the challenger

A Publication of the NATIONAL ALLIANCE for the MENTALLY ILL in Buffalo & Erie County

vol. 20, no. 6
September-October 2004

Mark Your Calendar

September

NAMI Business Meeting, Thursday, September 1st, 7:30 PM, NAMI Hope House, 432 Amherst Street, Buffalo. All members welcome to attend.

NAMI Family Meeting, Thursday, September 9th, St. Paul's Lutheran Church, 4007 Main Street, Amherst. ***Note new location!*** Library and Hospitality Hour: 7:00 PM. General Meeting: 7:30 PM. Guest speaker: Michael Weiner, Erie County Commissioner of Mental Health.

NAMI Family Support Group, Wednesday, September 22nd, 7:30 - 9:00 PM, NAMI House, 432 Amherst Street, Buffalo. For all family members with a mentally ill loved one.

October

NAMI Business Meeting, Thursday, October 7th, 7:30 PM, NAMI Hope House, 432 Amherst Street, Buffalo. If you're a NAMI member, you're welcome to attend.

NAMI's 20th Anniversary Celebration of Service, Friday, October 15th, Samuel's Grande Manor, 8750 Main Street, Williamsville. Keynote speaker, Prof. Gerard Hogarty, University of Pittsburgh, and Western Psychiatric Hospital and Clinic. ***Don't miss this very special evening!***

NAMI Family Support Group, Wednesday, October 28th, 7:30 - 9:00 PM, NAMI Hope House, 432 Amherst Street, Buffalo. A healing place with folks who know what families go through.

November

NAMI Business Meeting, Thursday, November 4th, 7:30 PM, NAMI Hope House, 432 Amherst Street, Buffalo. All NAMI members are welcome!

NAMI Family Meeting, Thursday, November 11th, St. Paul's Evangelical Lutheran Church, 4007 Main Street, Amherst. Library and Hospitality Hour: 7:00 PM. General Meeting: 7:30 PM. Guest speaker: Ann Birmingham, Attorney-at-Law, on Special Needs Trusts

December

NAMI Business Meeting, Thursday, December 2nd, 7:30 PM, NAMI Hope House, 432 Amherst Street, Buffalo. Join your Executive Board for an informative evening.

NAMI Holiday Party, Thursday, December 9th, 7:00 PM, St. Paul's Lutheran Church, 4007 Main Street, Amherst. Bring a plate of holiday goodies to share and enjoy a night of respite and fellowship with NAMI friends.

NAMI "Christmas is for Kids" Wrapping Session, Saturday, December 11th, 10 AM til we're done, NAMI Hope House, 432 Amherst Street, Buffalo. Bring a pair of scissors. Volunteers needed!

Mental Illness & Violence

Item: Friday, May 7. Norris E. Wells, stabs and kills his wife and injures his son three days after being treated at Erie County Medical Center. Mr. Wells has "a history of mental illness."

Item: May 28. Kristen Vanderline, a diagnosed schizophrenic and in outpatient treatment, beats her eight month of daughter to death on the sidewalk in front of her apartment.

Item: June, 2004. A Niagara Falls mother diagnosed with schizophrenia stabs and kills her nine year old daughter, claiming she had stopped taking her Zyprexa that day.

What these tragic situations have in common:
All three individuals were diagnosed with a serious mental illness. All three were currently or recently in treatment.

All three individuals have created havoc and tragedy in their own families.

All three are likely to serve long prison sentences for their actions regardless of their mental state at the time of their actions. It's highly unlikely that anyone in the mental health system will be held accountable for what has happened. The community's fears of mental patients are reinforced and validated.

It's a fact that a very small number of people with mental illness ever injure or kill anyone, and that such ill individuals are far more likely to be victims than perpetrators. But that fact gets lost in situations of high drama and death splashed on the front pages of the newspapers or broadcast on the news. What also gets lost are two incontrovertible truths. Predicting violence in a specific case or in a specific individual is impossible, so providers can escape all responsibility, even for what can be done, which is to hospitalize patients long enough for medications to stabilize an individual patient, react more quickly AND effectively on reports of

Continued on page 10

Mailing Address • 264 Hamilton Drive • Buffalo, NY 14226 • 716 839-0548
HOPE HOUSE • 432 Amherst Street • Buffalo, NY 14207 • 716 877- 9415
www.namibuffalo.org

Program to Ease Tensions Inside Androscoggin County Jail Could Become a Model

AUBURN, Maine (AP) A six-month-old program to train Androscoggin County Jail guards to calm inmates who may be mentally ill is being looked at as a potential model for easing tensions in jails around the country.

The Maine chapter of the National Alliance for the Mentally Ill plans to study the program's effectiveness by interviewing guards and examining jail records. Activists say that documenting the jail's success would be a first step toward persuading more facilities to adopt similar programs.

"It's working," said Lt. Michael Braun, the Auburn jail's assistant administrator. "But we don't have an easy yardstick" to measure progress, he cautioned.

The program began in December when 10 correctional officers were selected to receive a week of classes in subjects ranging from substance abuse to legal issues to psychiatric medications.

Workers from Tri-County Mental Health Services and St. Mary's Regional Medical Center taught some of the classes. Guards toured local facilities, and health workers toured the jail.

The focus was on "de-escalation," calming situations in which someone may be threatening to harm himself or others.

The aim is to change traditional responses in which guards either ignored sudden mood shifts or other unexplained behavior by inmates or demanded that the behavior stop.

Instead, if an inmate's behavior suggests a possible mental illness, a member of a crisis-intervention team is summoned. The newly trained correctional officers created the team, and two of its members are on duty at all times.

Suicide threats and behavioral issues account for many of the problems, particularly in the first 24 hours after an arrest. "That's when it hits people the hardest," said Braun.

Other times, people are having problems with illicit drugs. In a few cases, inmates have been diagnosed with mental illnesses and have stopped taking prescribed medications.

"Some of them are wild," Braun said. "But in a day or two, they can be acting pretty regular."

During the first six months, the new team was alerted 29 times, but only once did it have to use force. In that case, the inmate was banging his head against a cinder block wall, and he was strapped to a special chair to stop him from hurting himself.

The Maine chapter of the National Alliance for the Mentally Ill is pleased with the results thus far. The group led police in Portland to create their own crisis-intervention team last year. When that went well, the group decided to try a jail, and chose Androscoggin County.

According to the national group, 16 percent of the inmates in U.S jails and prisons have mental illnesses, while in Maine that number is 25 percent.

"It's skyrocketed in the past five years," said Carol Carothers, executive director of the Maine chapter, citing a shrinking number of beds at Augusta Mental Health Institute and other hospitals in the state.

Foster's Online June 7, 2004

Spotlight on Health

Saturdays 8:00-8:30 a. m.

Hosted by

Tom McNulty

On

WECK-AM 1230

A Production of

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WANTED, occasional, part-time, senior male to visit, observe, help schedule, comment on status/problems of mid-fifties,mentally ill but stable, mid-fifties male in Amherst, who resides alone. This would supplement visits and contact by his siblings, mostly out-of-town. We are interested in perhaps a retiree, who could help evaluate house, car, appliance, car, or other problems, suggest how to handle, and contact us about needed repairs, etc.

Please call toll-free 1-877-836-5237 and leave message about contacting you.

Upsurge in People with Mental Illness Seeking Treatment in Emergency Departments is Taking Toll on Patient Care

A recent upsurge in people with mental illness seeking treatment in emergency departments is taking a significant toll on patient care and hospital resources nationwide, according to a new survey of emergency physicians conducted by the nation's leading mental health organizations and the American College of Emergency Physicians.

Six in 10 emergency physicians surveyed report that the increase in psychiatric patients is negatively affecting access to emergency medical care for all patients, causing longer wait times, fueling patient frustration, limiting the availability of hospital staff and decreasing the number of available emergency department beds. Two-thirds (67 percent) of emergency physicians attribute the recent escalation of psychiatric patients to state health care budget cutbacks and the decreasing number of psychiatric beds. One in ten report there is nowhere else in the community where people with mental illness can receive treatment. Mental health leaders claim that without ongoing, community-based services, people may see their illnesses worsen and be forced to seek care in Emergency Departments.

The new survey by the American Psychiatric Association (APA), National Alliance for the Mentally Ill (NAMI) and National Mental Health Association (NMHA) is part of a larger campaign on the issue of access to treatment and services for people with mental illness. Seventy percent of emergency physicians report an increase in people with mental illness "boarding," which is when patients are admitted to the hospital and forced to wait in the emergency department until inpatient beds are available in the hospital.

More than 80 percent report that this practice of "boarding" negatively affects the care of emergency department patients. This agreement was almost universal (97 percent) among those who reported a rise in the "boarding" of psychiatric patients over the prior 6-12 months.

"Emergency department overcrowding is a growing and severe problem in the United States," said Dr. J. Brian Hancock, President of ACEP. "As dedicated as emergency physicians and nurses are to caring for patients, we are reaching a breaking point where we may not have the resources or the surge capacity to respond effectively.

This affects everyone's access to lifesaving medical care." The report finds psychiatric patients board in hospital emergency departments more than twice as long as other patients. And, emergency physicians say their staff spends more than twice as long looking for beds for psychiatric patients than for non-psychiatric patients. "The findings underscore the serious consequences state budget cuts to programs like Medicaid are having not only to people with mental illness, but on anyone who may find themselves in an emergency department," said James H. Scully, Jr., MD, Medical Director, APA.

Medicaid is the single largest source of financing for mental health care in the U.S. Other survey highlights include: * About 2/3 (67 percent) of the emergency physicians in this sample reported a decrease in the number of psychiatric beds in their region in the prior 6-12 months.

Those who reported such a decrease in beds were also more likely than those who did not to report an increase in the number of psychiatric patients "boarding" in their emergency departments: 85 percent for those who reported decreased beds compared to 52 percent for those who did not. More than 90 percent of survey respondents say "boarding" people with mental illness reduces the availability of emergency staff, decreases the availability of beds in the emergency department (96 percent), causes longer waits for patients in the waiting room (85 percent), results in patient frustration (89 percent), and increases the number of times the hospital diverts ambulances to other hospitals (31 percent).

"We caution states to think twice before slashing their Medicaid budgets. These budget cuts force people with mental illness to seek care in emergency departments because they have nowhere else to turn," said Michael Faenza, MSW, President and CEO, NMHA. "Nobody wins when this happens." "The increase in people with mental illness in emergency rooms is rapidly becoming a national crisis," said Michael Fitzpatrick, MSW, Acting Executive Director, NAMI. "Solutions require that policymakers understand the negative effects of these budget cuts on the community."

Methodology In March 2004, American College of Emergency Physicians fielded the Psychiatric Emergencies Survey in partnership with APA, NMHA and NAMI. The intent of this study was to research potential effects that recent trends in access to care for psychiatric patients have on emergency department environments.

This survey was conducted entirely online; survey invitation URLs were printed and disseminated through the March edition of the ACEP member newsletter, reaching an approximate 12,000 active members.

Between March 5 and March 23, 353 members accessed and provided responses to this survey. All responses reported in our data are for the 340 of those with enough experience to provide an informed perspective: those that had been providing direct patient care in an emergency department since 2002.

The active emergency physicians who responded to the survey come from all regions of the U.S. including 47 states and Puerto Rico, as well a broad variety of hospital settings: teaching and non-teaching hospitals; hospitals that serve predominantly urban, suburban, rural, and mixed suburban/rural and urban/suburban populations.

The patterns of response displayed in this report are remarkably similar for physicians in each of these hospital settings. ACEP is a national medical specialty society representing emergency medicine with more than 23,000 members.

News-Medical
April 27, 2004

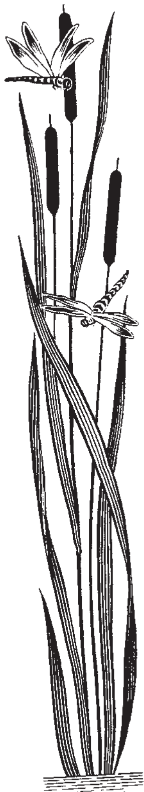
DAEMEN COLLEGE
Fall Lecture Series

Frederick Frese, PhD

Recovery from Mental Illness: Myths Mountains and Miracles

October 25, 2004
7:30 PM

Wick Center
Daemen College



How Genes Affect Moods

Genes don't stop working the day we're born. They're active throughout life, switching on and off in response to cues from the environment. Unfortunately, they don't always respond in optimal ways. For every 100 people born, one ends up with schizophrenia, one develops bipolar disorder and 20 experience some form of depression. Heredity may account for as much as 80 percent of the risk for these illnesses, but we still know little about how, exactly, genes affect our risk. Fortunately, scientists are starting to find clues.

Like the building of the transcontinental railroad, the study of genes and mental health is a race from the ends to the middle. If researchers can pinpoint a suspicious gene in people from afflicted families, they can try to figure out its function. Conversely, if they know something about the physiology of the illness, they can sometimes use that knowledge to zero in on offending genes. Either way, they gain new insight into the biology of the illness.

One of the most important findings to date came out this summer, when a group of researchers from the United States, Britain and New Zealand showed that a gene involved in the brain's use of serotonin affects our vulnerability to depression. The so-called serotonin-transporter gene comes in 'short' (less efficient) and 'long' (more efficient) versions, and each of us inherits two copies--one from each parent. No combination of short or long variants leads directly to depression, but short versions of the gene put people at a distinct disadvantage if they experience stressful life events. In tracking more than 800 young adults over a five-year period, the researchers found that 33 percent of those with at least one 'short' became depressed after a series of stressful life events, such as divorce or the loss of a job. People with two copies of the short variant fared worse than those with a single copy, and their risk of depression rose steadily as their lives became more stressful. By contrast, only 17 percent of those with two 'longs' grew depressed in similar circumstances,and their risk of depression remained flat as their stress levels rose.

No one knows just how this gene exerts its effect on mood,a question that could keep researchers busy for decades. But this study carries seminal lessons. It reminds us that all mental activity is a reflection of brain function, and it illuminates the fascinating interplay between heredity and experience. Genes, as it turns out, don't cause depression. They leave us more or less vulnerable to stressful life experiences. By amassing hundreds of discoveries like this one, we may someday gain a full picture of contentment and despair. The pace of progress may seem glacial. But glaciers change the contours of the world.

Newsweek
Dec. 8 , 2003

2003 -2004 NAMI Officers & Board

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The Challenger
Editor: Lynne Shuster

Lead Exposure identified As Possible Risk Factor

Babies exposed to lead in the womb may be at increased risk of developing schizophrenia as adults, new American research has revealed.

Scientists have long known that toxins such as lead and alcohol can harm a mother's unborn child and lead to developmental problems during childhood. But the new study, presented at the annual meeting of the American Association for the Advancement of Science in February, is one of the first to suggest that this exposure can lead to disorders that strike decades later.

Dr. Ezra Susser, a psychiatrist at Columbia University in New York, led the research team that tested stored blood samples collected from expectant California mothers between 1959 and 1966. They compared the blood lead levels of 44 women whose children went on to develop schizophrenia with 75 others whose children did not.

Children of mothers whose blood had levels of 150 micrograms of lead per litre or more were twice as likely to develop schizophrenia than those whose blood levels were below this threshold, Dr. Susser said.

In the 1950s and 1960s, lead exposure in California was relatively high because of the use of leaded gasoline at the time. The researchers suggest that if their findings are found to be similar in other groups, as many as a quarter of all schizophrenia cases in this same age group could be explained.

"The results of our study suggest that lead-induced prenatal damage to the developing brain may show itself decades following initial exposure to the substance," Dr. Susser said.

Schizophrenia Digest
Spring 2004

CSK Foundation Charity Golf Outing

Saturday, September 11, 2004

12:00 PM Registrations/Lunch
1:30 PM - Shotgun Start

Chestnut Hill Country Club,
Darien, NY
585.547.3616
Cost: $75.00

Included:

18 Holes with cart
Lunch before tee-off — Hotdogs/Hamburgers, Beer & Soda
Dinner — NY Strip Steak, Salad, Potato, Beer, Soda and PRIZES

Directions:

I-90 to Exit 48 A (Pembroke), RT 77 South - 5 miles - Right turn to course

Reservations:

Contact any board member or send a check with names of golfers to Linda Youngman, 3214 Angle Road, Orchard Park, NY 14127.
Please make reservations early as we have filled up in the past.

Help us fund the fight against major mood-disorder brain diseases.

Health Insurance Firms Block Parity Bills

Aided by House Speaker Dennis Hastert, insurance companies successfully have blocked legislation to make them provide equal coverage for mental and physical illnesses if their policies include both.

President Bush endorsed the concept two years ago. Today, supporters of the bill are willing to settle for a scaled-back version they hope Congress will pass in 2004.

The original legislation has 69 sponsors in the Senate and 246 sponsors in the House, clear majorities in both chambers. It was named for late Sen. Paul Wellstone, a Minnesota Democrat who championed the issue for years.

Hastert, however, has declined to schedule a House vote. In the Senate, Republicans blocked an attempt to win passage last fall, on the one-year anniversary of Wellstone's death in a plane crash.

"The bottom line is there is still enormous resistance from employers and health plans, and they've been able to turn to allies in the Senate and especially the House," said Andrew Sperling, a lobbyist for the National Alliance for the Mentally III.

Companies such as BIueCross BIueShield Association, United Healthcare Corp. and WellPoint Health Networks have worked to defeat the legislation, in addition to the trade group America's Health Insurance Plans, lobbying reports show.

Those groups combined to spend more than $13 million in lobbying last year on issues such as the mental health parity bill. The bill would expand a 1996 law prohibiting health plans that offer mental health coverage from setting lower annual and lifetime spending limits for mental treatments than for physical ailments. The proposed legislation also would require equal treatment for co-payments, deductibles and limits on doctor visits.

Karen Ignagni, chief executive of America's Health Insurance Plans, said employers worried that would drive up health care costs and might cause some to drop mental health coverage altogether.

The Congressional Budget Office has estimated that the legislation would increase health insurance costs slightly less than 1 percent, or roughly $23 billion a year.

Ignagni said her group also is concerned about covering every mental health illness, from caffeine addiction to adjustments to adulthood.

Sponsors of the legislation say they are willing to require only coverage for whatever mental illnesses are already covered by a specific health plan.

'The coverage has been scaled back significantly," said Rep. Jim Ramstad, R-Minn., one of the bill's leading supporters. He said Hastert, R-III., has been the main obstacle.

I've spoken to him until I'm blue in the face," said Ramstad, a recovering alcoholic.

Hastert's office did not return phone messages, but the speaker has expressed concerns in the past that the bill would drive up premiums.

Paul Dennett, vice president for health policy at the American Benefits Council, which represents primarily Fortune 500 companies, said the scaled-back legislation would be an improvement but not enough to win his group's support. He said employers do not want any expansion of the 1996 law.

In an April 2002 speech to mental health professionals in New Mexico, Bush said the health insurance system must treat mental illness like any other ailments.

Americans with mental illness deserve our understanding and they deserve excellent care," Bush said. ' 'They deserve a health care system that treats their illness with the same urgency as a physical illness."

Bush added: "Health plans should not be allowed to apply unfair treatment limitations or financial requirements on mental health benefits."

Officials with the White House and the Health and Human Services Department did not return phone messages, nor did Senate Majority Leader Bill Frist, R-Tenn. During debate last year, Frist said he supported the legislation, but said it should pass out of the Senate Health, Education, Labor and Pensions Committee before coming to a floor vote.

The committee chairman, Sen. Judd Gregg, R-N.H., has told Frist he is fine with the bill going directly to the floor, said Gregg's spokeswoman, Gayle Osterberg. She said Gregg is considering an amendment that would expand mental health benefits without causing people to lose their coverage but declined to elaborate.

The Senate sponsor, Sen. Pete Domenici, R-N.M., said Gregg's amendment would require that cost increases not exceed 1 percent. Domenici said he was hopeful for a vote this month.

Frederic J. Frommer
The Associated Press
June 11, 2004

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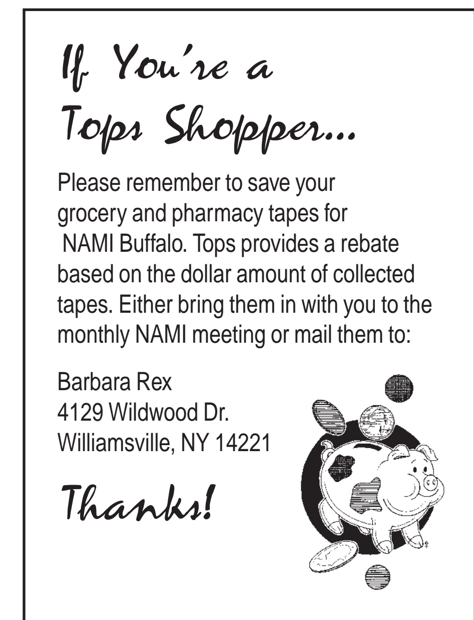


Change in UK Diets Could Trigger Mental Health Crisis

Changes in British diets are going to lead to an explosion in mental health problems, medical experts said yesterday. They warned of a crisis even bigger than the epidemic of obesity afflicting the UK.

They said that most of the increase could probably be blamed on changes in farming and food over the past 20 years, which have led to deficiencies in essential omega-3 fatty acids.

Experts will present new evidence at an international conference into the study of the impact of fatty acids in Brighton this week.

The role of omega-3 has previously been underplayed by scientists, but evidence is emerging that it could have a big affect on mental well-being.

Last week, the Food Standards Agency issued new advice encouraging people to eat more oily fish such as tuna and mackerel in a bid to increase intake of omega-3. Scientists are considering whether food should be fortified with the fatty acid in order to avert a health crisis in the future.

Professor Michael Crawford of London Metropolitan University, said: "This is a major health crisis and a really serious issue, which hasn't really been looked at before.

"We are going to have an epidemic of mental health problems in the future if we do not deal with this now Omega-3 has a major role to play in mental health and we need to start recognising that."

Research due to be released at the conference of the International Society for the Study of Fatty Acids this week will show that pregnant women with lower intakes of omega-3 are more likely to have children who will go on to have behavioural problems, attention disorders and other problems.

The mothers themselves were more likely to suffer from depression if they had lower-than average intakes of the fatty acid.

Professor Crawford warned: "We are facing a monumental crisis here, and a lot of it is due to the very simple issue of diet."

This follows a study highlighted earlier this year by the Royal College of Psychiatrists, which revealed a world-wide link between a lack of omega-3 in the diet and schizophrenia. This research showed that people who ate high levels of sugar and dairy products, instead of oily fish, were more likely to develop severe mental illness.

Omega-3 is linked to brain development and mental health and is found in "green" foods such as cabbage due to the photosynthesis process.

Professor Crawford said that at the beginning of the century, people's omega-3 intake was higher because of traditional farming practices where cows and lambs were fed on grass.

However, intensive agriculture practices over the past 50 years have meant that livestock is now fed on grain and vitamins rather than omega-3-rich foods.

Mental health problems are already predicted to become the third most costly burden of disease in the world by 2020. *The Independent on Sunday* has been campaigning for more than two years to improve access to treatment for the mentally ill.

Scientists are concerned that unless the role of diet is highlighted by the Government, that burden could become worse. Researchers are already looking at ways to alter the feeding of dairy cows in order to increase the production of omega-3 in their milk.

Decreasing intake of omega-3 has also been linked to low rates of fruit and vegetable consumption in the UK.

Maxine Frith and Sophie Goodchild
The Independent
June 27, 2004

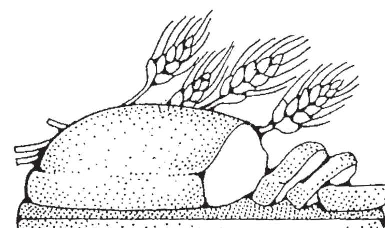
Gluten intolerance Linked to Schizophrenia

People with a genetic intolerance to gluten may also be at increased risk for schizophrenia, new research suggests. Investigators say the link, if proven, could lead to new treatments for a small subset of people with the disorder.

By studying a Danish health registry, researchers from Johns Hopkins University's Bloomberg School of Public Health found people with the genetic digestive disorder known as celiac disease to be three times as likely as the general population to develop schizophrenia. Lead researcher William Eaton, a professor at Johns Hopkins, says the next step is to determine if following a gluten-free diet makes a difference in the symptoms of people with schizophrenia who have celiac disease. Celiac disease is a lifelong condition in which foods that contain gluten damage the small intestine. Gluten is a form of protein found in some grains such as wheat, rye and barley. The damage to the intestine makes it hard for the body to absorb nutrients such as calcium, iron and fat from food.

The findings of the study were published in the *British Journal Of Medicine* in February.

Schizophrenia Digest
Spring 2004



Ten Things You Can Do to Fight Stigma

1. LEARN MORE ABOUT MENTAL ILLNESS. To the extent that you are better informed about mental illness, you will be better able to evaluate and resist the inaccurate negative stereotypes of mental illness that are so common. One place to start is the National Mental Health Services Knowledge Exchange Network.

2. LISTEN TO PEOPLE WHO HAVE EXPERIENCED MENTAL ILLNESS. These individuals can describe what they find stigmatizing, how stigma affects their lives, what they would like others to know about life with mental illness, and how they would like to be viewed and treated.

3. WATCH YOUR LANGUAGE. Most of us, including mental health professionals and mental health consumers, use terms and expressions related to mental illness that may perpetuate stigma. We use psychiatric labels to disparage, such as when we complain about aggressive drivers and call them "nuts" and "lunatics." We also depersonalize sufferers of mental illness by referring to them generically as "the mentally ill" or as "a schizophrenic." We can avoid contributing to stigma by avoiding such language and by using People First language to refer to individuals with psychiatric disorders.

4. MONITOR MEDIA AND REPORT STIGMATIZING MATERIAL to any of a number of organizations. Organizations such as the National Stigma Clearinghouse, the National Mental Health Association, and the National Alliance for the Mentally Ill protest such material by contacting the people-authors, editors, movie producers, advertisers-responsible for the material.

5. RESPOND TO STIGMATIZING MATERIAL IN THE MEDIA. Write, call, or e-mail stigmatizers yourself, expressing your concerns and providing more accurate information that they can use. The organizations mentioned above can help you figure out who to contact.

6. SPEAK UP ABOUT STIGMA. When someone you know misuses a psychiatric term (such as "Schizophrenia"), let them know and educate them about the correct meaning. When someone disparages a person with mental illness, tells a joke that ridicules mental illness, or makes disrespectful comments about mental illness, let them know that that is hurtful and that you find such comments offensive or unacceptable. Let others know your preference for People First language.

7. TALK OPENLY ABOUT MENTAL ILLNESS. Don't be afraid to let others know of your mental illness or the mental illness of a loved one. The more mental illness remains hidden, the more people continue to believe that it is a shameful thing that needs to be concealed. Talking about it can also be empowering for individuals with mental illness and help to relieve the "internalized stigma" they feel.

8. DEMAND CHANGE FROM YOUR ELECTED REPRESENTATIVES. Policies that perpetuate stigma-from poorer health insurance coverage of mental illness than physical illness to limited funding for research into the causes and treatments of mental illness to inadequate budgets for public mental health services-can be changed if enough people let their representatives know that they want such change.

9. PROVIDE SUPPORT FOR ORGANIZATIONS THAT FIGHT STIGMA. Join, volunteer, donate money. The influence and effectiveness of the organizations fighting mental illness stigma depend, to some extent, on membership size and adequacy of finances. They also rely heavily on the effort and passion of their volunteer members. You can make a contribution through them.

10. CONTRIBUTE TO RESEARCH RELATED TO MENTAL ILLNESS AND STIGMA. To the extent that mental illness can be understood and treated, stigma will be reduced. When we can be confident that mental illness can be treated quickly and effectively, it will be less frightening. When we know how stigma is perpetuated and, better still, changed, we will be better able to assist those with mental illnesses to deal with it. Research will help us to learn these things.

Otto F. Wahl, Ph.D.
George Mason University

Do the Eyes Have It?

According to a popular, if cliched, adage, the eyes are the window to the soul. Researchers at the University of Illinois at Chicago believe the eyes may also help diagnose mental disorders such as schizophrenia, depression and autism.

Researchers have long reported irregularities in the eye movements of patients with mental disorders. Patients with autism have difficulty maintaining eye contact with others. Schizophrenics are often unable to keep their eyes focused on slow moving objects. These abnormalities, researchers say, reflect defects in the neural circuitry of the brain - defects that are well documented but as yet poorly understood.

With a renewed $1.2 million grant from the National Institute of Mental Health, which has funded their work since 1988, John Sweeney, director of the Center for Cognitive Medicine in UIC's department of psychiatry, and his colleagues are spearheading a research initiative to study and catalog eye movement patterns in patients with psychiatric disorders.

In these experiments, test subjects with maladies ranging from severe brain trauma to bipolar disorder undergo a battery of visual tests.

They wear infrared glasses linked to a computer that measures and records subtle eye movements. Similar tests, administered to the participants in an MRI scanner, allow the researchers to monitor brain function associated with eye movement and pinpoint inconsistencies. Sweeney says noting parallels in abnormal eye movement and brain activity gives us an objective way of evaluating patients and treatment responses that clinical evaluations, while crucial, can't provide. This line of research may also help identify at-risk individuals before the onset of mental illness.

Dan Schulman
Psychology Today
September/October 2003

Life Before and After Electro Shock Therapy

In October 2002 I celebrated my 60 the birthday. Seventy-five of my friends and family feted me. I said "Thank-you for coming to make my day so special. Everyday, I am awakened at 5 am by my puppy, Danielle and we set out for our first walk. Because it is cold at that time, I often wear a facemask and cannot wear my glasses. I walk along the shore of Lake Erie. Most of my life has been like that: putting one foot in front of the other and trudging on through the darkness.

Today, I do not feel that way. In fact, I am more peaceful now than I have ever been.

I had my first breakdown when I was 13 years old and have suffered from clinical depression for most of my life. I was the victim of childhood sexual, physical, mental and emotional abuse and neglect. I have been on many anti depressants and for years self medicated with alcohol.

I am a recovering alcoholic and in November, celebrated 20 years of sobriety. I have been to many psychiatrists and psychologists throughout the years. Once I stopped drinking alcoholically I had to change my outlook on life. I attended 12 step meetings but I was one of `those with grave emotional or mental disorders. Many of them do recover, if they have the capacity to be honest." (Alcoholics Anonymous p.58)

I was in intensive psychotherapy since 1983. I seemed to be coping better and then in March of 1990 I was assaulted. This assault apparently triggered flashbacks to former abuse and plunged me into a dark abyss from which I saw no escape. I was consumed with thoughts of self-destruction and suicidal ideation. I was obsessed with thoughts of my own death. I couldn't die but neither was I living. I would dissociate often and had frequent panic attacks. I only felt comfortable at home or with 2 trusted relatives. I couldn't go to the store or be around people.

When I was at obligatory functions such as funerals or wakes I saw everyone around me as if they were in a Charley Chaplin movie. They moved frenetically and I couldn't understand what they were saying. Sometimes, I was the frenetic one, when I would become a rage-a-holic. These rages were my response to fight, flight or freezing. I wanted to die or I wanted someone to kill me.

I realized that I could not go on this way. I was hospitalized in August 1999 and was so decompensated that when I got the bill for the hospital stay, I denied I was ever there. The Doctor had to show me the medical records. I researched ECT and I wrote my psychiatrist, begging for what I saw as my last chance. I was hospitalized for 3 weeks and had a series of 6 treatments. This was not an easy decision and I was somewhat apprehensive about the side effects.

Why would the possible loss of memory affect me, when I had nothing worth remembering anyway?

Before ECT, I was helpless, useless and hopeless. Today, I have friends I never had before, I can go out in public, I can shop, I walk 3 miles a day and swim continuous laps for 55 minutes, 3 times a week. This summer, I swam in Lake Erie everyday, read and understood novels and began the daily practice of meditation. I was able to confront unresolved grief. I participate in my life and am no longer overwhelmed by life's happenings. In September, I was able to give the eulogy at a beloved friend's funeral service. I enjoy my life and my puppy. I do all my own yard work, pay most of my bills on time and am a productive citizen. As one AA speaker said:" I keep walking and turn left at the walls."

Barbara in Progress
December 2002

[Barbara, a member of NAMI Buffalo, continues to make progress. Ed.]

Misplaced Kids

It's a tragedy that prisons and jails in the United States are warehouses for the mentally ill. Currently, Rikers Island Prison in New York and the Los Angeles County Jail are providing mental health care to more people than any other facilities in the country.

Now congressional investigators have reported that thousands of children with psychiatric disorders are suffering the same kind of fate.

Mental health advocates and juvenile justice officials are right to demand that mental health care be available to more of those in need.

According to a congressional survey, 15,000 mentally ill children nationwide were incarcerated last year when mental health care was unavailable. Some had committed crimes attributable to their mental illness. Others, who had no charges against them, were simply held in detention because they had no place to go while waiting for treatment. At least four juvenile detention centers in New York reported inappropriate incarceration of youths who really needed medication or psychotherapy. Leaving the criminal justice system to deal with mental illnesses is neither humane nor effective. And it costs more to incarcerate a person who suffers with mental illness than to provide preventive mental health care that would allow him or her to live as a healthy, productive and stable member of society. Congress and the state Legislature should keep that in mind when allocating funds for mental health.

It can also help by enacting legislation to require more equitable insurance coverage for mental illnesses. The state Senate and the Assembly have both passed bills toward that goal. A compromise should be found quickly.

In children and adults, mental illness should be treated, not punished.

Rochester Democrat and Chronicle
July 9, 2004

Passion, Persistence, and Pals Helped Turn Tragedy into Activism

Kendra's Law is named in memory of Kendra Webdale. In January 1999, the 32 year old Buffalo native was killed after being pushed into the path of a New York City subway train by Andrew Goldstein, a man with severe mental illness who had a history of noncompliance with treatment. Kendra's family was instrumental in the passage of this law, advocating tirelessly for reform. Here, Pat Webdale offers some things she learned throughout the difficult battle for passage.

My daughter Kendra was pushed off of a subway platform into the path of an oncoming train on January 3, 1999. Her assailant was diagnosed with schizophrenia and was not taking his medicine. I vowed to do something to help prevent future tragedies.
Kendra's death was high profile, one of 11 million subway riders trying to make her way in a big city. Would a law named in her honor bring peace to another family?

Know your subject

We hooked up with the experts, the people at the Treatment Advocacy Center and NAMI. My daughters purchased *Out of the Shadows* and *Surviving Schizophrenia* by TAC president Dr. E. Fuller Torrey. We read about the loss of a family member to mental illness and about the system; navigating, negotiating, the throwing up of hands in total disillusionment at its inadequacies. The mentally ill had to live on the street, be thrown in jail or become dangerous to self or others in order to receive treatment.

Watch for opportunities

Only five days after Kendra died, I wrote a letter to Eliot Spitzer, the Attorney General of New York State, challenging procedures in which his office would no longer review OMH discharges. New York was under fire after Judith Scanlon, a psychiatric nurse and intensive case manager, had been murdered by her client while making an unaccompanied home visit. .. daughter Krista send a letter to Governor Pataki. saying, in part: "When Mrs. Scanlon started her psychiatric nursing career, the Buffalo Psyche Center had 3,000 beds and today there are 260 beds. We are releasing far too many patients into unsupervised environments where they are unable to function."

The attorney general was about to introduce an assisted outpatient treatment bill to help people with serious brain disorders to obtain treatment. He suggested the law be named to honor Kendra.

Ask questions

Suzanne, a mental health professional, questioned the bill - would it work? She opposed putting Kendra's name on a law that would have no teeth. In response, the attorney general allowed her to work closely with his office as the bill was drafted.

Be persistent

We traveled to Albany seven times and met with the attorney general three times in Buffalo. We endured traffic jams, getting lost, bad meals, late nights and unkempt hotels.

We called and wrote personal letters to the senate, the assembly and the governor almost daily. I spoke to the NAMI board of New York, to ask for its support for assisted outpatient treatment.

Be creative

We approached the matter with a bipartisan attitude. Copyboy donated 1,000 business cards with Kendra's picture on it to be distributed statewide - the cards read "Pass Kendra's Law" with phone numbers of strategic legislators.

Be passionate and compassionate

Kendra is grieved everyday and we understand that the mentally ill are also grieved and lost to their families. Other passionate people were definitely a huge help — for instance, all the people who made phone calls, who knows how many of them had a mentally ill family member?

Since it was passed, Kendra's Law has had a proven track record and has changed the system in substantial ways in New York. We are confident that our passionate crusade is saving and improving lives.

Pat Webdale
Reprinted from ***The Catalyst***
Treatment Advocacy Center

Continued from page 1

a patient's deterioration, listen to friends and family who seek help and act promptly, develop a flexible case manager system that can cover all patients when worrisome reports are received.

Such tragedies are not always avoidable, but some are. But after the victims are tucked away under a headstone, and the patient-perpetrators are behind bars, who will remember, who will pay attention?

Lynne M. Shuster
Editor, The Challenger

It's Not Just You

An article in *Medscape* reported on a Stanley Foundation study of 2,839 of its bipolar patients, which found that:

- 85.1 percent had been hospitalized in the past, on average three times.
- The peak age of onset was between 15 and 19 years of age.
- The rate of suicide attempts was 50.3 percent.
- 54 percent had a family member with bipolar disorder, and 32 percent of family members had unipolar depression.
- A third were currently married, another third single, and the rest were separated, divorced, or widowed.
- Despite the fact that approximately 90 percent had high school diplomas and a third had completed college, almost 65 percent were unemployed and 40 percent were on welfare or disability.
- The rate of depressive symptoms over six months was twice the rate of manic symptoms (63.6 percent vs 33.1 percent).

http://www.medscape.com/viewarticle/441618

Killing Off Housing for the Poor

The Bush administration's tax cuts for the well-to-do have taken a heavy toll on the nation's most important social programs for the poor and working class. Prominent casualties include child care assistance for working mothers and federal aid for needy college students. The latest victim appears to be Section 8, the government's main housing program for the poor. The program provides rent subsidies for two million of the country's most vulnerable families and encourages private developers to build affordable housing.

Section 8 subsidies go primarily to families that live at or below the poverty level, in households that include children, disabled people or the elderly. These families pay 30 percent of their incomes toward rent and the Section 8 vouchers pay the rest. Some cities give priority to battered women, many of them with children, who have to find a new place to live to escape danger. The need is so great that families often wait years for vouchers, which become available when voucher holders die or become ineligible after getting better jobs.

Congress rejected an administration proposal that would have placed a financing cap on the program and turned the money over to the states. But the administration's assault continues, through the appropriations process in the House and through administrative rulings at the Department of Housing and Urban Development, which has been trying to put the brakes on the voucher program. Last month, the department issued new guidelines to the country's 2,500 public housing agencies declaring that it would no longer pay the full cost of the vouchers but would cap the federal contribution at the level of August 2003, adding an adjustment for inflation.

This has already caused some private builders and financiers to back away from projects that would have produced desperately needed affordable housing. In addition, public housing officials in many states have made it clear that the new policies will force them to raise rents or evict tenants. Having paid lip service to the goal of ending chronic homelessness, the Bush administration is now threatening to kill off the only program that could possibly achieve it.

Legislative Alert: Speak out about the proposed budget cuts in funding for HUD's Sec. 8 housing program. Contact your Senators and Representatives by calling the Capitol switchboard at 202-224-3121 or toll free: 1-800-839-5276 or online through www.congress.org.

The New York Times
May 10, 2004

Depression Fallout

By Anne Sheffield

Depression Fallout is an interesting and informative book about the impact of depression on the relationship of couples. The beginning sentence, "Love and depression speak different languages", describes well the essence of the subject.

Drawing from the experiences shared on her online message-board, www.depressionfallout.com, the author explains: "The depressed think very poorly of themselves. The torrent of criticism directed at partners is the overflow from the reservoir of self-hatred in which their psyches soak." Bombarded by criticism and ignored, spouses attempt to empathize, cajole, beg, argue, blame, and often become depressed themselves. Statistics rate divorce and separation at 60% for this group.

Anne Sheffield encourages involvement of the well partner in treatment and stresses how critical persistence and asking the right questions are. Sections on medications and herbal remedies also warn of dangerous interactions if used in combination. She compares trying to have a relationship with a depressed person to "being on a rollercoaster blindfolded", or "trying to walk across a floor strewn with marbles". Advice she gives on caring for oneself and on dealing with violence in the relationship is invaluable.

I found this book a useful tool for any couple trying to work through the terrible influence depression can have on a loving relationship.

Review by Marcy Rose

Out of the Darkened Room

By William R. Beardslee, MD

Out of the Darkened Room is written by a Boston psychiatrist who is a professor of psychiatry at Harvard Medical School, and Chair of the Department of Psychiatry at Boston Children's Hospital.

The book deals especially with how depression in a parent affects children in the family. It includes insightful discussion about how children cope with assuming responsibilities beyond their years, worrying that voicing their own concerns may stress a parent, or that they may have caused the parent's illness.

Of particular interest is a listing and explanation of the characteristics of resilience in children. Topics include suicide, violence, and depression in children as well as the challenge faced by families struggling with a member who has clinical depression.

Dr. Beardslee offers empathy, wisdom, and hope while addressing the everyday concerns of family life in crisis.

Review by Marcy Rose

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Mary Kirkland
President, NAMI of Buffalo
264 Hamilton Dr
Buffalo, NY 14226

Dear Ms. Kirkland:

I am writing to express my concerns with the column printed in The Challenger for June 2004 entitled "ECMC: Déjà Vu All Over Again". The Challenger is a well written, professional newsletter that provides very valuable information to individuals with mental illness as well as the families and clinicians who care for them. However, I think you are doing a disservice to your audience by printing articles that are vindictive and anonymous. This article is very one sided, and does not address the civil rights of the individual and the numerous legal and ethical issues involved in treatment of the mentally ill. Instead its point appears to be to disparage doctors, lawyers and others who care for the mentally ill in our community. Use of thinly disguised descriptions of the individuals involved does not appear to me to be a fruitful means of improving the care that is provided. I have read a number of similar articles in your journal and it is my opinion that they lower the standard of your newsletter and your organization. If you feel it is appropriate to continue to publish such articles, I recommend that they be signed by the author so that a rebuttal can be made if appropriate.

I appreciate your consideration of this issue.

Sincerely yours,

Carolyn Young, M.D.
Medical Director
Assertive Community Treatment Program

In Response...

We're always pleased to learn that professionals as well as families are reading *The Challenger*, and that the information provided is helpful to all readers.

We would disagree that our occasional editorials are "vindictive" or that the point is to "disparage doctors, lawyers and others who are for the mentally ill...." And the article is certainly not anonymous, but an editorial stating our collective experience. Frustrated? Yes. Angry? Yes, indeed. We believe that much of the rhetoric about families being "involved" is so much hogwash in many instances. And we **know** that there are staff who are simply going through the motions.

We don't know whether it's burnout, indifference, incompetence. It doesn't make any difference though, when our sons or daughters, mothers or other loved ones, aren't getting the care and treatment they need.

Yes, the laws of confidentiality and involuntary treatment can present a challenge. But we've found that in most cases the really good staff find a way to skirt them and deal with families' concerns and issues, rather than avoiding them or just going through the motions.

As Dr. Young notes, the article "is very one-sided, and does not address the civil rights of the individual and the numerous legal and ethical issues involved. True. There are many in the professional medical, legal, administrative, and political arenas who can and do serve as apologists for the system. That's not our job. We present the facts as we know them, knowing also that care and treatment in other places is far better than it is here (and probably also worse in other places, as well). That's no excuse for the inadequacies we struggle with here. We've brought these conditions to the attention of hospital administrators, agency and program directors, and oversight authorities. And mostly we've just heard more excuses. But families aren't stupid—and we **know**. We know that often there is no excuse for things as they are.

Sometimes the best that we can do is to make sure all our members know what they're likely to encounter, so that they can be prepared. They have no other defense when they're helpless in the system.

Lynne Shuster
Editor, *The Challenger*

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Rick's Thoughts

**NAMI in Buffalo & Erie County
20th Anniversary
1984—2004**

Thanks to Eli Lilly & Co. for underwriting this issue of *The Challenger*