

the challenger

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

vol. 21, no. 6 December 2006

Mark your Calendar

December

NAMI Christmas Parry, Thursday, December 14th, 7:00 PM, St. Paul's Lutheran Church, 4007 Main Street, Amherst. Bring a plate of holiday goodies to share. Meet old friends and make new ones. A wonderful lift for your spirit!

January

No NAMI Business Meeting.

NAMI Family Meeting, Thursday, January 11th, St. Paul's Lutheran Church, 4007 Main Street, Amherst. Library and Coffee Hour: 7 PM. General Meeting 7:30 PM. Guest speaker: Horacio Capote, MD on the new Vagus Nerve Stimulation for Treating Depression.

February

NAMI Business Meeting, Thursday, February 1st, 7:30 PM, St. Paul's Lutheran Church, 4007 Main Street, Amherst. All NAMI members welcome.

NAMI Family Meeting, Thursday, February 8th, .St. Paul's Lutheran Church, 4007, Main Street, Amherst. St. Paul's Lutheran Church, 4007, Main Street, Amherst. Library and Coffee Hour: 7:00 PM. General Meeting: 7:30 PM. Guest speaker: Richard Bennett, MD on achieving wellness in spite of a serious mental illness.

March

NAMI Business Meeting, Thursday, March 1st, 7:30 PM, St. Paul's Lutheran Church, 4007 Main Street, Amherst. Find out what your NAMI Executive Board is doing!

NAMI Family Meeting, Thursday, March 8th, . St. Benedict's RC Church, 1317 Eggert Road (corner of Main and Eggert), Amherst, NY 14226. Library and Coffee Hour: 7:00 PM. General Meeting: 7:30 PM. Guest speaker Tom McLaughlin of City Mission discussing the mentally ill at the Mission.

April

NAMI Business Meeting, Thursday, April 5th, 7:30 PM, St. Paul's Lutheran Church, 4007 Main Street, Amherst.

NAMI Family Meeting, Thursday, April 12th, St. Paul's Lutheran Church, 4007 Main Street, Amherst. Library and Coffee Hour: 7:00 PM. General Meeting: 7:30 Pm. Guest speaker: Marcia Langa, RN on Using Clozaril When Nothing Else Works.

From the Editor...

I've always said that NAMI is about today and tomorrow. For many people, mental illness is a life-long struggle, for both patients and families. Sometimes, everybody get lucky, and gets a break. A patient is stable, doing well, taking meds. And often, the family disappears from the NAMI radar screen. We don't see or hear from them for months or even years. Then everything falls apart and we get the phone call: "Hi. Remember me?" We understand that when everything is okay, people get on with their lives, but just as families never know when they'll need NAMI, and we'll be there for them, NAMI members also need to remember that we're a grassroots organization, and we need our members to help lift the load consistently.

Resources for treating mental illness, housing and services, vocational programs, Medicaid, are all publicly supported and subject to changing political winds and competing priorities. Our best, indeed our only hope, for changes and improvement, is the active involvement of our NAMI members making their voices and concerns heard.

We need all of us to write letters, send emails, call legislators, make noise, make known that our sons and daughters deserve and need the resources and opportunities necessary for a life of dignity, quality care, for research on better medications and treatments, and essential financial support. No one else can speak with our authentic, powerful voices.

For over twenty years, I've had no family member in the mental health system and thought that heartbreak and worry was behind me. And then in November my eldest grandson was hospitalized for the first time with severe depression and suicidal tendencies. So I'm back on the front lines again, not only for all NAMI families, but for my own.

I know there are anxious times ahead, and am thankful that NAMI friends will be there for me when the road is rough, and to celebrate the days that go well.

Lynne Shuster

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Setting Goals: A Reason for Hope

Finishing school, finding a job, getting married and starting a family - many of us share these common goals for our future. But when illness strikes, dreams of a productive, fulfilling life may slip away as you struggle to get well again.

"Very often, health care providers and people with schizophrenia become focused on just the disease. They forget there's more to life than being ill," says Ronald J. Diamond, MD, a board-certified psychiatrist and medical director of the Mental Health Center of Dane County in Wisconsin. "But people with schizophrenia deserve to reach their full potential. The road to recovery may be hard and frustrating at times, but it is worth fighting to have a full life despite the challenges caused by the disease."

The key, Dr. Diamond says, is to set personal goals, some short-term and some long-term.

"A lot of people with schizophrenia are overwhelmed by things they cannot do. They become convinced they cannot have goals — or when they try to set goals, they are told their goals are unrealistic or unachievable. However, it is important that providers and people with schizophrenia realize that goal setting is a critical part of the recovery process. It can help someone regain his or her sense of personhood and enjoy a fuller, more satisfying life," says Dr. Diamond, who is also a professor of psychiatry at the University of Wisconsin, Madison.

For Stuart S., a consumer living with schizophrenia, setting both short- and long-term goals has been instrumental in helping him recover.

"After I became ill, I knew I wanted to someday re-enter the mainstream and reclaim my life as a productive member of society. It's a long process that takes time, but now I have a full-time job and I'm setting short-term goals. My daily goals include going to the gym after work, eating better and walking for 30 minutes on weekends," he says.

Helping You Help Yourself

Dr. Diamond encourages schizophrenia consumers to take an active part in managing the disease, and that includes looking at what you want to accomplish in your life and identifying

barriers that may slow your progress. Also, it is important that health care providers work with consumers to help them realize these objectives by taking the time to discuss their goals and aspirations.

"Before you became ill, what did you picture your life would be like? Were you hoping to buy a car? Get an apartment? Have a girlfriend or boyfriend? Go to college?," asks Dr. Diamond. "Don't give up on your dreams. Dreams for all of us may need to change and adapt, but do not let the illness take these dreams away. All of us benefit by setting and achieving goals. Goals give us direction. They motivate us and give us a reason to get up and start the day."

Overcoming Barriers

Because schizophrenia is a relapsing illness, people make strides and then have setbacks. "You may get a job, but then lose it. You try again and try again. The ups and downs become very frustrating for patients and the people around them," notes Dr. Diamond.

Setbacks can be disappointing and sap your motivation, but Dr. Diamond encourages patients to be persistent. "The secret is having hope, believing that circumstances will improve," he says.

"Make sure the goals you set are reachable," adds Stuart S. "If you have set a goal and you're finding you cannot reach it, you might want to reconsider that goal and choose something more realistic."

"Once you and your treatment team have found the right medications and treatment plan for you, experts recommend that you discuss personal goal setting with your doctor. You may also wish to involve your loved ones, who can provide much-needed support and encouragement.

Strategies for Success

"When it comes to personal goal setting, the following tips may help you achieve your personal best:

"Start small. Break down complex tasks into simpler tasks, and don't try to accomplish too much at once. If your long-term goal is finishing school, for example, develop a list of day-

to-day, short-term tasks that contribute to the larger goal. Keep a daily calendar of when you will do homework. Four hours of homework at once could be overwhelming, but sitting down for 20 minutes might be more realistic.

"Celebrate your successes. When you make progress toward a goal-big or small-take time to acknowledge your accomplishments. When you finish a homework assignment, for example, cross it off your list so you can see the progress you are making.

"Take your medicine. Medications will not cure your disease, but they can relieve the delusions, hallucinations, disorganized thinking, and other symptoms you may experience. When your symptoms are under control, you may find it easier to focus on your goals and complete the steps needed to achieve them.

"Look beyond the label. Because of the stigma associated with serious mental illness, other people may fail to see you as an individual apart from the disease. But you are more than "just" a person with schizophrenia. You are a person who may live independently, have a job, contribute to your family and community, drive a car, enjoy a relationship and more.

"Find a source of strength. Recovery is a life-long process, and ups and downs will happen. Seek comfort through supportive counseling, self-help groups, reconnecting spiritually through your church or synagogue or re-establishing bonds with those you love. Advocacy groups such as the National Mental Health Association (NMHA) and the National Alliance for the Mentally Ill (NAMI) can provide resources for consumers and families living with schizophrenia.

"And, most of all, keep your sense of hope and be patient," suggests Dr. Diamond. "Progress you can see and feel may take a while."

For more information, visit:
www.mentalwellness.com.

Christine Cardellino

We Get Letters.....

"In my opinion, a large part of the mental problems [patients experience] are due to the psychiatrists [in the hospital]. In 1988, I was in extremely difficult circumstances.

The symptoms I was exhibiting were not moving or talking. I was forced there to come to the conclusion that I was a better judge of my own being than the hospital staff and decided to go home. When I tried to leave security attacked me and locked me in an eternal metal box called a seclusion room for twenty-four hours without any explanation, without judge, jury trial, without a psychiatrist, without a lawyer, regardless of my physical or mental condition. Without an explanation, they were punishing an innocent citizen just for trying to go home.

This confirmed my idea that psychiatrists [and doctors] are not to be trusted and led me to repeatedly reject medication and needed treatment. In fact, two years ago I came to the point of death before I would go to the doctor's for help with pneumonia.

In 1998 I was again having a difficult time and the police took me to ECMC where I was again held, this time for three months. Many hurtful things happened again. One of them [the staff] would decide a false opinion of something I said, and the rest would follow that false opinion.

They called strange behavior "pathological" without investigating the reasons behind it or trying to help me. It was strange, but not immoral or criminal. They attack anything strange.

They would wait til the last moment before meds, saying "take it or else." They would kneel in the leg and even bit my head to inject me with their meds, against my right to refuse treatment. They would not give me a lawyer until I was under a medicinal fog of their prescriptions. They isolated me for three months from family and friends--people who really would have helped me.

In 2004, I finally surrendered to the doctors for

treatment of pneumonia. This time the nurses [on the medical unit] were nice. I was in ECMC for almost four months. ECMC spent \$300,000 trying not to lose me to the pneumonia their psych meds made me susceptible to. My only complaint was that patients were not protected from pornography and horror movies--on the mental health floor especially.

If you intend to run a medical hospital, first **DO NO HARM!**

If you intend to run a mental hospital, first **DO NO HARM!**

You should not have treated me [and other patients] the way you did in 1988, and 1998. You also should not be showing horror movies as I saw in 2004. And don't label yourself as the enemy of the patient by locking him up without any explanation."

J.R. McN.

(Edited for brevity and clarity. ED.)

"Thank you so much for your help with our recent crisis with my son, Kevin, in Orleans County. God knows what people do without NAMI and people like you who have dedicated their lives to helping the mentally ill. I am totally grateful that I learned about NAMI when my son was first hospitalized twelve years ago. You have been my lifeline."

Jeanne F.



Thanks....

To **Sophia Drapanas Paivanas** for sharing her lovely home with us for our NAMI summer picnic. In spite of a misty rain, everyone had a wonderful time. We're hardy folks!

To the late **Hugh Roden**, a long-time NAMI member, who thoughtfully provided for a generous bequest to NAMI Buffalo in his will.

To **Gail Battaglia**, NAMI member and HSBC employee, who arranged for us to have a table at their recent health fair, and for NAMI Buffalo to receive a generous donation from HSBC employees who participated in their "dress down" Friday.

To **Susan Minotti** who made arrangements for her former employer, Eli Lilly and Co., for a donation to match her own contribution to NAMI Buffalo.

To **Roger and Pat Watkins** who arranged for a very generous donation to NAMI Buffalo from the Kenmore Lions Club.

To **Kathleen Whelehan** who designated NAMI Buffalo to receive a \$500 donation from HSBC Bank in lieu of a retirement gift.

To **The Young Family** for their donation of an enormous snow blower which we were able to sell for \$400.

To **Dr. Adam Ashton** for the latest book he has donated to NAMI Buffalo's library.

To **Sue and Gerry Keppel**, who every month open St. Paul's Church for us, arrange our monthly meeting refreshments, and are always the last to leave following cleanup in our meeting rooms.

To all **NAMI members** who gave so generously of their time in preparing multiple mailings of the new edition of "The Mind Matters."

To all our **NAMI members and friends** who provide financial support for our many activities. We couldn't do it without you!

To **Josie Olympia, MD** and **Brenda DiMillo, MS, RD, CDN** for serving as guest speakers at our Simple Measures conference.

From the President...

Every year is an eventful year in the lives of NAMI families. Days of trauma and confusion, pain, and even the occasional success follow one another in the struggle to come to terms with living with a loved one's serious mental illness.

After four years of very hard work in Albany, we came so close to triumph with passage in both houses of the legislature of the SHU bill, and the passage of a bill to create a state-wide waiting list which would at long last document what we already know to be true--that there is a desperate need for group homes and supervised living arrangements for our family members struggling with mental illness. Both of these bills were vetoed by Governor Pataki.

As I'm writing this, we're waiting with bated breath to see if the legislature will vote to override the Governor's unconscionable actions. PLEASE make phone calls to your New York State Senators and Assembly members urging them to override the Governor's actions!

We're still waiting for the Assembly to pass Timothy's Law once again either for Governor Pataki to sign, or possibly for them to wait and pass it so that Governor-elect Eliot Spitzer can act on it.

Here on the home front, we celebrate the opening of Buffalo Psychiatric Center's beautiful new group home on Letchworth and Grant Street. It doesn't increase the number of beds so desperately needed in group homes, since it replaces a residence in Gowanda which was closed, but it will make life significantly better for those fortunate enough to live there.

While we're thankful for ONE group home housing fourteen people, the State Office of Mental Retardation and Developmental Disabilities has FIFTEEN group homes in the works. We're behind the curve and will be working hard to increase residential

options for our own loved ones in need in the coming years.

2006 marked the publication of the sixth edition of "The Mind Matters: A Practical Guide to Services for the Mentally Ill in Erie County." Special thanks are due to JoEllen Pennella, Lynne Shuster, and Sherwin Greenberg for hundreds of hours spent revising and update this invaluable resource guide for families, patients, and professionals.

NAMI Buffalo members have enjoyed the mutual support, friendships, and understanding gained through our numerous activities—the summer picnic, our NAMI Christmas is for Kids project, our annual garage sale, the NAMI holiday party, monthly educational meetings, our Family to Family classes, and NAMI's support group.

Lynne and I continue to respond to hundreds of phone calls during the year from families, patients, and professionals seeking services, housing, treatment providers, information and referral, or just a chance to talk with someone who truly understands the pain and plight of families trying to cope with a fragmented, rigid "system" of care.

Lynne continues to serve on the New York State NAMI Board of directors, sharing her drive, dedication, and commitment with other NAMI chapters and working both locally and state-wide to improve treatment and care for people with serious mental illnesses.

In September, we sponsored Simple Measures, a holistic approach to living well for families and patients. More than 80 people enjoyed an informative evening of ways to live longer and better, even with serious mental illnesses.

We've been blessed with a wonderful variety of guest speakers at our monthly educa-

tional meetings, providing insight, understanding, and coping skills for the challenges our families face on a daily basis.

Finally, NAMI is a beacon of hope for today and tomorrow--our strength in our daily struggles, and our best hope for a better future for our loved ones. We're all in the struggle together, and working together, we ARE making a difference.



Mary Kirkland

Our Sympathy...

To NAMI member **Beth Andersen** whose husband Neils recently passed away. **Neils** was a retired professor of physics at ECC.

To **Fred Connine**, on the loss of his wife Marilyn. The Connines were two of the original twelve NAMI Buffalo members. We're honored that in lieu of flowers, Fred has chosen NAMI Buffalo to receive donations in her memory.

To **Dorothy Roden**, on the loss of her husband, Hugh. Both Hugh and Dorothy have been NAMI members and supporters for more than twenty years.

To **The Vacarro Family** who designated NAMI Buffalo to receive memorial gifts for their dear son David.

Combo Drug Therapy Won't Improve Schizophrenia Care

Combining two antipsychotic drugs, clozapine and risperidone, offers no benefit in treating people with severe schizophrenia compared to the use of either drug alone, Canadian researchers report.

The findings cast doubt on the widespread practice of "polypharmacy" for schizophrenia, when two or more drugs are prescribed together.

"This study does not offer any support for antipsychotic polypharmacy," says study author Dr. William Honer, a professor of psychiatry at the University of British Columbia in Vancouver.

"The study is a very well-written report of a very meticulously conducted clinical trial, so it carries a lot of weight," adds Dr. Leslie Citrome, a professor of psychiatry at New York University School of Medicine in New York City.

The findings appear in the Feb. 2 issue of *The New England Journal of Medicine*. Schizophrenia is a chronic mental illness with symptoms that can include hallucinations, delusions and disordered thinking. The disease affects about 3.2 million Americans.

The treatment landscape for schizophrenia has been relatively static over the past 15 years, experts say. The antipsychotic medication clozapine represented a major advance when it was approved in the United States in 1990. Drugs released since then have not provided any significant improvement for symptoms, although some have different side effect profiles, meaning they may be better tolerated by some patients.

"There has been an improvement in allowing us to match individual patients to individual medicines, but we are still frustrated at the inability to really control the symptoms of the illness in all patients," Honer says.

Even adequately treated with the available drugs, as few as 20 percent of patients see all of their symptoms resolve. And because so many people have such a poor response to single antipsychotic drugs, the practice has been to prescribe multiple antipsychotic drugs -- despite a lack of evidence that this is any more effective than using one drug alone.

"Current evidence for using more than one

antipsychotic is limited to mainly anecdotal reports," Citrome says. "A lot of people do use more than one, and I think it's driven by our desperate need to get patients better. However, the evidence doesn't really support this strategy."

According to Honer, 25 percent to 50 percent of patients who are being prescribed one antipsychotic medication are also taking another one, and sometimes as many as five.

In the study, the researchers wanted to see if symptoms improved when the antipsychotic drug risperidone was added to the drug regimens of patients who had only a partial response to clozapine.

Both drugs are widely used antipsychotics. In all, 68 patients with schizophrenia and a poor response to clozapine were randomly assigned to receive clozapine plus a placebo or clozapine plus risperidone for eight weeks, followed by additional, optional 18 weeks of clozapine plus risperidone.

At the end of the study period, researchers found no statistically significant difference in symptom relief between the two groups. In other words, adding risperidone conferred no extra benefit.

"This indicates that antipsychotic polypharmacy is unlikely to produce a major effect," Honer says. "It doesn't! anything about other combinations example, an antipsychotic with an antidepressant."

So where does this leave patients struggling with schizophrenia?

One possibility is to combine antipsychotics with drugs in another class, such as mood stabilizers or antidepressants. "Since they have different mechanisms of action, they might have better synergy," Citrome speculates. There may also be other ways to make single medications more effective, such as optimizing the dose or making sure medications are being taken on schedule.

Beyond that, however, Honer says we're left with "the unexplored area of, can we really come up with drugs that have different mechanisms that might really benefit people in ways that the current group of antipsychotics do not?"

*New York Times Syndicate
February 1, 2006*

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The Challenger

Editor: Lynne Shuster

Our Library...



Depression and Bipolar Disorder in His Children

by Paul Raeburn

Imagine having not only one child diagnosed with a major mental health diagnosis, but two. This is what happened to author Paul Raeburn. Alex, his then eleven year old son was admitted to a psychiatric hospital for the first time in the fifth grade. It was three years before his parents were given a diagnosis of bipolar disorder. Prior to this, many inappropriate medications were used and many wrong diagnoses were made.

Shortly thereafter, Raeburn's younger daughter Alicia, twelve, was diagnosed with depression with thoughts of suicide and episodes of self-mutilation. She too was hospitalized numerous times.

As if all this was not enough, Raeburn's marriage was falling apart during this very difficult and stressful time. To save his children's lives he used many resources available to him as a writer and a science reporter to educate himself on their illness and the various drugs available.

For those of us dealing with a child or family member with mental illness, this is a must read.

*Donated and Reviewed
by Nancy Kaszubski*

In Brief...

Northwest Buffalo Community Health Care Center, 155 Lawn Ave., has opened a new dental clinic, doubling its capacity to serve patients regardless of their ability to pay. The clinic serves Medicaid and low income patients.

Antidepressants Found to Raise Risk of Suicidal Behavior in Young Adults

WASHINGTON - Using antidepressants increases the risk of suicidal thoughts and behavior among young adults but lessens it for senior citizens, the Food and Drug Administration said Tuesday.

It now appears there is an increased risk among adults between ages 18 and 25.

"When results are analyzed by age, it becomes clear that there is an elevated risk for suicidality and suicidal behavior among adults younger than 25 years of age that approaches that seen in the pediatric population," the FDA said.

The effects of antidepressants on adults from 25 to 64 were so mixed that the FDA

would conclude only that the drug had a neutral effect on suicidal behavior for them but possibly lowers the risk of suicidal thoughts.

The information came from a mass review of 372 studies involving roughly 100,000 patients and 11 drugs, including Lexapro, Zoloft, Prozac and Paxil. The FDA analysis will be incorporated in future changes to antidepressant labels, but the agency wants to first discuss its plans with outside advisers at a meeting next Wednesday.

In 2004, the FDA ordered the placement of strong warnings on antidepressant labels about the pediatric risk of suicidal tendencies and began analyzing whether adults face a similar risk, in part by requesting data from drug companies.

The FDA's analysis of multiple studies suggests an age-related shift in the risk of suicidal thoughts and behavior associated with treatment with the drugs. That means the risk appears to decline with age, even if the numbers do not explain why, the FDA said. The issue is complex to sort out because depression itself can lead to suicide.

All antidepressants now bear a so-called "black box" warning about the increased risk of suicidal thinking and behavior in children and adolescents.

In May, GlaxoSmithKline and the FDA warned that Paxil may raise the risk of suicidal behavior in young adults, too, and changed the drug's label to reflect that risk

*Buffalo News
December 6, 2006*

Letters...

The residents and staff of the 2268 Main St. Young Adult Program would like to thank you for the wonderful gifts you were able to donate to us this holiday season. Your generosity and care enabled our young adults to receive gifts they may have otherwise not received. We wish you the best this upcoming new year and again thank you for making this a memorable Christmas for our residents.

Sincerely,

*Young Adult Program Staff
Transitional Services, Inc.*

December 22, 2006



Please Remember

NAMI

Buffalo

&

Erie County

in your Will



Helping Western New York's Children in Need

The National Alliance on Mental Illness in Buffalo and Erie County (NAMI) is preparing for their annual Christmas is for Kids Campaign.

The campaign was designed for children and adolescents who suffer from mental illness. The children are often victims of abuse and abandonment, and have been placed in foster care. Christmas is for Kids and NAMI volunteers have been providing gifts to these special children for more than 16 years.

"Every child should have at least one new thing for Christmas," said Lynne Shuster of Tonawanda, president of NAMI.

NAMI is an organization of families who have or had a mentally ill loved one, usually a child. The members of the organization are all volunteers who understand the adversities of mental illness and who want to improve the care and treatment of the mentally ill. NAMI is also committed to fostering the funds for research on mental illness, providing housing and inpatient care programs, educating and supporting families, and developing a community of acceptance and understanding.

The Christmas is for Kids Campaign began many years ago after a social worker from the Children's Psychiatric Center joined NAMI in their monthly November meeting. The social worker suggested starting a collection of gifts for the children at Christmas time. The children ranged from 4 to 20 years old. They had all been diagnosed with a serious emotional disturbance (S.E.D).

Disorders such as childhood schizophrenia, conduct disorders, and bipolar disorder were only a few of the disorders that plagued the lives of these innocent chil-

dren. Many of the children were from broken homes who had already been through the judicial system and who were placed in homes or foster care.



The staff shows off some of the gifts.

Usually, Christmas is a time for laughter and joy, but this was not the case for many Western New York children.

"We made a mistake the first few years. We forgot about these kids' brothers and sisters," said Shuster.

The Christmas is for Kids Campaign needed help raising money for more gifts. Word of the campaign spread to Buffalo resident Sonny Miano who was running an informal soup kitchen on Massachusetts Avenue in Buffalo. He decided to lend a helping hand by throwing a Christmas party to raise money and gifts.

Milano has continued his fundraising efforts by throwing Thanksgiving and Christmas parties each year.

As the word spread throughout Buffalo, more local residents wanted to help. Seven years ago, Thomas McNulty, Christmas is for Kids volunteer coordinator, heard about the project and wanted to join in on the efforts as well.

Every year around this time, his family sits

down and writes more than 100 letters to local businesses and residents announcing the campaign's efforts. McNulty also helps by taking time out of his workday at

Success Stories Inc. to pick up toys from the many participating businesses throughout the area. "We couldn't do it without him (McNulty)," said Shuster with appreciation.

This year participating businesses include: Dent Neurological Institute, Canon Design, The Mansion, and Lancaster Pediatrics. Volunteers from Christ the King School, Orchard Park,

and the Orchard Park High School will be gathering this December to wrap all of the gifts.

Seven hundred children and adolescents from Bry-lin Hospital, Erie County Medical Center's Psychiatric Ward, Niagara Falls Memorial Hospital, Gateway, Haven House, and Corner Stone Manor will be receiving gifts this year.

The wrapping of the gifts will take place at 10 a.m. Saturday, Dec. 9, at the N.A.M.I Hope House located at 432 Amherst St., Buffalo. If you are interested in volunteering to wrap the gifts, bring a pair of scissors with you. For more information on the Christmas is for Kids Campaign or how you can make a donation, contact McNulty at 662-3922 or go online to www.namibuffalo.org.

Sometimes we must accept the things we cannot change, but have the courage to change the things we can for our Western New York youth.

*Andrea Weishaupt
November 25, 2006
Metro Source*



What you need to know about Electroconvulsive Therapy

What is Electroconvulsive Therapy?

Electroconvulsive therapy is a modern medical treatment for certain illnesses that have mental or emotional symptoms. In this treatment, the patient goes to sleep under anesthesia, receives muscle relaxants and oxygen, and then receives a brief electrical stimulation to the scalp. The resultant nerve-cell activity releases chemicals in the brain and helps to restore normal functioning. ECT resembles cardioversion, a common medical procedure in which the heart is stimulated electrically to restore its normal functioning, but ECT uses a much smaller amount of electricity.

ECT has been used for over 50 years. The American Psychiatric Association concluded in 1978 that ECT was both safe and effective for cases of severe depression and several other severe mental illnesses. More recently, a blue ribbon panel convened in 1985 by the U.S. Government's National Institutes of Mental Health found that ECT was "demonstrably effective for a narrow range of severe psychiatric disorders", including depression, mania and schizophrenia.

Medication helps many people suffering from the aforementioned psychiatric disorders but for over 30,000 U.S. patients each year, ECT is the most effective treatment. Some patients do not respond to medications, others cannot tolerate the side effects, and still others - those whose illness has made them seriously suicidal, for example - urgently require the reliable symptom relief that ECT can provide.

How is ECT Given?

ECT is given by a treatment team of doctors, nurses, and nursing assistants, often with an anesthesia specialist. With the patient reclining, a sleeping medication is injected in a vein and the patient rapidly falls asleep. A muscle relaxing medication is then injected, while the patient breathes pure oxygen. When the muscles are relaxed, a brief electrical charge is applied to the scalp, stimulating the brain into rhythmical activity that lasts about one minute and is accompanied by release of chemicals from nerves in the brain. Mild contrac-

tions of the muscles occur during this 'convulsion'. When it is over, the patient is taken to the recovery area and observed by trained staff until he/she awakens, usually in about 20 minutes.

ECT is usually given two or three times a week, typically Monday, Wednesday and Friday mornings, for a total of 6 to 12 treatments. A few patients may require more than 12 treatments for maximum benefit.

Is ECT Curative?

ECT is an exceptionally effective medical treatment, helping 90% of patients who take it. Most patients remain well for many months afterwards. The tendency to relapse after a favorable treatment outcome can often be countered by medication taken for about half a year after ECT. Permanent cures for psychiatric illnesses are rare, however, regardless of the treatment given.

How Safe is ECT?

is a -very safe medical treatment. A recent study in California found about one death per 50,000 ECT treatments, a risk far below the risk of child birth. Another study observed the death from heart attacks and suicide were less frequent among depressed patients who had received ECT than among those who had not. With modern anesthesia, fractures and oxygen deprivation virtually never occur, and many patients with high blood pressure or heart conditions can safely be treated.

The dramatization of ECT in movies like 'One Flew Over the Cuckoo's Nest' bears no resemblance to modern ECT, which is neither painful nor a punishment. Most patients surveyed after ECT said it was no worse than going to the dentist, and many found ECT less stressful.

How Does ECT Work?

Although it is necessary for the brain cells to interact with each other chemically and electrically for ECT to work, exactly how this interaction is therapeutic needs further investigation. We believe that patients with melancholia have a severe biochemical disorder of the nervous system that ECT corrects. A number of rigorously designed research projects are under way to study this question.

What are the Main Side-Effects of ECT?

On awakening from ECT, it is customary for patients to experience some confusion, which gen-

erally clears within an hour. Memory for recent events, addresses, and telephone numbers may not be as good. In most patients, the memory disturbance goes away within a few days or weeks, but it can continue in a mild form for a period of months. Many patients will find that their memories are somewhat hazy for the time they were ill; the same period is frequently experienced by depressed patients who do not receive ECT. Memory disturbances are not needed for ECT to work and doctors use special techniques (such as brief pulse ECT) to minimize or avoid any effects on memory.

Can ECT Cause Brain Damage?

The available evidence speaks against this possibility. Patients receiving ECT show no evidence of brain enzymes that are released into the bloodstream when brain damage occurs, such as after a stroke. Animal studies have shown that oxygen administration is essential during ECT, as it is in surgery. Even after experimental seizures lasting for hours, with plentiful oxygen, there is no evidence of brain damage. This is why ECT is always given under oxygen and with muscle relaxants to aid oxygen delivery.

Does ECT cause Permanent Memory Loss?

o inmost people. Most important y, ECT does not interfere with the ability to learn, and many studies have shown better learning after ECT than before it, probably because of improved concentration from relief of depression. A few patients, however, still have not regained some specific personal memories when tested six months after receiving a form of treatment called bilateral ECT. Generally, these memories are for events in the months immediately preceding. No long term or persistent effects of ECT on intellectual abilities or memory problems in patients with psychiatric illness result more often from medication and incompletely treated illness.

Why Does ECT's Public Image Suffer?

Just as with other medical treatments, ECT was used excessively in the past, mostly in large understaffed mental hospitals in the 1940's. The drama of mental illness has also been exploited by fictional movies such as 'The Snake Pit' that indicates stark and more exaggerated portrayals of ECT to emphasize a story. More recently, quasi-religious groups have received media attention for unsubstantiated claims that all medical approaches to psychiatric illness are undesirable. ♦

Lawmakers Torn on Court-ordered Treatment for Mentally Ill

ALBANY - For some 15 years, Joyce Claypool watched as her brother's life was taken over by paranoid schizophrenia.

He went through bouts of hospitalization and homelessness. Fights with the police landed him in jail. He did things like stalk a woman, jump out of a moving car and cut himself. And he always maintained that he was not sick.

"He has no insight into his illness at all," said Claypool, who lives in Albany.

About five years ago, her brother was ordered into treatment by a court under a new law named for Kendra Webdale, a 32-year-old woman pushed to her death in front of a New York City subway train by a schizophrenic man.

It hasn't been a panacea, but the court-ordered treatment has given Claypool's brother and their family more stability and peace than they've known in a while. He lives with his mother, and trips to the hospital are less frequent.

"The only thing that works is Kendra's law mandating him. If he has to take the medication, he takes the medication," Claypool said. "Life has been so much better the past five years."

Now, legislators are weighing what to do with the law setting up court-ordered treatment, which expires June 30.

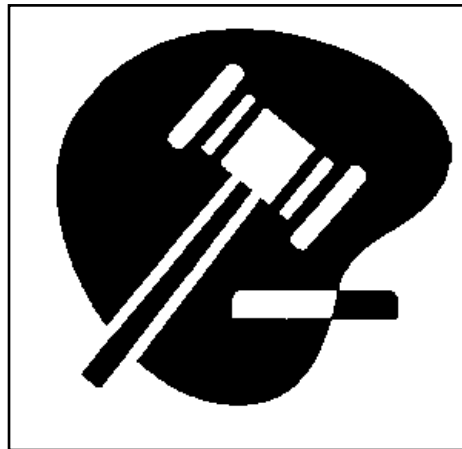
Some families and groups want to see it made permanent, but others are raising questions about why the law doesn't seem to be uniformly applied across the state and whether using the court system is a good way to help the mentally ill.

Lawmakers say they are likely to take a middle course of extending the law for several more years and ordering more study of it.

"I think the wisest course now is to extend

it for three to five years, get the appropriate research and see if we can deal with the concerns of most advocates," said Sen. Thomas Morahan, R-New City, Rockland County, chairman of the Senate's mental health committee.

His counterpart in the Assembly, Peter Rivera, held two hearings on the law in Buffalo and New York City.



"It's a good law. All the parents that came and testified said, but for Kendra's law, the parents would be living lives of desperation," Rivera said.

The law is strongly supported by Gov. George Pataki, Attorney General Eliot Spitzer and the state chapter of the National Alliance for the Mentally Ill, one of the leading groups for families of mentally ill people. Both Pataki and Spitzer proposed bills making the law permanent.

"We don't see any point in continuing a trial period for a law that has definitively proven itself to be successful," said Assistant Attorney General Brian Stettin.

But another influential lobby group, the Association of Psychiatric Rehabilitation Services, is pushing for further study.

Its director, Harvey Rosenthal, said the law was adopted in an atmosphere of fear of the mentally ill and under the false premise that many of them are violent.

Rosenthal said what's needed is better, more accessible treatment, not court coercion.

"I think it's unconscionable that people should have to go to court," Rosenthal said. "It's an inappropriate mechanism. The real answer is better services."

Since the law was adopted in August 1999, more than 10,600 cases have gone to the courts and some 4,100 court orders have been issued. Another 3,000 people have committed to voluntary agreements with counties to participate in outpatient mental health treatment.

In most cases, county mental health officials seek the court orders, sometimes on behalf of families. State psychiatric hospitals also try to obtain court orders for patients they are releasing who they fear will not participate in outpatient treatment. Families can also directly file for a court order, but that rarely happens.

Under the law, there's a psychiatric evaluation and court hearing before a mentally ill person is placed under a court order.

The person must have a history of hospitalization, violence, failure to stay in treatment or take care of herself, or other serious problems.

Someone who is an immediate danger to himself or others can be involuntarily committed to a psychiatric hospital -

Kendra's law is aimed at people who can live in the community but need regular care to avoid hospitalization, suicidal tendencies and violence.

"Kendra's law is not about the mentally ill in general. It's about a very special population of mentally ill folks who don't take their medicine or comply with other treatment," Stettin said.

LAWMAKERS continued on page 10

A state study of the law found 71 percent of people under court-ordered treatment had schizophrenia and 13 had bipolar disorder. The average court order lasts 16 months.

The Office of Mental Health report found court-ordered treatment helped many, but not all, of the people involved take their medicines and participate regularly in mental-health services.

Life skills, such as preparing meals, taking health-care advice and keeping appointments, improved as well.

The proportion of people abusing alcohol or drugs fell from about 45 percent to 23 percent, while those threatening suicide or hurting other people fell from 15 percent to 8 percent, according to the report.

"The patients are doing a lot better. There are fewer people roaming the streets, unmedicated and unmonitored," Stettin said.

Court orders are used much more frequently downstate than in most of upstate. While about 60 percent of cases in New York City lead to court orders, just 7 percent of those in Western New York did.

People ordered into treatment under Kendra's law often don't like it - some fight the court orders and more than half of about 80 interviewed for the state report said they were angered or embarrassed by the experience.

But those around them say they sometimes have to be forced into doing what's good for them.

*Erika Rosenberg
Elmira Star-Gazette
Gannett News Service
May 14, 2005*

Should the Catie Study be a Wake-up Call?

Mark Ragins, M.D.

I was surprised by reports that the National Institute of Mental Health's Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study found no substantial difference between atypical antipsychotics and perphenazine. When I read the article in the September 22, 2005 issue of the *New England Journal of Medicine*, I was more amazed to read how poorly the patients had fared.

The numbers are truly stunning: Overall, 64 to 82 percent of patients in the multisite study dropped out of treatment in an average of 3.5 to 9.2 months. They benefited for an average of only one to three months. The hospitalization risk rate ranged from 11 to 20 percent over the study period. Substantial side effects were reported by 64 to 70 percent of patients, although only 30 to 36 percent told their physician about them without additional "systematic questioning." I wonder whether a placebo group would have done worse. No wonder no difference was found between the medications: everyone did very poorly.

If patients in our program did this poorly, I'd decide that our treatment was in shambles and in need of total transformation. I would ask myself five questions: How is the relationship between the doctors and the patients? How much do the patients understand and believe in the medications? Are the medications improving people's lives or just treating symptoms? Were the medications integrated into other services and supports? Were the medications used as a tool to promote the recovery of each patient? Unfortunately the researchers did not address any of these questions.

The authors conclude that "antipsychotic drugs, though effective, have substantial limitations in their effectiveness in patients with chronic schizophrenia." I would instead conclude that antipsychotic drugs, though effective, will have limited benefit for patients unless attention

is paid to the doctor-patient relationship, patients' understanding of and belief in the medication, integration of other services and supports, and treatment in the context of recovery. More than anything else, this study suggests that even the best and most expensive medications have little effect as used within our present system. In short, they don't work by themselves.

I hear a great deal of talk about "evidence-based practice" and "research informed clinical treatment." An increasingly frustrated group of effective clinicians urge "practice-based evidence" and "clinically informed research". I don't think the CATIE study should be a wakeup call to "clinician, patients, families, and policy-makers." I think it should be a wakeup call to researchers. If we are to achieve the vision of a transformed mental health system, mental health research must be transformed too.

Dr. Mark Ragins is the medical director at Village Integrated Services Agency, Long Beach, California.

*Psychiatric Services
December 2005,*



Antidepressants Can Lead to Tooth, Gum Disease

The U.S. Academy of General Dentistry (AGD) has warned that people receiving medication for the treatment of mood disorders are at greater risk of tooth and gum disease.

Up to 37 percent of adults experience mood disorders at some point in their lives, and many receiving treatments may undergo adverse dental side effects according to a study that appears in the September/October 2004 issue of General Dentistry, the AGD's clinical peer-reviewed journal.

Mood disorders are a group of mental conditions, including depression and bipolar disorder, which are common among adults. Early diagnosis and treatment can greatly reduce the risk of suicide.

The AGD said medications prescribed as treatments for mood disorders can result in dry mouth (xerostomia), an increased rate of dental caries and periodontal (gum) disease. "Many patients who are taking antidepressants will have dry mouth," said AGD spokesman David F. Halpern. "In an effort to curtail any tooth decay, we stress with patients the importance of maintaining an extremely high level of oral hygiene care by brushing, flossing and daily fluoride therapy."

Dry mouth can be treated by sipping water during the day and chewing sugarless gum. Halpern also suggests artificial saliva substitutes such as gels, liquids or sprays. Individuals with dry mouth should contact a dentist for an evaluation.

September 3, 2004

More Beds Sought for Mentally Ill Youths

The only hospital unit in Niagara and Orleans counties that now treats mental illness in children and adolescents cannot handle its escalating number of cases. Niagara Falls Memorial Medical Center has only 12 hospital beds for the treatment of mental health patients between the ages of 6 and 17, not enough to deal with an epidemic, Joseph A. Ruffolo, president of the medical center, said Wednesday. There has been a 15 percent increase in adolescent behavioral problems so far this year compared with last year, already exceeding the 12 percent climb in 2004 over the previous year, Ruffolo said. "There's no place for many of these children to go," he said. The only hospital unit in Niagara and Orleans counties that now treats mental illness in children and adolescents cannot handle its escalating number of cases.

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There has been a 15 percent increase in adolescent behavioral problems so far this year compared with last year, already exceeding the 12 percent climb in 2004 over the previous year, Ruffolo said.

"There's no place for many of these children to go," he said. The shortage of hospital beds for mentally ill youngsters extends beyond the region. The Niagara Falls hospital is receiving patients from as far away as New York City, Ruffolo said, although most of those admitted are from Niagara, Erie, Orleans, Monroe, Wyoming, Chautauqua and Cattaraugus counties.

The closest hospitals with similar mental health units are Buffalo's BryLin Hospital,

which has 20 beds for children and adolescents ages 5 to 17, and Erie County Medical Center, with 16 beds to care for youngsters between the ages of 12 and 17. Niagara Falls Memorial and BryLin are the only hospitals in the region that treat mentally ill children under 12. BryLin is nearing full capacity and planning to expand, said Mark Nowak, director of marketing.

At ECMC, the situation is similar. The cry for help in Niagara Falls was the opening salvo in a community campaign to raise \$600,000 to increase the capacity of the medical center's Bridges Child and Adolescent Unit to 18 beds.

While facing the growing need for more inpatient beds, the medical center is looking at proposed cuts totaling \$1.4 million under Gov. George E. Pataki's proposed 2005-06 state budget.

"We're facing a double hit: meeting the needs of these children and finding the resources to expand the unit," Ruffolo said. "Closing the unit is not an option, so we need help."

The long-range goal is to shorten the stay of young patients in the unit - currently averaging 12 days - and pass the responsibility of their care on to their parents, said Kim Orffeo, director of the medical center's Inpatient Behavioral Health Services. Often the first signs of mental illness in young people are seen in the schools. The medical center wants to forge a partnership with the various school districts to raise the money to enlarge the unit.
e-mail - bmichelmore@buffnezes.com

*Bill Michermore
News Niagara Bureau
September 13, 2006
Niagara Falls*



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