems to be interested in doing something about it. The signs are everywhere.

Wide Recognition of the Need to Combat Stigma

An unprecedented number of mental health organizations have united in supporting *Bring Change2Mind* campaign, an anti-stigma campaign started by Glenn Close with the help of Ron Howard; Howie Mandel, former host of the popular TV show, *Deal or No Deal*, is crowing with pride on Twitter that his autobiography, *Don't Touch Me,* about his struggles with OCD is enjoying its fourth straight week on the *New York Times* best seller list; the chair of the NYS Assembly Mental Health Committee, Peter Rivera, is bringing the *Open Minds, Open Doors* program from Texas to 700 schools in New York State along with the *I am Not My Mental Illness* promotional materials.

Moreover, the national interest in overcoming stigma is matched by an international one as well. An example is Scotland's *See Me* campaign that features brothers and sisters in TV ads playing golf and shoe shopping together with the tagline "How you support someone with a mental health problem makes all the difference." And just this past week we received a request from the Virgin Islands for a cost estimate on purchasing our *Breaking the Silence* instructional materials for use in schools throughout the educational system.

How Best to Fight Stigma?

But at the same time that there is universal agreement about the need to overcome stigma, there is no agreement about how best to accomplish this daunting task. *Bring Change2Mind*, with TV commercials shot by Ron Howard in Grand Central Station, emphasizes the prevalence of mental illness and features real people in supportive relationships, including Glenn Close with her bipolar sister. Although the commercials are quite different, the approach is similar to that taken by Scotland's *See Me* campaign, which emphasizes the importance of supportive relationships.

Another approach is that described in *Schizophrenia Magazine*, newly dubbed *SZ.* In an article subtitled *Taming the Criminal Myths* they argue that the root cause of stigma is media portrayals of people with schizophrenia as violent, and cite the *Time to Change* campaign in Britain that blames Hollywood for erroneously portraying people with schizophrenia and other mental illnesses as evil, taking the British press to task for their exceptionally graphic headlines such as "Father who ate son's eyeball may be schizophrenic." This is, of course, an approach that has long been adopted by NAMI's Stigmabusters, and Jean Arnold's Stigma Clearinghouse in the 90s. *Time to Change* seeks to counter these images by raising awareness about famous people in the past who struggled with mental illness, such as Winston Churchill, Abraham Lincoln and Florence Nightingale, and asks what our world would be like without their accomplishments.

Perhaps most controversially, the January 10, 2010 issue of *New York Times Magazine* features an article called the *The Americanization of Mental Illness,* which argues that the approach taken by organizations such as NAMI that seek to destigmatize mental illnesses by portraying them as no-fault brain diseases paradoxically has the contradictory effect of increasing stigma. They say research shows that people are more likely to be sympathetic when given a psychosocial explanation for a mental illness rather than a biological one, which they tend to view as intractable. This is already a much emailed article and will no doubt be hotly debated in the weeks to come.

NAMI Queens/Nassau Can Play an Important Role in Changing Perceptions about Mental Illness

So where does this leave us as we pursue our goal of fighting stigma through NAMI. As you know, for the past two years we've been engaged in a National Institute of Mental Health (NIMH) research study to test the effectiveness of our *Breaking the Silence* (BTS) middle school plans in increasing knowledge and changing attitudes and behavior about mental illness. In doing this we have had the good fortune to partner with Professor Otto Wahl from the University of Connecticut, one of the leading experts on stigma in the country. Using test sites in New Mexico, South Carolina, Florida, and New York, we compared students who received instruction about mental illness through BTS with other students who did not. We've finished crunching the data and are happy to report that the study shows that BTS is effective in increasing knowledge and changing attitudes and behavior. To quote Otto Wahl's Executive Summary: "Even brief instruction (2 1/2 to 3 hours) can produce change in how students understand mental illnesses. Given the ease of administration of this program, BTS is a very promising approach to improving the way children perceive and respond to mental illness."

At the same time, misperceptions about mental illness persist even after instruction. They include seeing schizophrenia as a mental illness involving multiple personalities and violence. Moreover, students did not improve in their perception of mental illnesses being biologically

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Breaking the Silence Proven to be Effective; Mental Illness Education Does Make a Difference!

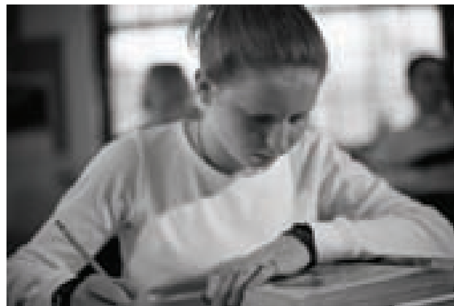
National Institute of Mental Health Research Study Completed for the Mental Health Education Program, "Breaking the Silence"

NAMI QUEENS/NASSAU Press Release

Long Island, N.Y., January 2010**-** A two year study sponsored by the National Institute of Mental Health (NIMH) to assess change in knowledge, attitude, and behavior relating to mental illness in middle school students through instruction with *Breaking the Silence* (BTS) lessons has concluded that the BTS program is effective in promoting growth in these areas.

"Even brief instruction (2 ½-3 hours) can produce change in how students understand mental illnesses. BTS is a very promising approach to improving the way children perceive and respond to mental illnesses, "stated Dr. Otto Wahl, Ph.D., director, Graduate Institute of Professional Psychology, University of Hartford and principal research investigator. Dr. Wahl added, "Although the BTS program has been around for many years and has received much praise, it has not previously received a careful empirical assessment of its effectiveness. It was important to address the question of whether this widely used program is accomplishing its goals. Middle school students from different parts of the U.S. were the focus of the research and we can now statistically document that instruction in BTS does result in improvements in knowledge, attitudes, and/or behavior related to mental illnesses."

"Substantial research has established that the public holds inaccurate negative beliefs about those with mental illnesses, seeing them as dangerous, unpredictable, unattractive, unworthy, and unlikely ever to be productive members of society; creating an environment that impedes both treatment seeking and recovery. Children and adolescents are particularly sensitive to public opinion and attitudes. Ostracism, rejection, teasing, and damage to self-esteem, as well as reluctance to seek or accept mental health treatment, are among the possible consequences. Given the results of this study, we can now site that by educating children about mental illnesses we can change attitudes and foster more accurate understanding and acceptance of people with psychiatric disorders," explains Janet Susin, president of NAMI Queens/Nassau and NAMI New York State.



Research methodology included the development, pilot testing and revision of questionnaires about mental illnesses. Two groups of students from middle schools in NY, Florida, South Carolina and New Mexico were administered questionnaires; one group received BTS instruction, the other (control group) did not; both groups received the questionnaires a second time after BTS instruction; both groups completed questionnaires a third time, six weeks post instruction.

Students in the groups that received BTS instruction showed a statistically significant increase in accurate knowledge of mental illness after receiving the BTS instruction. Those in control groups showed no significant improvement in knowledge. Improvements in attitudes were maintained through the six-week follow-up period.

BTS is an innovative teaching package which includes lesson plans, games, and posters on mental illness for three grade levels—upper elementary, middle school, and high school. Students learn the warning signs of mental illnesses, learn that mental illness can be treated successfully, and learn how to recognize and combat stigma. The BTS program also has the relatively unique feature that it is delivered by regular teachers rather than by outside experts.

From the President: Greeting the New Year...

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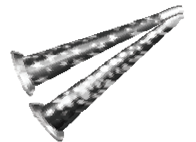

based. We look forward to tackling these challenging areas when we next revise our materials.

NAMIWalks can also be a powerful stigmabusting tool. If there's one thing that encourages social acceptance, it's the "each one, reach one" approach that our Walkathon fosters. The more proactive we can be in shaping the image of mental illness through sharing our stories, the more likely we are to move the anti-stigma needle .

Finally, we are beginning to make progress with our *In Our Own Voice* program. Using a structure developed by NAMI national, consumers use their own stories to take audiences on a journey from their dark days through to their recovery and hopes and dreams for the future.

So please help us make this the decade when we take a huge leap forward in gaining social acceptance for everyone struggling with mental illness by playing an active role in promoting and taking part in these NAMI stigmabusting projects. How's that for a New Year's resolution!

Study: More of Today's US Youth Have Serious Mental Health Issues Than Previous Generations

By **MARTHA IRVINE** (CP)
Canadian Press

CHICAGO — A new study has found that five times as many high school and college students in the U.S. are dealing with anxiety and other mental health issues than youth of the same age who were studied in the Great Depression era.

The findings, culled from responses to a popular psychological questionnaire used as far back as 1938, confirm what counsellors on campuses nationwide have long suspected as more students struggle with the stresses of school and life in general.

"It's another piece of the puzzle - that yes, this does seem to be a problem, that there are more young people who report anxiety and depression," says Jean Twenge, a San Diego State University psychology professor and the study's lead author. "The next question is: what do we do about it?"

Though the study, released Monday, does not provide a definitive correlation, Twenge and mental health professionals speculate that a popular culture increasingly focused on the external - from wealth to looks and status - has contributed to the uptick in mental health issues.

Pulling together the data for the study was no small task. Led by Twenge, researchers at five universities analyzed the responses of 77,576 high school or college students who, from 1938 through 2007, took the Minnesota Multiphasic Personality Inventory, or MMPI. The results will be published in a future issue of the *Clinical Psychology Review*.

Overall, an average of five times as many students in 2007 surpassed thresholds in one or more mental health categories, compared with those who did so in 1938. A few individual categories increased at an even greater rate - with six times as many scoring high in two areas:

- "hypomania," a measure of anxiety and unrealistic optimism (from 5 percent of students in 1938 to 31 percent in 2007)
- and depression (from 1 percent to 6 percent).

Twenge said the most current numbers may even be low given all the students taking antidepressants and other psychotropic medications, which help alleviate symptoms the survey asks about.

The study also showed increases in "psychopathic deviation," which is loosely related to psychopathic behaviour in a much milder form and is defined as having trouble with authority and feeling as

though the rules don't apply to you. The percentage of young people who scored high in that category increased from 5 per cent in 1938 to 24 per cent in 2007.

Twenge previously documented the influence of pop culture pressures on young people's mental health in her 2006 book *Generation Me: Why Today's Young Americans Are More Confident, Assertive, Entitled - and More Miserable Than Ever Before*. Several studies also have captured the growing interest in being rich, with 77 per cent of those questioned for UCLA's 2008 national survey of college freshmen saying it was "essential" or "very important" to be financially well off.

Experts say such high expectations are a recipe for disappointment. Meanwhile, they also note some well-meaning but overprotective parents have left their children with few real-world coping skills, whether that means doing their own budget or confronting professors on their own.

"If you don't have these skills, then it's very normal to become anxious," says Dr. Elizabeth Alderman, an adolescent medicine specialist at Montefiore Medical Center in New York City who hopes the new study will be a wake-up call to those parents.

Students themselves point to everything from pressure to succeed - self-imposed and otherwise - to a fast-paced world that's only sped up by the technology they love so much.

Sarah Ann Slater, a 21-year-old junior at the University of Miami, says she feels pressure to be financially successful, even when she doesn't want to.

"The unrealistic feelings that are ingrained in us from a young age - that we need to have massive amounts of money to be considered a success - not only lead us to a higher likelihood of feeling inadequate, anxious or depressed, but also make us think that the only value in getting an education is to make a lot of money, which is the wrong way to look at it," says Slater, an international studies major who plans to go to graduate school overseas.

The study is not without its skeptics, among them Richard Shadick, a psychologist who directs the counseling centre at Pace University in New York. He says, for instance, that the sample data weren't necessarily representative of all college students. (Many who answered the MMPI questionnaire were students in introductory psychology courses at four-year institutions.)

Shadick says his own experience leaves little doubt more students are seeking mental health services. But he and others think that may be due in part to heightened awareness of such services. Twenge notes the MMPI isn't given only to those who seek services.

Others, meanwhile, say the research helps advance the conversation with hard numbers.

"It actually provides some support to the observations," says Scott Hunter, director of pediatric neuropsychology at the University of Chicago's Comer Children's Hospital. Before his current post, Hunter was at the University of Virginia, where his work included counselling a growing number of students with mental health concerns.

While even Twenge concedes more

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Houses of Worship Help Spread the Word

By **ELIZABETH REILLY**

Way back in September '09, the NAMI Queens/Nassau Board was brainstorming ways we could make Mental Illness Awareness month, that occurs in October, known and significant to people other than our members.

One idea that I thought promising was for each of us to contact our own church or synagogue and tell whomever we contacted about NAMI.

I contacted Father Tom Tassone, a former student, but presently a parish priest at St. Aidan Roman Catholic Church, Williston Park. It was Father Tom who suggested I write an article for the church's monthly magazine. He felt that an article would serve to inform many, many people about our organization and the help that awaits them. Here is the article as it appeared in the magazine:

My names is Elizabeth Reilly, a St. Aidan's parishioner, and I wish to tell you about an organization that has given me hope, help and friendship.

When our daughter was hospitalized, my husband and I were told about NAMI — the National Alliance on Mental Illness — by a social worker. She said the organization met monthly and was composed of people who had a loved one suffering from mental illness, such as bipolar disorder, schizophrenia, obsessive-compulsive disorder, etc. As a NAMI member, I learned I was not alone. There are many, many people who are learning to cope with the fact that their child or loved one is mentally ill.

When I first became aware of our daughter's illness, I panicked. I asked, "How could this be?" To my knowledge there was no one in either of our families that had a mental illness. However, back in "those days," families would not have acknowledged such an illness. Mental illness was hidden, denied. It was something to be ashamed of; as if the sick person had committed a crime. Thankfully, time marches on and attitudes change. Today, as we learn more about mental illness, our heads inform our hearts that mental illness, like other illnesses such as diabetes or heart failure, attacks an organ of the body — in this case, the brain — and needs to be treated with intelligence and compassion. There is no disgrace attached to suffering from cancer, is there?

Like other illnesses, when mental illness strikes, it is devastating not only to the affected individual, but also to their family. I want you to know that there is help for family members. NAMI offers a variety of support and education groups. To mention only a few: Family to Family; Sharing and Caring; NAMI Basics. If you want a complete listing of groups whose main purpose is to help you and your family to cope with mental illness or if you simply want more information, please contact NAMI, whose Queens and Nassau office is located at 1981 Marcus Ave, Lake Success, NY, 516-326-0797.

There is an organization that offers hope, help and friendship. All you need to do is call. NAMI is made up of people who have been helped. They care and want to share. Give us a call.

You are encouraged to ask your church, congregation or other organizations to publish in their bulletins or newsletters the availability of our support groups and our meetings.

Study: More of Today's Youth...

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research is needed to pinpoint a cause, Hunter says the study "also helps us understand what some of the reasons behind it might be." He notes Twenge's inclusion of data showing that factors such as materialism among young people have had a similar upswing. She also noted that divorce rates for their parents have gone up, which may lead to less stability.

Amid it all, Hunter says this latest generation has been raised in a "you can do anything atmosphere." And that, he says, "sets up a lot of false expectation" that inevitably leads to distress for some.

It's also meant heartache for parents.

"I don't remember it being this hard," says a mother from northern New Jersey, whose 15-year-old daughter is being treated for depression. She asked not to be identified to respect her daughter's privacy.

"We all wanted to be popular, but there wasn't this emphasis on being perfect and being super skinny," she says. "In addition, it's 'How much do your parents make?'

"I'd like to think that's not relevant, but I can't imagine that doesn't play a role."

Bipolar Disorder Center Opening

We would like to announce the opening of the Long Island Jewish - Zucker Hillside Hospital's Center for Treatment and Research in Bipolar Disorder. We offer a wide of array of clinical services for the patient and their families, including evidence-based psychopharmacological treatment, psychotherapies and the opportunity to participate in cutting-edge research studies.

For an appointment, please call 718-470-4BPD(4273).

Food and Mood

New Research Centers On Link Between Nutrition And Brain Function

By **BINA VENKATARAMAN**
Boston Globe, December 7, 2009

Not all foods are created equal, whether the goal is having a healthier heart or losing weight. And the same could be true when it comes to what we eat and how depressed or happy we feel, how well we learn, and whether we suffer from mental illness.

A study published last month in the *Archives of Internal Medicine* divided a group of 106 overweight and obese people into two groups: About half spent a year following a diet low in fat — say goodbye to steak and pastries — and high in carbohydrates (breads, pastas, beans, potatoes, and rice). The other half went for a year on a low-carb, high-fat diet — have a burger, but skip the bun. In both groups, people lost an average of 30 pounds each and generally said they felt happier two months into the diet.

But after a year on the diet, the people who ate less fat and more carbs continued to report feeling happier and less depressed and anxious than they had before. The other dieters, who ate more fat and less carbohydrates, felt their moods decline from the early rise they had noted.

One reason for the difference, the researchers argued, might be that eating more carbohydrates than fat and protein pumps up the production in the brain of serotonin, a chemical that has been linked with improved mood and mental health.

"There's tremendous interest in how nutrition is related to brain function,'' said Dr. Perry Renshaw, who formerly directed the Brain Imaging Center at McLean Hospital in Belmont, and currently is a psychiatry professor at the University of Utah School of Medicine. Renshaw is studying whether creatine — a chemical found in fish, meat, and eggs — helps women respond more quickly to antidepressants known as SSRIs (selective serotonin reuptake inhibitors). Examples of SSRIs include Prozac and Zoloft. "It does seem there are natural products that have effects on mood.''

Scientists haven't yet developed clinically proven methods to treat mental illnesses and learning impairment with food, but many are working on it.

"Most people thought, until maybe five or 10 years ago, that food's biggest effect on the brain was through regulation of the cardiovascular system and through the rest

of the body,'' said Fernando Gomez-Pinilla, principal investigator for the Neurotrophic Research Laboratory at the University of California-Los Angeles, and the author of a review published last year in the journal *Nature Reviews Neuroscience* on food and the brain.

"The new research shows that the effect of food can be direct on the brain, and that it can be directly related to mood and behavior,'' Gomez-Pinilla said. Advances in physiology, molecular biology, and brain imaging have allowed more of this research to come to light, he added.

No consensus exists among scientists about which foods are most important to mood and mental health. But a number of studies suggest connections between certain nutrients and brain functions. For example, several studies have linked deficiency in omega-3 fatty acids — especially one found in salmon and other fish — to psychiatric disorders, including depression, bipolar disorder, dementia, and schizophrenia, as well as learning and memory problems. Researchers have also drawn links between the antioxidants found in blueberries and improvements in mood and the ability to stay focused. Folic acid, found in spinach and boosted via vitamin B supplements, has been associated with the brain functions needed to prevent depression, and learning and memory problems.

Judith Wurtman, co-author of *The Serotonin Power* Diet and former director of the Triad Weight Management Center at McLean Hospital, advocates a carbohydrate-rich diet for women, whose brains seem to deplete their store of serotonin more rapidly than men, as a way to prevent depression and anxiety. Wurtman's research has shown that carbohydrates found in pretzels, popcorn, or bread — when eaten without protein or fat — can increase serotonin, which improves mood. She recommends that women eat plain pretzels, crackers, or bread, daily at around 4 in the afternoon, when they feel themselves lacking energy or becoming irritable. This can be especially helpful to those suffering from premenstrual syndrome.

Some of the most extensive research linking nutrients to mood, learning, and behavior has focused on omega-3 fatty acids. Omega-3s are an important part of cell membranes vital to brain functions, said Dr. Joseph Hibbeln, acting chief of nutritional neurosciences at the National In stitute on Alcohol Abuse and Alcoholism. The role of those membranes in the nervous system could be compared to the plastic that surrounds wires in the electrical system of a house. Without them, the neurons lack protection and do not function as well.

"If you eat a diet that is deficient in omega-3 fatty acids, it can alter your brain,'' Hibbeln said. "Omega-3 fatty acids can actually reduce suicidal thinking and depression,'' as well as violent behavior.

Over the past century, Hibbeln added, American consumption of foods with omega-3 fatty acids, such as fish, has declined, while we've eaten more fast food and processed foods rich in omega-6 fatty acids (found in soybean oil and seed oils). The omega-6 fatty acids not only do not help brain function, they harm it — by pushing omega-3 fatty acids out of body tissue, according to Hibbeln.

As neuroscience advances, researchers hope to better understand how food and diet influence mental health and behavior.

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Kids' Mental Health Problems Often Unaddressed

By **MEGAN BROOKS**, *Reuter*
SOURCE: *Pediatrics*, online December 14, 2009.

NEW YORK (Reuters Health) - About 13 percent of American children and young teens have at least one mental health disorder, yet only about half have been seen by a mental health professional.

That's according to a survey funded in part by the National Institute of Mental Health (NIMH) and released online today ahead of print in the journal *Pediatrics*.

"We need to get these kids the help they need and determine what the best type of intervention to help kids from suffering needlessly," NIMH researcher Dr. Kathleen R. Merikangas noted in a telephone interview with *Reuters Health*.

The problem, she said, is that there is a severe shortage of mental health professionals with expertise in child psychiatry in the US. "There simply aren't enough child psychiatrists to go around. It's an urgent crisis."

The survey, conducted from 2001 to 2004 among a nationally representative sample of 3,042 children aged 8 to 15, provides a comprehensive look at the rates of six common mental disorders: anxiety disorder, panic disorder, eating disorders (anorexia and bulimia), depression, attention-deficit/hyperactivity disorder (ADHD) and conduct disorder.

Overall, 13 percent of the children met criteria for having at least one of the six mental disorders within the last year. Nearly 2 percent of them had more than one disorder, usually a combination of ADHD and conduct disorder.

Among the specific disorders: 8.6 percent had ADHD, with boys more likely than girls to have the disorder; 3.7 percent had depression, with girls more likely than boys to have the disorder; 2.1 percent had conduct disorder; 0.7 percent had an anxiety disorder (generalized anxiety or panic disorder); and 0.1 percent had an eating disorder (anorexia or bulimia).

With the exception of ADHD, those rates, Merikangas noted in an NIMH-issued statement, are lower that some other surveys have found, although they are comparable to rates in certain studies.

A closer look at the data revealed that children and teenagers of a lower socio-economic status were more likely to report any disorder, particularly ADHD, while those of a higher socioeconomic status were more likely to report having an anxiety disorder.

Mexican-Americans had significantly higher rates of mood disorders than whites or African-Americans, but overall, few ethnic differences in rates of disorders emerged.

Overall, 55 percent of those with a mental disorder had consulted with a mental health professional. Only 32 percent of youth with an anxiety disorder sought treatment.

African-Americans and Mexican-Americans were significantly less likely to seek treatment than whites, highlighting the need to identify and remove barriers to treatment for minority youth, the researchers note.

"We need to raise awareness that most of the problems that we see in adults in terms of depression, anxiety, substance abuse, even psychosis, begin in adolescence, some in childhood," Merikangas told *Reuters Health*. "We need to identify these kids so that we can prevent these conditions from interfering their development — and life."

Food and Mood...

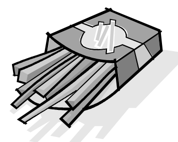
(Continued from page 7)

But understanding how nutrients change brain chemistry will not necessarily mean scientists will know how to treat psychiatric disorders with food. The challenge lies on the level of human decision-making.

"Our diet is very complicated,'' said Robin Kanarek, a psychology professor at Tufts who is conducting research with Renshaw. "We are not just eating one food.'' With the exception of experiments such as the one popularized in the film *Super Size Me*, it's difficult to measure the effect of particular foods because people's diets vary from day to day and month to month. Exercise, stress, and other aspects of lifestyle and the environment can affect how the brain responds to nutrients, and they also affect mood and behavior. And an important, lingering question is what role diet plays relative to genetic predisposition to psychiatric and behavioral disorders. All those factors make it difficult to use food as a treatment for mental illness.

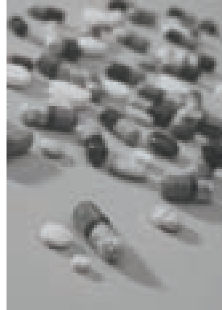
"I think the big picture is that we may never know the role of food,'' said Renshaw. Part of the problem, he added, is that pharmaceutical companies have no incentive to finance the large clinical trials required to prove whether particular foods can treat a mental illness, comparable to the trials done for testing drugs. Government funding, he said, has also been inadequate.

"We'd all like to think there's some food that will make people feel better quickly like the drugs do,'' said Bill Carlezon, a psychiatry professor at Harvard Medical School and director of the behavioral genetics laboratory at McLean Hospital. "I personally don't like taking drugs; I would try the food first.''



Psychiatric Polypharmacy Continues to Grow

By **JOHN GEVER**, Senior Editor
MedPage Today, January 4, 2010
Primary Source: *Archives of General Psychiatry*



Psychiatrists who prescribe drugs for their patients today usually give more than one at a time, often with little scientific basis, researchers said.

About 60% of patients with psychiatrist office visits leading to a drug prescription received at least two medications in 2005-2006, according to government survey data analyzed by Ramin Mojtabai, MD, PhD, MPH, of Johns Hopkins University, and Mark Olfson, MD, MPH, of Columbia University.

That was up from about 43% in 1996-1997 ($P<0.001$), the researchers reported in the January *Archives of General Psychiatry*.

They also found that 33% of prescription-associated visits led to three or more medications in the latter period, compared with 17% nine years earlier ($P<0.001$).

These multiple combinations sometimes involved drugs within the same class — two or more antidepressants for depressed patients, for example — but more often drugs of different classes.

Gaining in popularity during the study period were combinations of antidepressants and antipsychotic drugs, with an adjusted odds ratio of 1.96 ($P<0.001$) for each year during the study period.

"While some of these combinations are supported by clinical trials, many are of unproven efficacy," Mojtabai and Olfson wrote. "These trends put patients at increased risk of drug-drug interactions with uncertain gains for quality of care and clinical outcomes."

Jeffrey Lieberman, MD, of Columbia University, who was not involved with the study, told *MedPage Today* in an interview that the findings were "disturbing and not entirely surprising."

He said earlier studies as well as his own experience had suggested that psychiatric polypharmacy is a growing phenomenon.

We are looking for Men and Women who have Bipolar Disorder

If you have a diagnosis of Bipolar Disorder and are at least 18 years of age, you may be eligible to participate in a research study involving tests of concentration, memory, and thinking.

The study will last approximately 3-5 hours and will involve interviews as well as pencil/paper and computerized tests. Qualified participants will receive $100 for participating. This is not a treatment study.

For more information call:

Nisha Chilkara, M.A.
Study Coordinator
The Zucker Hillside Hospital
Department of Psychiatry Research
75-59 263rd St.
Glen Oaks, NY, 11004
718-470-8935

North Shore LIJ The Zucker Hillside Hospital

Do you have a diagnosis of

Schizophrenia or Schizoaffective Disorder

and are interested in participating in a research study?

Are you between the ages of 18 and 59?

The Zucker Hillside Hospital of the North Shore-LIJ Health System is conducting a number of research studies devoted towards improving the lives of people who suffer from schizophrenia or schizoaffective disorder.

To learn more about our ongoing schizophrenia and schizoaffective disorder research studies, please contact:

Jason Gentile, B.S. • Phone: (718) 470-8183 • E-mail: jgentile@lij.edu
Department of Psychiatry Research • 75-59 263rd St. • Glen Oaks, NY 11004

North Shore LIJ The Zucker Hillside Hospital

Stigma Over Mental Ill-Health Is Worst Among Family

By **REBECCA MCQUILLAN**
Scotland Herald, January 4, 2010

Friends and relations are the main source of discrimination towards people with mental health problems.

See Me, the campaign to end the stigma attached to mental ill-health in Scotland, found that 47% of people with mental health problems cite family and friends as the main source of negative attitudes.

However, 62% said that once this stigma has been broken down, support from those groups is the most important factor in aiding recovery.

See Me launches a publicity drive today, aimed at encouraging more positive, supportive behaviour towards those living with mental health problems.

Suzie Vestri, *See Me*'s campaign director, said: "When we speak to people with experience of mental health problems, by far the biggest scenario in which they experience stigma is from family and friends.

"For many, stigma can be more distressing than the symptoms of the condition itself.

"The aim of this campaign is to raise awareness that support from friends and family is the most important aid to recovery and even small things you do can make a big difference. Learn the facts about mental health problems and just be there and be yourself."

The research found that 72% of people with experience of mental health problems say the effect of being stigmatised is to feel that people think less of them due to their problem, while 46% of people noticed that they were contacted less by friends and relatives.

Social Security Administration Launches "Choose Work" Web Site

The Social Security Administration (SSA) and CESSI, the program manager for Recruitment and Outreach for the Ticket to Work (Ticket) program, are pleased to announce the launch of the new Choose Work web site for people with disabilities receiving Social Security disability benefits in celebration of the 10th Anniversary of the enactment of the Ticket to Work and Work Incentives Improvement Act (Ticket Act).

In 1999, Congress passed the landmark Ticket Act to expand choice and provide improved services and supports to beneficiaries with disabilities who decided to Choose Work. SSA has worked continuously to improve the Ticket program over the past decade and the program has come a long way since the first Ticket was issued in 2002.

Based on input SSA received from beneficiaries, Employment Networks and the disability community, regulatory improvements were made to the Ticket program in July 2008 and those changes have resulted in significant program growth and the emergence of some very encouraging trends:

- **Increased Ticket Assignments:** Over 270,000 beneficiaries are using their Ticket to get help finding a job. That is up 72% from the beginning of 2007.
- **More Beneficiaries Are Working:** In 2008, 96,993 beneficiaries had their Ticket in use and were working. That is up from 59,443 in 2007, a 63% increase. Many of these beneficiaries are achieving significant levels of self sufficiency and some have successfully transitioned off SSA benefits.

And these are just a few of the positive trends that have emerged since the new regulations were implemented. Stay tuned in the new year for a full report on the impact of the regulatory changes.

SSA is launching this web site to renew Congress' challenge to willing SSI and SSDI beneficiaries to "Choose Work" by participating in the Ticket to Work program and using the other SSA Work Incentives. For the first time, those unfamiliar with the program can view short, informative videos; hear powerful stories told by people just like themselves whose circumstances have led them to explore the Ticket and other Work Incentives; experience a Work Incentive Seminar Event; find local resources and other helpful information in one interactive location online.

Stop by *www.ChooseWork.net* and hear directly from some of the people with disabilities the Ticket program has helped to Choose Earnings, Choose Fulfillment and Choose Work.

Ticket to Work is a voluntary employment program for people with disabilities administered by the Social Security Administration (SSA). The Ticket program offers people receiving Social Security disability benefits age 18 through 64 expanded opportunities to obtain the services and supports that they need to work and to achieve their employment goals.

Caregivers Must Act When Weight Gain is Ignored by Providers

By **ANONYMOUS**

For the past seven and one-half years, I have been the primary caregiver/advocate and loving father for my son who has a diagnosis of schizoaffective disorder and major depression.

I really wish to alert you and all of my NAMI friends about the role required by a father/caregiver/advocate for a family member who has a very serious mental illness.

My son each day goes for outpatient treatment at a well known psychiatric hospital, where he has weekly therapy with a social worker and attends group therapy for symptom management and related topics. He also receives medication administration and monitoring at the hospital for two antipsychotics (Clozapine and Risperdal), one major antidepressant, one mood stabilizer medication and one anti-anxiety medication.

As most of you know, atypical antipsychotics are a mixed blessing! They relieve psychotic symptoms. However, they potentiate rapid weight gain. This results in the scary scenario of our loved ones putting on substantial weight — to the point where they are at risk for diabetes type 2 and heart disease.

In such cases, the goal is weight reduction to prevent the onset of these dreaded diseases and to enable our loved ones to not suffer the added indignity and horror of a shortened lifespan. The literature I have read indicates that a person who has schizophrenia and is on atypical antipsychotics faces the horrific likelihood of a 25-year shortened lifespan. This is an unacceptable side effect of any medication, in my view.

I have learned the critical lesson that as caregivers we cannot expect that medical providers will be looking out for our loved ones to fix the horrific side effect of this weight gain. The numerous providers who prescribe these medications are apathetic to the point of inaction when it comes to suggesting remedial action to effect weight loss in our loved ones who have put on life-shortening weight due to their needs to take atypical antipsychotics.

So what is the solution that I have found? It is the following: I, the caregiver and father of a son with schizoaffective disorder, have assumed the role of “Initiator of Solutions” to providers to begin appropriate and necessary solutions! Examples: I actually need to propose to my son’s providers that he should be enrolled in the hospital’s weight loss program. In another instance I needed to bring to their attention that he is experiencing some medication-related movement disorders and that they need to address this issue.

I consistently remind myself to *never* expect that mental health outpatient providers will be as caring and proactive as I will be on behalf of my son. Therefore, I offer for all patients and caregivers the following advice:

- Let proposals for the sensible and appropriate care of your mentally ill loved one begin with you, the caregiver.
- Make such proposals to the outpatient treatment team(s) in a cogently written proposal.
- In this proposal state the benefits of the action proposed (for example, enrollment in a weight loss program is needed so that a patient will have a normal lifespan without falling victim to the diseases related to obesity).
- Stipulate that a weight loss program, or similar program where indicated, is needed for the well-being of the patient.
- Be aware a mentally ill patient may not have the capability to speak up on his/her own behalf, so we as caregivers are acting in a noble, lifesaving way by making sensible and proactive proposals.

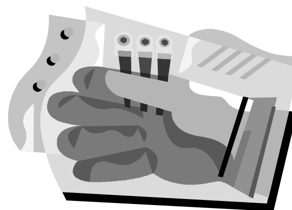
A strongly proactive approach by caregivers is necessary to break through the burned-out mindset of outpatient providers who are frequently overwhelmed with many patients and are not thinking of our loved one’s needs. Thus, it behooves us to embrace the perspective and action which is encapsulated in the phrase, “Let it begin with me.”

Only when we as fathers/mothers/advocates/caregivers act in such a loving and sensible way, defined as encouraging and partnering with mental health providers, can we expect our mentally ill loved ones to have a fair chance at the recovery that they so richly deserve.

I, for one, will continue on this quest, simply because I know no other way. It is a labor of love and devotion.

Many Antipsychotic Users Not Getting Needed Tests

By **MEGAN BROOKS**
Reuters Health, January 5, 2010
Source: *Archives of General Psychiatry*, Jan 2010



People who take newer drugs for schizophrenia and other psychotic conditions are supposed to have their blood sugar and cholesterol levels checked regularly but many don't, according to a study released today.

These so-called "second-generation" antipsychotic drugs, which include olanzapine (Zyprexa), risperidone (Risperdal) and aripiprazole (Abilify), were developed because older antipsychotics have significant side effects. However, the newer drugs are known to significantly increase blood sugar and cholesterol levels, raising the risk for diabetes and heart disease.

In a study, researchers found that less than one-third of low-income Medicaid patients who are treated with these drugs have their blood sugar and cholesterol levels checked.

And perhaps even more concerning, say the researchers, screening rates did not increase following government warnings and recommendations calling for increased blood sugar and cholesterol monitoring.

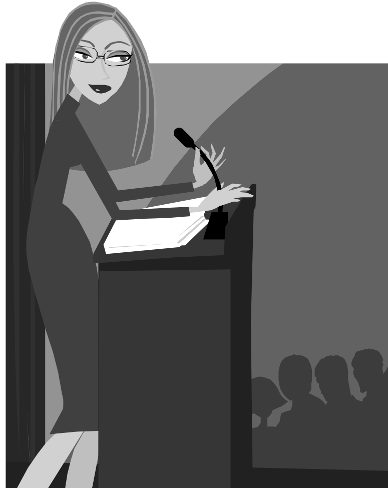
Fighting Stigma in My Own Voice

By **GLORIA ANN KEYLOUN**

Did you ever think all the work you did managing your mental illness made you realize you had a story to tell about your own personal situation and that you didn't know how to get the message out to your friends, family and fellow consumers? Do you feel like you spent such significant time and experience learning about your diagnosis that on a daily basis you find more and more interesting things about your life? Did you think the day-to-day steps you follow living with your mental illness were worth enough to share with others? Did you ever want to give others the chance to hear your personally described experience? These are the questions I found myself answering when I attended my first NAMI *In Our Own Voi*ce (IOOV) program training to become an IOOV presenter.

The NAMI *In Our Own Voice* program (IOOV) is a unique public education program in which two trained consumer speakers share their personal stories about living with mental illness and achieving recovery. IOOV is an opportunity for those who have struggled with mental illness to gain confidence and to share their individual experiences of recovery and transformation (www.nami.org). NAMI's training focuses on five components: The first is *Dark Days,* where presenters-to-be describe to an audience of their peers their personal situation leading to their diagnosis. The *Acceptance* segment is where each trainee discusses their individual point of view understanding and taking responsibility of living with their diagnosis. The third part is talking about the *Treatment* and illustrating how to manage symptoms and maintain wellness through medical intervention. The fourth, which promotes gaining individual skills while *Coping* and sustaining wellness. The *Successes, Hopes, and Dreams* is the final segment of the presentation, where trainees summarize their achievements, satisfaction and fulfillment with 'the big picture' – successfully incorporating all these components into creating a powerful, positive mental health presentation from the individual "face" of the consumer telling their story. This helps the consumer/presenter gain confidence, self-identity, empowerment and recognition through their own interpretation of feelings, ideas and mind-set. Overall, it establishes a positive face to the public in keeping with the IOOV Program standard.

As a person who is familiar with sharing their personal story on mental illness, I can tell you my IOOV training was one of the many supportive environments I've lived



through. It enhanced my recovery and gave me confidence to earn more accomplishments. I've met so many people from all walks of life who had significant stories to tell. I've related to people from all different kinds of backgrounds who shared their personal experiences, either by speaking from their written stories or journals, accounting their most difficult moments, happiest moments, or even recounting the scariest or lighthearted moments in their lives. Some reflected how they've overcome the most challenging of experiences to make themselves stronger and better individuals in order to succeed at living with a mental illness. Others chose to talk about how they still currently manage adversity, yet offer guidance, describing their own acceptance and coping skills, talking about their treatment regimen and the ways in which they've come to care and manage their symptoms to keep in good physical and/or mental health. Most may just choose to listen to a personal story being shared and then reflect on the circumstance, in the hopes of relating to an experience. In my training, I've come across those individuals who may not have wanted to discuss their own personal situation living with a mental illness, I found after learning *how* to incorporate their challenges into real successes, they've found one or two of their peers, or a family or a couple of friends, had a similar story, and it empowered them to feel more confident to speak out. Fellow trainees' support people like themselves – other consumers, family and friends alike – and all tell their personal story with the goal of educating individuals on the real issues surrounding the stigma of mental illness.

Since I became a presenter, I offered IOOV presentations at local high schools and told my story to my peers and medical professionals at local outpatient facilities. I have been able to recruit enough people to form a team (and be team captain) for the 2009 NAMI Walks at Jones Beach, NY, and recruit my friends, family and supporters to promote mental wellness through NAMI Walks 2010 *In Our Own Voice* team. I hope to present an IOOV talk to the law enforcement community and emergency service professionals in the near future.

I became an IOOV presenter because everyone needs to hear a story, and everyone needs someone to tell *their own personal* story. Speaking about my dark days, acceptance, treatment, coping skills and successes, hopes, and dreams brought my challenging moments to real life, and I continue to share my successful achievements in a positive manner. What's really mind-blowing is seeing the reactions from people after a presentation. One comment for example was someone coming up to me and saying, "I wouldn't know that you had a mental illness because you present so well and you are so balanced." That to me is one of the ways I use IOOV presenting to help eliminate the stigma associated with mental illness.

Gloria Ann Keyloun is a consumer who works in the corporate world full-time, is a part-time fitness instructor, and avid musical theatre enthusiast. She is the facilitator for the Mood Disorder Support Group of LI and a NAMI Walks 2010 Team Captain for the 'In Our Own Voice' Team..

Letters of thanks...

SEETH VIVEK, M.D., DF, A.P.A.
CHAIRMAN
DEPARTMENT OF PSYCHIATRY

November 9, 2009

Dear Mrs. Susin:

Thank you for your excellent presentation at our Grand Rounds on October 29, 2009. We enjoyed having you with us.

Your touching personal story, combined with the work of NAMI, has had a positive impact on the perceptions of our staff about mental illness, and informed them about a community resource they can refer their patients and families to.

Evaluations of your talk were overall excellent, and we appreciate your having provided us with this interesting and useful information.

We hope you will return soon.

With kind regards,

Seeth Vivek, M.D.

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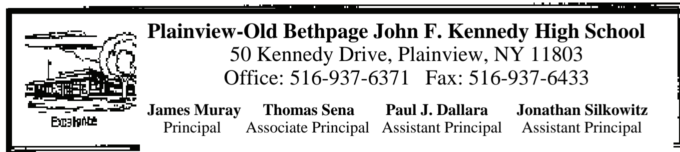

Plainview-Old Bethpage John F. Kennedy High School
50 Kennedy Drive, Plainview, NY 11803
Office: 516-937-6371 Fax: 516-937-6433

James Muray, Principal; Thomas Sena, Associate Principal; Paul J. Dallara, Assistant Principal; Jonathan Silkowitz, Assistant Principal

December 18, 2009

Dear Janet,

I am writing this letter on behalf of Gloria Keyloun and Emily Hughes, two very inspirational women. They were invited to speak to my students at Plainview Old Bethpage High School on 12/10 and 12/11/09. The impact of their presence and message with my students has been profound, and has sparked growth and change among my students.

As a seasoned high school health educator, I would like to take this opportunity to express my appreciation for the time these two ladies gave sharing their personal stories about mental illness. It takes a lot of courage to stand in front of three hundred teenagers and share their very personal experiences and knowledge. Without a doubt, they exceeded my expectations!

I feel it is so important to breakdown the stigma attached to mental illness, to increase people's knowledge and to improve attitudes towards those who experience psychiatric disorders. Having people like Gloria and Emily, two very committed individuals, is a great way to start! It is evident that they both have the fire and passion to get out there and make a difference.

I overwhelmingly recommend *In Our Own Voice* trainers Gloria and Emily to speak on behalf of the National Alliance on Mental Illness.

Sincerely,

Laura Meyer
Health Educator

...and congratulations

JUDI BOSWORTH
LEGISLATOR DISTRICT 10

NASSAU COUNTY LEGISLATURE
1550 FRANKLIN AVENUE
MINEOLA, NEW YORK 11501
(516) 571-6210

December 18, 2009

Dear Ms. Susin,

I was catching up on my reading in the *Manhasset Press* and saw that you have been elected president of the Board of Directors of the statewide organization of the National Alliance on Mental Illness (NAMI-NYS). Congratulations!

You make our community a special place to live by giving of your time and energy toward the cause of mental health. Thank you for your selfless service.

Sincerely,

Judi Bosworth
Legislator, 10th L.D.

COMMITTEES:
EDUCATION, CHAIR
TOWNS, VILLAGES AND CITIES, CHAIR
MINORITY AFFAIRS, VICE CHAIR
ECONOMIC AND COMMUNITY DEVELOPMENT
FINANCE
GOVERNMENT SERVICES AND OPERATIONS

Friendship Network Trip to Carnegie Deli and Radio City Music Hall

by **STEPHEN CANNIZZARO**

The Friendship Network socialization group met at the Carnegie Deli on Tuesday, December 15th, at 5:15 p.m. for a light dinner in Manhattan. I arrived 25 minutes early since I traveled from the Long Island Railroad to Penn Station and took a cab to The Carnegie Deli. I was greeted by Alice Cohen and her husband, Cliff. As I entered the dining room I noticed many pictures of famous celebrities hanging on the walls. I noticed Rich Little, the comedian, among many other famous people. More members started to arrive at 5 p.m., and we greeted each other. Alice planned many fine foods to be shared by the group. There were potato latkes, overstuffed sandwiches such as corned beef on rye bread, which I had. We also enjoyed a number of side orders, such as green kosher dill pickles, baked beans, coleslaw and beverages such as diet coke. We shared a delicious dessert of chocolate cheese cake.

After dinner we walked to Radio City Music Hall. We went as a group and had to wait outside until Alice got the group their tickets and gave them to all members. Radio City Music Hall is impressive inside, with large staircases which we took to the upper balcony. Beautiful curtains and massive chandeliers grace the lobby of the Music Hall. The seating was fine, and we had a magnificent view of the stage. There were attractive wreaths surrounding the stage and lights, with two enormous Wurlitzer organs, which are the world's largest, and a wonderful orchestra. Daniel Troub and Dave Pierce were the orchestrators.

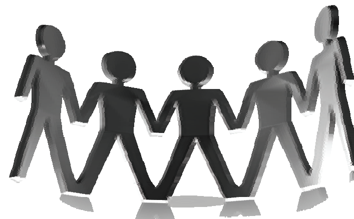
The first act was the sleigh ride through the snowy, magical Northern Forest. The LED screen made for a wonderful fantastic visual effect of snow. The 3-D glasses were great, as the audience could see Santa on his sleigh with reindeers pulling the sleigh and presents in the back of the sled. It was a dazzling effect as it made the audience feel as if it were on the sled with Santa traveling through Times Square at nighttime. The effect I liked most was the skating rink and the Christmas tree at Rockefeller Centre. The Rockettes were dressed as Santa's reindeer and had several beautiful costumes, one being the wooden soldier's costume. The special effect of the wooden soldiers falling as a cannonball was shot from a cannon was thrilling. The dancing blocks and dolls was fun for children. Another special effect was a life-size, customized, double-decker bus spinning on stage. The Rockettes danced to the song *Let Christmas Shine*, among other songs. My favorite performance was approximately 40 Santas on stage, all singing *You'd Better Be Good*, and each Santa ringing two large bells. *Here Comes Santa Claus* was another popular song. The finale was The Living Nativity Scene, and the cast wore traditional costumes dressed as Mother Mary, Joseph, the Three Wise Men, and Jesus in the manger. Appropriately, the show ended with *Joy to the World*, sung by all on stage.

After the show, Beth took us to the souvenir shop to purchase a mug. The whole group left the Music Hall with fond memories of a show well-performed and a fun evening.

Socialization with Alice and Chris

by **CATHY**

If a dear friend came into my life several years ago and promised me a light at the end of the tunnel, I probably would have expressed hope. But in the midst of my pain, I did not recognize the light until I believed in myself. I then realized that I could bring that light to others.



Yes, I have many blessing: new friends, faith, and — most of all — hope. But it requires some bravery. Life gives us options when we seek them. With Alice and Chris's monthly "socialization," there is an opportunity to share and communicate as a group with positive outlook. There is encouragement, curiosity and new discoveries that are welcomed by Chris and Alice. But the best part is receiving kindness and enthusiasm from friends at the table.

At the most recent socialization, Chris put a smile on my face when she remembered my love for painting and her willingness to share it with the group. This led to other friends expressing their own hidden talents. For example, Ira loves the transportation system; Bob loves art and poetry; Louis loves fixing lamps and is very mechanical; and so on. We might all even venture into painting together soon. What a joy!

The more smiles there are, the brighter the feeling is inside and out. Take a step and you might feel warmly surprised. Keep hoping, believe in yourself, and understand with all your heart that friendship awaits you. May your light be as bright as your smile.

Key NAMI Priorities in HR 3962

Among the key provisions in HR 3962 that will expand access to coverage and improve health care for people with mental illness are:

Insurance Market Reforms

HR 3962 contains a full range of reforms to the current health insurance market. These changes are critically important to people living with serious mental illness excluded from coverage on the basis of pre-existing medical conditions. Among these important new protections are:

* Requirements for guaranteed issue and guaranteed renewal of coverage in the individual and small group markets;

* A prohibition of pre-existing health condition exclusions as well as restrictions to severely limit the use of health status in determining premium rates;

* A prohibition on the application of annual and lifetime insurance caps and limits on out-of-pocket spending; and

* Creation of a high-risk pool to provide immediate assistance to those currently uninsured with pre-existing conditions before insurance market reforms go into effect.

Inclusion and Equitable Coverage of Mental Health and Substance Abuse Benefits

A key goal for NAMI in health reform has been ensuring that all expanded health coverage for the uninsured BOTH includes coverage for mental illness and substance use treatment AND does so in compliance with the new Wellstone-Domenici parity law. It is critical that all plans offered through the Exchange - whether purchased through the individual or small group market - comply with this important new law. The House bill accomplishes these goals by including mental health coverage in the required basic benefits package and referencing the parity law in a separate non-discrimination standard for all plans offered through the Exchange. This will significantly erode the individual market and small employer (50 and under) exemptions to the parity law that we were forced to accept in 2008.

Medicaid Expansion

The House bill includes the largest expansion of Medicaid eligibility since 1965 - requiring states to cover individuals and families up to 150% of the federal poverty level (about $16,200 for an individual).

This change alone is the largest coverage expansion ever for childless adults living with mental illness - especially for those unable to qualify for SSI, who work intermittently and do not qualify for Medicaid in their state. This coverage expansion begins in 2013 and 2014 with a 100% federal match rate, declining to 91% in 2015 and beyond.

The House bill also contains a proposal drafted by Representative Bart Gordon (D-TN) authorizing a new Medicaid demonstration program for emergency psychiatric services (lifting the Medicaid IMD Exclusion for acute care in free-standing psychiatric hospitals). Finally, the bill adds a new requirement for state Medicaid programs to cover preventive services without cost sharing.

Improvements to Medicare

The largest changes to Medicare relate to the Part D prescription drug benefit, including filling the so-called ³doughnut hole² coverage gap - initially with a 50% discount on brand name drugs and eventually closing the gap entirely by 2019. The bill also expands the Low-Income Subsidy (LIS) program (e.g., increasing the asset test) and adds new protections for dual eligible beneficiaries (e.g., minimizing disruption from annual switching between plans).

In addition, the bill eliminates cost sharing for preventive services under Medicare and authorizes a new Medicare ³medical home² pilot program to provide more coordinated and comprehensive care for beneficiaries with multiple medical co-morbidities.

Comparative Effectiveness Research (CER)

The merged bill brought forward by Speaker Pelosi improves provisions from the Energy and Commerce Committee bill setting forth structure and oversight to guide implementation of comparative effectiveness research (CER). This provision in the bill sets forth oversight and structure for federally funded research designed to compare two or more treatments for a particular disease or medical condition. NAMI supports investment in CER to improve quality and better inform treatment decisions. At the same time NAMI also wants to ensure that CER studies are well designed and reflective of real world treatment settings (e.g., differences among racial and ethnic minorities, complexity of medical co-morbidities, etc.).

Changes contained in HR 3962 will help ensure that differences among ethnic and minority subpopulations are more accurately measured in CER.

New language will also ensure that CER is not used to inappropriately mandate payment, coverage or reimbursement policies. NAMI is urging further improvements such as those in Representative Kurt Schrader¹s legislation (HR 2502) ensuring that CER is overseen, disseminated and implemented by an independent, non-governmental institute that genuinely represents the interests of patients, researchers and providers and reflective of how CER can best be used in real world treatment settings.

Community Living Assistance Services and Supports (CLASS) Act

NAMI is extremely pleased that HR 3962 includes the late Senator Edward Kennedy¹s CLASS Act, a new voluntary, public, long-term care insurance program to help support people with significant functional limitations, including serious mental illness. After a contribution period, individuals determined to need assistance as a result of functional limitations would qualify to receive assistance to purchase services to maintain personal and financial independence. CLASS Act assistance would supplement, and not supplant, other long-term care assistance such as Medicaid.

(Continued on page 16)

Opinion Piece

Still Being Treated Like Second-Class Citizens

By **ELISSA SILVERMAN**

Last week I had extremely severe stomach pains, so I did what anyone with bad medical problems would do: I checked myself into the nearest hospital that I thought would help me because I had good experiences with them. I checked myself into New York Hospital of Queens.

I had been there before for minor problems and usually had good results there, so I thought there would be no problem in going back there. Little did I know what I was in for!

I checked myself in on Wednesday morning, the day before Thanksgiving, complaining of stomach pains, and brought my medications with me to show them what I was presently taking. They weren't interested in the least about my new medicines and sealed the bag I had brought them in. Instead, they fed me a laundry list of old drugs, which I had not taken in some time. These drugs were old pysch drugs and had nothing to do with the condition that I came in with, which turned out to be an inflamed and infected colon that they told me was colitis. So in addition to my old medicines, they gave me antibiotics in drip bags. While continuing to give me the old medicines they overdosed me, and I was fighting to stay conscious. I was blacking-out; they almost killed me and I was literally fighting for my life! I was also trying to stay lucid since my regular psych meds had been suddenly stopped. (When I got home and spoke to my regular psychiatrist, we both agreed that it was a form of malpractice.)

It seemed that because I had psych medicines in my chart they thought they could have a field-day with me, and it was open season on the way I was being treated.

In addition to this, I was also not allowed to eat or drink anything for three and a-half days. While everyone else had their Thanksgiving turkey, all I was allowed to have were ice-chips to suck on. I understand that that was a normal procedure, but it didn't make me feel any better.

Seeing that I was basically alone most of the time, my boyfriend and his father came once to see me when they were able to. I had to do all the advocating I needed to do for myself, which made the nurses mad because I was forcing them to do their jobs properly.

The fact that I was advocating persistently for myself, and that I wasn't a blind sheep who would fall into line and follow the herd, as well as had a psychiatric history, really disturbed them.

They did everything they possibly could to make my life miserable. They took the lock out of the bathroom door, so anyone could walk in on me. They tangled me up in all the wires and tubing so I couldn't go to the bathroom myself. When I finally got them to unhook me so I could use the bathroom, they stuffed the bathroom with a large chair so I would have trouble getting in and out. They even threw one of my drip bags in the sink! When I tried to give them a stool sample, they wanted me to sit on a urine-drenched potty to do it!

When I complained about the fact that the lock was taken out of the bathroom door, the nurse said "all the doors are like that in the ward." Seeing that she was trying to play a head-game with me, I reminded her that the door locked only a few hours before.

They also played games with the machine that was monitoring me, making it say really outrageous numbers, like 650 mg/liter, while the other side had an extremely low number of mgs. Then they made the machine continually beep and say "occlusion" instead of giving the weird numbers (mgs/liter) that it was saying before. I called one of the doctors in my room and showed her what was going on, and she went to complain.

Fortunately, my next-door roommate had called the chaplain, who I had known from before, and God bless Rabbi Keane, when I told him how I couldn't stand it in there anymore, he said the right things to the right people, and I got out of the hospital Friday night even though the staff did their best to detain me.

What I wonder about is, if this the treatment you get in a "regular" hospital for a physical condition, imagine the long fight we still have ahead of us to get treated with dignity, respect and understanding in any hospital, especially in psychiatric hospitals where they're supposed to be understanding and sensitive to our needs. Many of the psych hospitals also give you lousy treatment as inpatients because of the lack of caring on the part of the nursing staff.

Although things have slowly gotten better over the years, we still have quite a way to go ahead of us. We need to have a stronger voice to make ourselves heard and our presence felt. One of the ways to do this is by joining an organization like NAMI.

NAMI can give a voice to the many who can't speak for themselves. Without NAMI we wouldn't have come as far as we have today, so please donate to your local NAMI chapter.

To lodge a complaint alleging abuse, neglect, discrimination or rights violations, contact the Quality of Care Commission, 1-800-624-4143.

NAMI Priorities...

(Continued from page 15)

New Standards for Federally Qualified Behavioral Health Centers (FQBHCs)

(HRSA) to establish new standards for Federally Qualified Behavioral Health Centers (FQBHCs) under the Public Health Service Act (Section 2513). These new standards include outpatient mental illness treatment services, targeted case management, crisis intervention services, family psycho-education, peer support and family supports. NAMI is extremely grateful to Representative Doris Matsui (D-CA) for her efforts to get this provision added to the House bill.

Support NAMI Queens/Nassau

Please help! Your donations help support NAMI Queens/Nassau's vital programs and services for those with mental illness and their families. In these tough economic times, every dollar counts!

There are several ways to donate to NAMI Queens/ Nassau:

- You can make donations in honor or memory of someone (see page 2). We will notify the recipient of your kindness, and your donation will be acknowledged in our newsletter.
- You can donate through our website, namiqn.org. Just click on *Donate Now* and follow the prompts. (Credit cards accepted.)
- Many employers offer a Matching Gift Program. They will match your contribution, dollar for dollar. Contact your Human Resources Department to find out if your employer offers that option. NAMI Queens/Nassau will benefit twice from your generosity!
- Consider a bequest to NAMI Queens/Nassau in your will. Leave a legacy of caring for those with mental illness and for their families.

Thanks to all the wonderful people who helped with our holiday party:

Jessyca Berkman & Eugene Volkov — Your music and festive decorations put us all in a great mood. It wouldn't be a holiday party without you!

Josh Rubin — Magician extraordinaire who calls himself the "almost perfect magician," but is really always perfect.

Don Levy —This was a holiday party debut for comedian Don Levy, who tickled our funny bone with mental health jokes. We look forward to an encore next year.

Liz Reilly — Thanks for ordering the food and laying out that good holiday spread.

Rosie Rinsler — Your greeting cards were a hit again. Thanks for donating the proceeds to NAMI Queens/ Nassau.

NAMI Queens/Nassau gratefully acknowledges the following donations:

In memory of Lawrence Suss: Carol Rothbell; Phyllis & Albert Freberge; Mr. & Mrs. Irving Phillip
Harriet Leef in honor of Arnold Gould
Maureen & John Josel with get well wishes to Jack Kelly
Sondra Cohen in memory of Marci Reller
Rhoda & Ron Nadell in memory of Bernard Amatenstein
Jocelyn Grossman in honor of Sandy Cohen; in memory of Elsie Kraut; congratulations to Maureen & John Josel on birth of granddaughter, Vienna Rose
Lorraine & Eli Kaplan in memory of Ken Luiser
Peter & Marie Pruden in honor of Sue Rubin
Betty Blond in honor of her sister, Lillian Meltzer's, birthday
Dorothea Braun in memory of James Tully
Anne & Ron Staheli in memory of Christopher Staheli
Rhoda & Ron Nadell in memory of Bernard Schmerz; Stephen Schenkel; Gela Madowicz; Miriam Klusner; Miriam Ageloff
Betty Blond in memory of Rita Rubin
Frances Brodsky in memory of Alfred Belotz
Jeanne & Karl Israel in memory of Arthur Abelman

General Donations:
Ray & Sue Miller; Robert & Estelle Isaacs; Joseph Shenker; Janet Tretin; Ira Breskin; George Drakos; Mary & Larry Kenny; Ann Jurdem; Norman Mason; Martha Tom; Helen Theodorou; Lorraine & Eli Kaplan; Andrew Chwick; Edward Rudin; Magazanick Family; Stuart & Lois Golin; Sidney & Grayce Falow; Michael & Marlena Relyea; Arlene Soifer; Clifford & Marsha Feuerstein; Estelle Sher; Betty Blond; Leslie Granoff; Louise DeStefano; Jean Arnold; Patricia O'Connor; Joan Sharkey; Geraldine Tyler; Rosie Rinsler; Ms. Gene Heller; Sandy Prinz; Marc Giber; Miriam Meadow; Joan & Herbert Greene; Bonnie & Robert Franco

The Friendship Network gratefully acknowledges the following donations:

Rose Soifer in memory of daughter Rhonda Freidman
Alice & Cliff Cohen in memory of Mr. & Mrs. Robinson's brother
Keinker & Family in memory of Lisa Franco
Daniel Isaacson in memory of mother; in honor of Alice Cohen & family
Mildred Fine in honor of Alice & Cliff's birthday
Bill & Dawn Jordan in honor of Alice & Cliff Cohen
Wendy Bruer in honor of Mary B & Meryl
Alice & Nancy in memory of Abramson Family's husband & father
Alice & Nancy in honor of June Dworkin

With deep appreciation

Funding from our local legislators to support the Friendship Network:

Senator Craig Johnson — $20,000

Michelle Schimel — $2,500

NAMI Queens/Nassau Support Groups

GROUP	LEADER/PHONE	DATE/TIME	LOCATION
Sharing & Caring	Hillside Hospita Social Worker	3rd Wednesday of each month 6:00—7:15 p.m.	The Zucker Hillside Hospital Sloman Auditorium 266th St. & 76th Ave. Glen Oaks
Evening Family/Sibling/ Adult Children	Rosalie Weiner, LMSW (718) 776-4790 *Please call first*	1st & 3rd Mondays 7:30—9:30 p.m.	NAMI Queens/Nassau office 1981 Marcus Ave, Suite C117 Lake Success, NY
Afternoon Family & Friends	Rosalie Weiner, LMSW (718) 776-4790 *Please call first*	1st Tuesday of each month 1:30—3:00 p.m.	Advanced Cntr for Psychotherapy 103-26 68th Rd. Forest Hills
Family/Friends	Christine Scotten, CSW (516) 521-8341 *Please call first*	2nd & 4th Wednesdays 7:30—9:30 p.m.	NAMI Queens/Nassau office
Families of Children & Adolescents	Joan Ambrosio, CSW (516) 633-3544 *Please call first*	2nd & 4th Tuesdays 7:30—9:00 p.m.	NAMI Queens/Nassau office
For Those Suffering from Anxiety/Depression	Lori Kalman, LMSW (718) 746-3092 *Please call first*	1st & 3rd Thursdays 7:00—8:30 p.m.	Zucker-Hillside Hospital Kaufman Bldg, Rm 204
Parents of Children & Adolescents with Emotional or Psychiatric Disorders	Amy Maximov (516) 884-6996 *Please call first*	Saturday mornings 10:00 a.m.	NAMI Queens/Nassau office
Those with Bipolar Disorder	Sandy Kalman, LCSW (718) 470-9552 *Please call first*	1st & 3rd Tuesdays 7:00—8:30 p.m.	Zucker-Hillside Hospital Ambulatory Care Paillion Room 1202
Keeping Hope Alive	Dr. Frances Cohen Praver (516) 676-1594 or drpraver@cs.com	2nd Sunday of the month 10:00 a.m.--Noon *Call to register*	Lattingtown
Family to Family 12-week Psycho-education Course	Susan Watson (516) 364-5414 *swatsontax@optimum.net*	Starting in January *Call to register*	Zucker Hillside Hospital, Queens Hospital Center, Greater Allen AME Church, Adelphi University
NAMI Basics 6-week Course for Parents of Children	Ceceile Green (718) 704-8690 Liz Hutner (718) 366-6742	Weeknights, 7:00—9:30 p.m, or Saturdays, 9:30a.m.—3:30 p.m. *Call to Register*	Holliswood Hospital 87-37 Palermo Street Jamaica
Korean Support Group	Jennifer Lim, CSW (917) 346-4038 *Please call first*	3rd Thursday of each month	Zucker Hillside Hospital Ambulatory Care Pavilion
The Day After DBT (co-sponsored with NAMI NYC Metro)	Pauline Prin (516) 361-6381 *Please call first*	1st & 3rd Wednesdays 6:00—7:30 p.m.	Holliswood Hospital 87-37 Palermo Street Jamaica