






# NAMI – GREATER DES MOINES

## AFFILIATE AND SUPPORT GROUP NEWSLETTER

March 2006

“Support, Education, and Advocacy”

<p><b><u>Education and Support Group Meetings</u></b> are generally the 1<sup>st</sup> <u>Sunday</u> of the month from 2 - 4 PM at Iowa Lutheran Hospital, Level B conference room. Dates on Sundays other than the 1<sup>st</sup> Sunday of the month are due to holidays or other special scheduled events. (Coffee and cookies are provided.)</p>		<p><b><u>Business and Committee Meetings</u></b> are the 2<sup>nd</sup> <u>Thursday</u> of the month at 4 P.M. at the NAMI-Iowa Office.</p>	
	Weekend of March 3-5	Family to Family <b>Teacher</b> training – Expenses paid by NAMI-Iowa. Location to be announced. Please contact Carol Porch at 319-351-4398 or leave a message at 800-417-0417 or e-mail porch@avalon.net for further details. <i>To date, 87 lowans have completed the teacher training.</i>	
	March 8	<b>The Virtual Hallucination Machine (VHM)</b> (from Jansen Pharmaceutica) will be available for Des Moines Police Dept. officers to experience in a training exercise. (NAMI-GDM arranged for this)	
<b>March 12</b> <b>2:00 PM</b> 	The topic is “schizophrenia”. The meeting will be at an alternative location-the <b>Temple for the Performing Arts at 1011 Locust</b> – “ <b>Out of the Shadow</b> ” -1 hr movie presentation and panel of experts – light refreshments will be served (free event). <b>Reunions</b> for Family to Family classes, Peer to Peer classes, and Visions for Tomorrow classes. <i>Contact your classmates!! See more information on this event inside this newsletter.</i> Please register by calling 254-0417.	<b>March 9</b>	We will be discussing and planning around the following topic areas: 1. Business 2. Marketing and membership 3. Support 4. Education 5. Advocacy 6. Fundraising 7. Special Events
	Thursday, March 9 	<b>Family to Family class starts (12 weeks)</b> Call NAMI-Iowa office to sign up – 254-0417. 6:30 P.M. to 9:00 P.M. at the NAMI-Iowa office, 5911 Meredith Drive, Suite E, Des Moines. <u>Severe mental illness is traumatic to the entire family</u> - you might consider asking other family members to attend with you—a friend, a parent, spouse, a sibling, or one of your children (must be at least 14 years old). <i>1000+ persons in Iowa have completed the course.</i> <b>Class is filling up quickly – so call soon!</b>	
	Wednesday, March 29 	<b>Advocating Change Day</b> – at the State Capitol 9AM to 2:30 PM. An event designed specifically for individuals with disabilities and their families to become skilled at communicating with their state legislators and state elected officials. There is no registration fee but you do need to register in order to guarantee a free lunch for those attending the event. Register on-line at <a href="http://www.sos.state.ia.us">www.sos.state.ia.us</a> or contact the Sec. of State’s office at 281-8993.	
<b>April 2</b>	The topic will be “self harm and emotional intensity disorder (borderline personality disorder)”.	<b>April 13</b>	We will be discussing and planning around 7 topic areas.
<b>May 7</b>	The topic will be “veterans issues and PTSD (post traumatic stress syndrome)”.	<b>May 11</b>	We will be discussing and planning around 7 topic areas.
<b>June 4</b>	The topic will be “depression and suicide prevention”.	<b>June 8</b>	We will be discussing and planning around 7 topic areas.
	June 28- July 2	<b>NAMI National Annual Convention</b> – “Changing Minds, Changing Lives, Keeping the Promise” at Washington (D.C.) Hilton Hotel. Check <a href="http://www.nami.org">www.nami.org</a> for more information and early bird rates.	

Mental illnesses are biologically based brain disorders. They cannot be overcome through “will power” and are not related to a person’s “character” or intelligence.

Mental illness can strike anyone. It knows no age limits, economic status, race, creed, or color.



### **WANTED – YOUR IDEAS - YOUR INPUT**

In order to give our full attention at our Sunday meetings to education and support, we are scheduling a separate day and time devoted to the business side of NAMI-Greater Des Moines. **We invite everyone** to join the Board of Directors and Officers to discuss and plan for NAMI-Greater Des Moines at our Thursday meetings.

## **MENTAL ILLNESS: THE FACTS**

*From NAMI: In Our Own Voice*

Mental illnesses are brain disorders. They are not defects in someone's personality or a sign of poor moral character or lack of faith. They certainly do not mean that the ill person is a failure. Chemical imbalances in the brain, from unknown or incompletely known causes, are much of the reason for symptoms of mental illnesses.

Mental illnesses are like other organ diseases in which body chemistry changes. The abnormal chemistry of mental illnesses affects brain function the same way that too little or too much of other body chemicals damage the heart, kidneys or liver.

A heart attack is a symptom of serious heart disease, just as hearing voices, mood swings, withdrawal from social activities, or feeling out of control are common symptoms of a mental illness.

Mental illnesses can affect people of any age, race, religion, education or income level. As you read this, five million people here in the United States are dealing with serious, chronic brain disorders.

Major brain disorders include schizophrenia, bipolar disorder (manic-depression), major depression, anxiety disorders, and obsessive-compulsive disorder.

There are many points on the continuum of wellness, and different degrees of recovery that can be reached with medication, therapy, and a strong support system.

*Mental health problems are real, common, and treatable. Seeking help is not a sign of weakness – taking care of yourself is an act of strength.*



### **Call 254-0417 to register for “Out of the Shadow”**

Our affiliate and support group meeting will be on Sunday, **March 12**, at the Temple for the Performing Arts at 1011 Locust (not our usual meeting place).

*Out of the Shadow* is a very personal documentary which chronicles the filmmaker's mother, Millie, who has schizophrenia, as she suffers through the chaos of our mental health system as well as that of her own mind.

This intimate film illuminates a national plight through one family's struggle and helps dispel the stigmas and misconceptions surrounding this illness.

Susan Smiley is a documentary producer, director and writer. After making documentaries for 7 years about other people, she was compelled to turn the camera on her own family, telling a story she had previously shared with almost no one. The result is *Out of the Shadow*, a chronicle of her mother, Millie, and her family over the course of 5 years.

After we view the film, we will have a panel of experts to give comments and answer questions. Light refreshments will be served.

This is a free event to all who would like to attend. Please call to register at 254-0417 so that we are sure to have enough food prepared.

Susan and her documentary - *Out of the Shadows* – are the lead article in the current issue of Schizophrenia Digest.



### **Film Reviews of “Out of the Shadow”**

*“Angry and fed up” with the mental health system, filmmaker Susan Smiley decided to document the challenges that she faced trying to help her mother, Millie battle paranoid schizophrenia. Chief among these were privacy laws that forced Smiley and her younger sister, Tina, to seek guardianship of their mother just so they could stay informed of her condition and Millie's own inability to recognize her illness for what it is. Smiley weaves recent interviews with her mother, sister, and other relatives with old family footage, which occasionally shows the young Millie, blond and gorgeous, playing happily with her babies – but more often find her staring blankly at the camera. Out of the Shadow succeeds in portraying the frustration of loving someone who's mentally ill, capturing both the times Millie is rational, warm, and funny as well as her chilling episodes of hostility and delusion. Sadly, the stability that is sought for Millie is curiously absent from her treatment, a blur of institutions – 47 in 20 years – and doctors. ---Washington City Paper.*

*“Out of the Shadow movingly captures a side of schizophrenia that few of us ever see, revealing the humility behind the disease without sentimentalizing it, and documenting the day-to-day injustices, tragedies and just plain frustrations experienced both by a woman who has schizophrenia and by those who love her. --- Sharon Begley, Health Reporter, The Wall Street Journal*

*I showed your documentary to our mental health agency, and people loved it. It's emotionally powerful and well balanced on many perspectives. It's a realistic view of the pitfalls of the “system,” the lengths families must go to, the ravages of illness and the prospects of recovery. Thank you for sharing this. Thank you even more for making it. --- Michael F. Hogan, Ph.D., Director, Ohio Dept. of Mental Health; Chair, Presidents New Freedom Commission on Mental Health.*

This is a powerful and moving film that inspires whether or not you know anything about mental illness. I laughed, cried and was spellbound. Through the story of her mother's fight with schizophrenia and her family's struggle to not only survive, but to love, Susan Smiley bring new meaning to the word hope. *Out of the Shadow* is ultimately a story about a family that was torn apart by schizophrenia and unexpectedly healed by the making of this film. --- Dr. Xavier Amador, former NBC Today Show contributor & NBC News consultant. Author of “When Someone You Love is Depressed”, “Being Single in a Couples' World” and “I am Not Sick, I Don't Need Help!”

*Thanks for producing such a touching, inspiring, and educational film about what living with schizophrenia can be like. I was moved to tears by the end of the film. I know it will help many people – physicians and psychiatrists included – to understand mental illness and the challenges faced by the mentally ill and their families. --- Robert Kelly M.D. (PGY 2, Beth Israel Hospital, NYC)*

**PLEASE JOIN US AT THE TEMPLE FOR THE PERFORMING ARTS ON SUNDAY, MARCH 12, for the film “Out of the Shadow”. Please register by calling 254-0417.**



## The Unreal Reality of Schizophrenia

Excerpt from Article by Lawrence A. Slager,  
M.S.W., A.C.S.W. – *Pine Rest Today* –  
*Schizophrenia: Understanding the  
Misunderstandings*

Imagine you have just awakened from a nightmare so real it took a few moments to realize it was just a dream. You are confused and frightened from misperceptions of sight or sound. Then relief sweeps over you as you sort reality from unreality.

Contrast your relief with what it would be like if the nightmare continued after you woke up. Add hearing voices others do not hear. Pretend you think a tragedy will strike a loved one unless you carry out certain actions others misunderstand. Or you are convinced you have discovered the key to the universe. You have a mission to persuade others of ideas that seem strangely unintelligible to all those around you.

Schizophrenia is one of the least understood and most frightening of mental illnesses. 1 out of every 100 Americans will be afflicted by the disease during his or her lifetime. Most typically, the first episode of major symptoms occurs during young adulthood, between ages 18 and 25.

Added to the tragedy of the disease is the stigma people afflicted and their families bear. For centuries, people have misunderstood schizophrenia. Our limited understanding – together with myths and misconceptions fed by sensational news reports – encourages a mystical perspective on this disease.

Many people think schizophrenia means a person will be violent or have a split personality. Believing they may have contributed to the development of the illness, families often feel devastated.

In fact, schizophrenia is a brain disease. It is a disease related to the structure and function of the human brain. Research does not prove that poor family relationships cause it. Neither does stress cause this perplexing disease. People suffering from multiple or split personalities have a condition different from schizophrenia.

Some persons with schizophrenia may be violent during the most disturbing part of their illness because their misconceptions make them frightened. However overall they have less history of violence than the general population of well people.

Schizophrenics know the meaning of intense psychological pain during episodes of “psychosis”. Psychosis is when they have a problem knowing what is real and what is not. Reality and unreality blur. During this “psychotic breakdown,” they may be preoccupied with strange sounds and voices called “auditory hallucinations.” These voices are usually unpleasant. They often blame the person for real or imagined misdeeds.

Sights and sounds people ordinarily wouldn't notice take on an ominous meaning for the acutely ill. They may have grandiose and irrational thoughts that make them act in ways that are confusing and outlandish to others. They may think they can control the other people's minds due to a special telepathy power. Their sense of identity and place blur. One patient wrote:

*I think I am going crazy or the world is getting goofy... I don't know what's going wrong... I don't think it is a pill thing. It is just that somebody's insides collapsed on them. I think all*

*the contents are spilling out. I don't know how to hold my insides in. I've got to pull my head together. Is it like Humpty Dumpty? Everything is like nothing and then it is like the hurricane hitting the window. It takes you by surprise every time. Too much of the world is leaking in. If a person can just hold themselves together, maybe it will go away. I don't know what to do. Fear comes creeping up my bones and makes my bones go soft.*

To understand the breakdown in a schizophrenia experience, think of a filter in people's minds. When the filter malfunctions, all kinds of extra and overwhelming sensations flood in. These cause thoughts to be too stimulated and disorganized. Another patient wrote:

*The mind must have a filter that functions without our conscious thought, sorting stimuli and allowing only those relevant to the situation at hand to disturb consciousness. And this filter must be working at maximum efficiency at all times, particularly when we require a high degree of concentration. What had happened to me... was a breakdown in the filter and a hodgepodge of unrelated stimuli was distracting me from things which should have had my undivided attention. By the time I was admitted to the hospital, I had reached a stage of 'wakefulness' in which the brilliance of light on a window sill or the color of blue in the sky would be so important it could make me cry. I had very little ability to sort the relevant from the irrelevant. The filter had broken down. Completely unrelated events became intricately connected in my mind.*

Because recent knowledge shows schizophrenia is a brain disease, we rely on medication as the base for treatment. The proper dose of medication helps correct the imbalance in the brain chemistry while it lessens the medications' unwanted side effects.

Schizophrenia – like arthritis, diabetes, and many other physical diseases – cannot be cured by current treatment. Instead, we think of a gradual process of recovery and rehabilitation. Occasional and temporary setbacks often mark this process. Living with the disease requires extraordinary patience and courage from both the afflicted people and their family members. The unknown and unpredictable aspects of the disease can cause nearly unbearable sadness and anger.

Our challenge and our hope is to achieve a partnership with patient, family, and mental health worker. Together, we work toward a growing success in managing the disease and experiencing a steady progress toward a life of meaning and purpose. A patient reflects this spirit:

*As of yet, I still have a long road ahead of me. There is much that I don't understand about schizophrenia, but I realize I am not alone in my lack of knowledge about the illness. Slowly I am learning to accept the limitations of my illness, and I feel that I am beginning to make more constructive choices than I have in the past. Life puts various limitations on each person, but within those limitations there is always the freedom to make certain choices...*

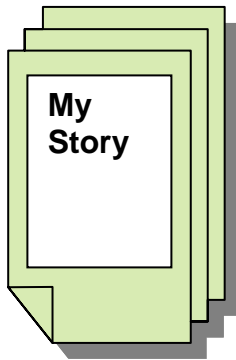
### Tools for Better Understanding of Schizophrenia

The magazine – *Schizophrenia Digest* - subscribe at [www.szdigest.com](http://www.szdigest.com) or call 1-888-834-5537 –\$20/yr- 4 issues.

*Surviving Schizophrenia* – book by E. Fuller Torrey, M.D.

*Choices in Recovery* newsletters – e-mail [editors@choicesinrecovery.com](mailto:editors@choicesinrecovery.com)

**The Mental Health Advocacy Coalition is asking for Your Help.**



We would like to compile stories that illustrate mental health issues. These can be anecdotes or human interest stories which help to identify important mental health issues and problems – stigma, lack of access to services, your story and struggle in dealing with mental illness, mental health problems of returning soldiers, importance of the right medications, lack of funding, etc – real stories of Iowans.

Copies of your stories should be sent to CeCe Arnold at [ncrlcca@mchsi.com](mailto:ncrlcca@mchsi.com). The person sending the story should “de-identify” information in the story for replication purposes but still provide attached identifying information to Cece in case she needs to contact you. Anyone with writing skills who would like to help with this project should send an e-mail.



**Need Help Paying for Medicine?**

The Partnership for Prescription Assistance can give you a helping hand. Call 1-888-477-2669 or visit [www.pparx.org](http://www.pparx.org) to see if you may qualify.

**Peer to Peer**



Peer to Peer is a 9 week course for individuals with severe brain disorders. Each 2 hour session is taught by a NAMI Iowa team of three trained “mentors” who are personally experienced at living well with mental illness.

Participants come away from the course with a binder of hand-out materials, as well as other tangible resources such as: an advance directive, a “relapse prevention plan” to help identify feelings, thoughts, behaviors or events that may warn of impending relapse; information on how to organize for intervention; mindfulness exercises to help focus and calm thinking; and survival skills for working with providers and the general public.

Class topics include: stigma and discrimination, relapse prevention planning, story telling, language, emotions, addictions, spirituality, medication, coping strategies, decision making, relationships, empowerment, and advocacy.

Call the NAMI-Iowa office to sign up for Peer to Peer– 515-254-0417.

*Mental illnesses can profoundly disrupt a person’s thinking, feeling, moods, ability to relate to others and capacity for coping with the demands of life.*

**Drug Discount Card**

Polk County residents without full health insurance coverage can save on prescription drugs under a county sponsored drug discount program. Discounts average 20% and can be used at more than 100 pharmacies throughout the county.

The cards are available at the county health department, Broadlawns Medical Center, senior citizen centers and other sites. There are no income or age restrictions. While anyone can use the cards for drugs not covered by an insurance plan, the program targets those without

insurance. For a complete list of card locations or a list of participating pharmacies, call 286-3895.



**[www.polk.ia.networkofcare.org](http://www.polk.ia.networkofcare.org)**

The web site contains information and resources regarding mental health in Polk Co. Some of the topics are community announcements, nation-wide news, services (who are providers?), library, legislate (state and national legislation), E-mail service to contact your state and national legislators), links, insurance (plans available), support & advocacy, emergency services.

*Investing in effective community mental health services saves families, lives and dollars.*

**SUPPORT GROUP MEETINGS**

**Every Monday evening – 6:30 – 8:00 P.M.** – the Support group meets at the Mercy Franklin West Conference Room (enter West side entrance) – 48<sup>th</sup> & Franklin, Des Moines. This is a support group for both family members and consumers.

**2<sup>nd</sup> & 4<sup>th</sup> Mondays of each month – 7 P.M.** – For depression and anxiety disorders only – WestView Church, 1155 SE Boone, in Waukee. Call Julie at 710-1487 or E-mail at [candlesinthedarkness@mchsi.com](mailto:candlesinthedarkness@mchsi.com)

**Every Tuesday afternoon – 1:30 to 2:30 P.M.**- A consumer support group meets at Res-Care located at the Hammer Medical Pharmacy building at 602 E. Grand. Come early at Noon and have a hot lunch.

**Every Tuesday evening – 8-10 P.M.** - Recovery Inc., a self-help group for people who have nervous and mental troubles – at St. Mark’s Episcopal Church, 3120 E. 24<sup>th</sup> St., Des Moines – Call 266-2346.

**Thursdays from 11:00 A.M. to Noon** - Anger Management class at Res-Care located at the Hammer Medical Pharmacy building at 602 E. Grand. A hot lunch is provided at noon.

**Every Thursday at 2:00 P.M.** - Recovery, Inc. - a self-help group for people who have nervous and mental troubles – at Central Iowa Center for Independent Living, 666 Walnut St., Des Moines – Call 237-0232

**Every Thursday evening – 7:45 – 9:45 P.M.** – Recovery, Inc. - a self-help group for people who have nervous and mental troubles – at St. Timothy’s Episcopal Church, 1020 34<sup>th</sup> St., in West Des Moines. Call – 277-6071

**Every Saturday morning – 10 A.M.** A group of people who have depression will meet at Lutheran Church of Hope, 925 Jordan Creek Parkway, Call 222-1520, ext. 175.

**Every Saturday afternoon – 2:00 – 3:30 P.M.** – the Depression and Bipolar Support Alliance meets at Iowa Lutheran Hospital – University at Penn Avenue – Level B – private dining room. This is a support group for consumers.

**Do you know of other support groups in the Des Moines area that we should list in our newsletter?**

**1-800-SUICIDE (1-800-784-2433)** is a 24 hour crisis line sponsored by the Kristin Brooks Hope Center. For more information, visit [www.hopeline.com](http://www.hopeline.com)

## Crisis in the Sky: Mental Illness and Airline Travel

– NAMI Connection – E-newsletter –  
January 2006



*Following the shooting death of Rigoberto Alizar in Miami by air marshals during a psychiatric crisis, NAMI consumers and family members have discussed potential precautions to take during travel. In the following article, NAMI Indiana's Steve Coburn shares his son's experience on an airplane in 2001.*

On Monday October 8, 2001, less than a month after 9/11, our son Ted, on a flight from Los Angeles to Chicago, stormed the cockpit of the airplane, believing that terrorists were going to crash the plane into the Sears Tower.

He was lucky. He is alive.

The Miami tragedy demonstrates that disruptive behavior on an airplane, train, or bus can have fatal consequences and highlights the continuing need for effective training of flight crews and air marshals in dealing with passengers with mental illness in crisis on airplanes.

Our son graduated near the top of his class from Purdue University with a degree in electrical engineering technology. He had been working as an industrial controls engineer in California for seven years. On Monday, October 1, 2001, we received a telephone call from our son saying that we should watch the movie *The Matrix*, and that if necessary, we should watch it repeatedly until we understood it. Late Thursday evening, we received a call that the world was coming to an end and that Ted was the savior of the world. On Friday, he returned to a friend's apartment and she was able to get him admitted to a mental health facility on a 72-hour commitment.

I arrived in California late Friday afternoon. As we approached the entrance of the mental health facility, two police officers asked if we were coming to visit Ted. They reported that he had had a very violent outburst. On Sunday, the psychiatrist called to say that he was ready to release Ted, who had consistently refused medication. When I asked whether we should fly or drive back to Indiana, he recommended flying.

Since this was our first exposure to serious mental illness, we had no idea what questions we should ask or what we should expect.

Shortly after the flight from Los Angeles to Chicago began, Ted said that we must study the safety card carefully because the plane was going to crash into the water. I knew immediately that we had a serious problem and alerted a flight attendant of the situation. They said they would put some blankets in the seat next to Ted (which they did) and that if I needed help, I should push the call button repeatedly and they would come to help restrain him. As the flight progressed, Ted's delusion changed from crashing into the water to terrorists taking over the plane and crashing into the Sears Tower. Initially, he said that we would not have to do anything until the terrorists caused a commotion in the cabin. Eventually, he said there would not be a commotion because one of the pilots was a terrorist. Ted believed he needed to get into the cockpit to make sure everything was normal. At that point I knew I needed help. I pushed the call button repeatedly, but no one came. Ted made a run

for the cockpit, before being tackled and restrained by the flight crew and passengers.

At Ted's trial, the statement from the flight crew indicated that they heard the bell, but there was no explanation as to why no one came to help. If the crew had followed the original plan, we could have kept him in his seat. We were told very bluntly that if there had been an air marshal on our flight, Ted would have been shot without hesitation.

Upon removing Ted from the airplane, the F.B.I. said that prior to 9/11 he would have been sent to a psychiatric hospital. However, in response to 9/11 he was placed in the criminal justice system and charged with interfering with a flight crew, which carries a maximum penalty of 20 years in prison and a \$250,000 fine.

During the next ten months, Ted continued to refuse medication. He was subjected to four psychiatric evaluations to determine whether he was competent to stand trial. All agreed he was mentally ill but differed on his competency. The fourth evaluation concluded that he would never be competent without medication. At that point, the judge ordered medication.

Ted responded well. It took another ten months to hold the trial, at which he was judged not guilty by reason of insanity. He was given a two-year conditional release which required that he cooperate with all aspects of his treatment, report to a probation officer, and obtain permission for any travel outside Indiana.

Six months after being released, Ted returned to work as an industrial controls engineer with a small company whose owner was familiar with Ted's history.

Our family would like to publicly acknowledge that even though severe manic episodes resulted in several stays in seclusion ("the hole"), we felt Ted received competent and compassionate treatment in the Federal prison system. On two occasions, when we arrived for visits during Ted's serious episodes, staff at the facilities in Chicago and Rochester, Minnesota, made special arrangements for us to visit. When it became apparent that being in Chicago seemed to precipitate serious incidents, the staff at Rochester arranged to conduct the court hearings and trial via closed circuit television, so that Ted could remain in Rochester and still participate in the Chicago proceedings.

Based on our experiences, I would make the following suggestions:

- Families need to be informed about the nature of their relative's illness. This was our first exposure to mental illness. I thought Ted might annoy passengers by talking about religion. I was totally unprepared for delusions about terrorists taking over the airplane. In our case, the psychiatrist specifically recommended that we should fly rather than drive back to Indiana from California, even though Ted was being released without medication from a 72-hour involuntary commitment, after 48 hours during which he had damaged the facility.
- Families need guidance on how to decide whether a relative should travel on public transportation, especially where they may encounter armed marshals. They need to know what precautions to take and how best to manage a crisis.

Putting disruptive passengers with mental illness into the criminal justice system adds legal and financial complications to the situation. We purchased a handbook on dealing with the criminal justice system. In the section on legal costs, it said that while the costs would depend on the individual case, you could be sure that a criminal defense will cost more than most people are ready to pay. In our case, the most highly recommended lawyer wanted a retainer of \$50,000 and said if expert psychiatric testimony was required, the cost could easily exceed \$100,000. We selected a different attorney and were able to keep Ted's defense under \$50,000.

Being convicted of a felony also imposes consequences which remain long after any prison time has been served. Even though Ted was not convicted and received good reports from his psychiatrist, probation officer, and employer, the judge was not willing to eliminate court supervision at the end of the two-year conditional release in August 2005. Ted returns to court in August 2006 for further review.

We want to acknowledge the tremendous support provided by NAMI. Suzanne Andriukaitis, Executive Director of the Chicago affiliate, accompanied us to one of the first court hearings. As a result of the extensive media coverage of the incident, two people from the Fort Wayne affiliate called to offer our family support. We accepted their offer and have missed very few meetings since then. It was a real life saver for us. We attended a Family to Family class and then completed the training to teach Family to Family and Provider Education courses. Ted has become active in the NAMI consumer group. We hope that NAMI can find ways to prevent further violent reactions to persons with mental illness in crisis on public transportation.

#### **Bipolar Disorder**

Bipolar affective disorder is a mood disorder characterized by mood swings from mania (exaggerated feeling of well-being, stimulation, and grandiosity in which a person can lose touch with reality) to depression (overwhelming feelings of sadness, anxiety, and low self-worth, which can include suicidal thoughts and suicide attempts). The periods of highs and lows are called episodes, with each rotation from one extreme to the other called a cycle. Abuse and violent behavior is common in the most severe form of the disorder. Some celebrities who have been confirmed as bipolar:

Patty Duke - actress, writer  
Connie Francis – actress, singer  
Peter Gabriel – musician  
Kristy McNichols – actress  
Spike Mulligan – comic actor  
Charley Pride – musician  
Barret Robbins – athlete  
Axl Rose – musician  
Ted Turner – entrepreneur  
Dimitrius Underwood – athlete  
Robin Williams – actor, comedian

#### **Letters to the Editor**

You are welcome to send letters to the editor by mail or E-mail. Letters can be sent to:

Teresa Bomhoff  
200 S.W. 42<sup>nd</sup> St.  
Des Moines, Iowa 50312

Or E-mail: [tbomhoff@mchsi.com](mailto:tbomhoff@mchsi.com)



#### **Many thanks to Nancy Hale, B.S., R.N.**

– our speaker at the Feb. 5 NAMI-GDM affiliate and support group meeting.

Nancy gave a very informative presentation about bipolar disorder and the U. of Iowa Dept of Psychiatry genomic study on the bipolar illness. The U. of Iowa is also conducting a study on early on-set depression.

Nancy ran out of sign-up packets of information because so many people in attendance signed up for the studies. Many more people (thousands) are needed for both studies to get as much data as possible before the grants run out.

If you think you or a member of your family would be eligible for either study **-please consider participating**. There is a stipend of \$80 paid for being a part of the study.

NAMI-GDM will be receiving more packets and brochures. These packets and brochures will be available at the NAMI-Iowa Office (254-0417), at future NAMI-GDM meetings, and by calling Teresa Bomhoff, Pres. of NAMI-GDM at 274-6876.

The toll free number to call to sign up directly - if you are interested in participating in either study is (888) 850-8531.

The individual with the illness will be asked to complete a diagnostic interview and answer medical and family history questions. Participants will be asked to donate a small blood sample for DNA testing.

Scheduling is done to best suit the participant. Weekend and evening appointments are available for those who need them.

#### **ALSO**

University of Iowa researchers invite participants for studies of schizophrenia or schizoaffective disorder. Ongoing studies include the following areas: antipsychotic medication studies, weight gain and wellness studies, studies of medications that may improve memory and thinking, and a study of non-medication treatment of auditory hallucinations.

Participation is voluntary. There are no charges for any of the study procedures or medications. Some studies involve medications or procedures that are not FDA approved and are considered experimental. Compensation is available for your time and travel expenses.

Toll free inquiries may be made at 800-777-8442. Ask for Jane Kerr or Tim Holman.

*We often feel helpless as we wait for new medications and new research to reveal more effective approaches and solutions in dealing with mental illness.*

*Participating in genetic studies goes to the heart of being a part of the solution.*

Nancy and her son are in a PBS documentary entitled "The Secret Life of the Brain". To locate the program - go to [www.PBS.com](http://www.PBS.com) and enter the name of the program in the search engine.



***Many of you have been receiving our newsletter even though you are not members.***

***Would you please consider joining our organization to help support our activities?***



**CITYVIEW  
YOUR LETTERS: SPEAK UP AND PAY  
DEARLY**

January 19, 2006

Dear Editors:

Thank you for including the issue of treatment of the mentally ill in Iowa's prisons among the issues that continue to cry out for oversight by the legislators.

I recently had a conversation with Dr. O'Brien, Medical Director for the Department of Corrections regarding whether suicide attempts by prisoners should be seen as a disciplinary issue or a mental health problem.

He said that only a small percentage of people who slit their wrists die because the blood vessels are small in that area, thus it takes a long time to bleed to death, so it isn't seen as a serious suicide attempt. Thus a person who slits their wrists is taken before the Administrative Law Judge and charged with "disruptive behavior" and "self mutilation" and sentenced to time in lock up.

It seems to me that there is definitely an underlying mental health problem that needs to be addressed by mental health staff.

In the past few months I have been contacted by 4 or 5 prisoners at Fort Madison who have made suicide attempts by various methods and have been taken before the Administrative Law Judge. The assumption by the staff is that they are "attention seeking."

Both William Angrick of the Iowa Ombudsman Office and Dr. White, the National Consultant brought in to the mental health care in Iowa's prison system warned of failure to take suicide attempts seriously. Angrick is quoted as saying prison staff sometimes are too quick to assume that strange behaviors are intentional attempts to gain special treatment.

"The unfortunate result is under diagnosis, which can lead to unfair punishment of prisoners' whose unacceptable behaviors are actually driven by their mental illness. Of course, the ultimate tragedy of over concern about malingering leads mental health staff to miss what would otherwise be clear signs of impending suicide."

I have spoken with prisoners at Iowa Correctional Facility for Women and Iowa State Penitentiary who tell me that suicidal prisoners are afraid to tell staff when they are having suicidal thoughts because they know that if they do, they will have their clothes taken away from them (replaced with a paper gown) be placed in isolation, and be watched by a stranger. That is the last thing they need at a time when they are feeling desperate.

At the Penitentiary the suicide cell is glass and is in full view of anyone coming off the elevator on to the pod, giving the person the feeling of being put on display.

Dr. White has said something must be done to give the suicidal prisoner more privacy, but the Iowa DOC says it can't do so due to security concerns.

Those in the field of mental health need to be brought in to work with the Department of Corrections and legislators in coming up with solutions to develop programs to help those who are mentally ill and have become involved with the criminal justice system.

*Jean Basinger, Chr., Steering Committee, Justice Reform Consortium*

**Amnesty International's Report on**

"The Death Penalty and Serious Mental Illness"

*Statement of Michael J. Fitzpatrick*

*Executive Director, National Alliance on Mental Illness*

Amnesty International's report today on the people with serious mental illnesses and the death penalty represents a compelling step forward in making the case that profound injustice exists at the most painful intersection of the mental healthcare and criminal justice systems in America.

NAMI opposes the death penalty for people with serious mental illnesses. The law has not kept pace with modern science. The criminal justice system is ill-suited to address biologically-based brain disorders that create illogical, confused patterns of thought.

Juries are called upon to apply narrow, irrelevant legal definitions to people who do not fit those terms. The law tries to paint bright lines between right and wrong in order to evaluate psychosis, delusions, and hallucinations. The death penalty poses issues that typically are never considered:

Stigma—the fear, ignorance, and prejudice—surrounding mental illness may influence jury decisions. Mental illness becomes an aggravating, rather than mitigating factor. Defendants with serious mental illnesses during trial may appear impassive, because of the effects of psychiatric medications. Juries wrongly interpret their demeanor as lack of remorse.

As noted by President Bush's New Freedom Commission on Mental Health, the mental healthcare system in America is a fragmented "system in shambles." Barriers to care exist. Individuals with serious mental illness often are unable to get help. Treatment or interventions may be inadequate, including long waiting lists or early discharge from hospitalization.

In supreme irony, defendants denied medical treatment before committing crimes may be forcibly medicated to make them competent to stand trial or be executed. States make people who are profoundly sick—through no fault of their own—marginally well for the sole purpose of putting them to death.

NAMI congratulates and thanks Amnesty International for its contribution to this growing debate.

We call on state legislatures to eliminate the death penalty in such cases.

We also believe the U.S. Supreme Court may ultimately rule its application to people with serious mental illness unconstitutional.

For a copy of the Amnesty International Report:

<http://web.amnesty.org/library/index/ENGAMR510032006>



**Did you catch this show?**

Iowa Public Television –

*The Infinite Mind:*

The remarkable stories of Four Lives  
(Broadcast January 26 and February 4, 2006)

In the first episode, two powerful tales of recovery from mental illness were told.

First, the former First Lady of New Jersey, Mary Jo Codey, revealed her courageous battle to overcome the postpartum depression that caused her to constantly think of killing

herself and her newborn son. After her husband was elected governor and a radio "shock jock" made her private struggle the brunt of a public joke – foreshadowing a similar, acrid exchange between Tom Cruise and Brooke Shields -- Ms. Codey realized she had a cause worth fighting for.

Next, renowned TV newscaster Jane Pauley told how steroids and anti-depressants, intended to treat a case of hives, instead sent her spiraling into depression and mild mania, unmasking a hidden vulnerability to bipolar disorder. When she started thinking about suicide, her doctor sent her to the hospital, and in the process, she re-evaluated who she was – emerging as an advocate for people with living with bipolar disorder and mental illnesses.

The second episode had two more stories of recovery. Judge Sol Wachtler, the former head of the New York State Court of Appeals had his first in-depth conversation about his illness and his stint in prison for acts related in part to his undiagnosed manic depression.

Actress Caris Corfman told how she's reclaiming the spotlight after an operation damaged her pituitary gland, leaving her unable to remember any new information – including the lines of her deeply personal one-woman show – for more than about five minutes.



### **New Resource Available for Advocates Addressing the Growing Numbers of People with Mental Illness in the Criminal Justice System**

February 2, 2006 -- The Council of State Governments' (CSG) Criminal Justice / Mental Health Consensus Project is pleased to announce the release of a new resource for advocates addressing the increasing numbers of people with mental illness involved in the criminal justice system, *The Advocacy Handbook: A Guide for Implementing Recommendations of the Criminal Justice / Mental Health Consensus Project*.

The Advocacy Handbook, the result of a joint effort among the Consensus Project, NAMI, the National Mental Health Association, the National Association of State Mental Health Program Directors, and the Bazelon Center for Mental Health Law, is available online at the Consensus Project web site: [consensusproject.org/advocacy](http://consensusproject.org/advocacy).

#### **Why Advocacy?**

People with mental illness are falling through the holes of this country's social safety net and landing in the criminal justice system at an alarming rate.

During the past decade, the advocacy community has mobilized to reverse this disturbing trend. Individuals with mental illness and family members, many of whom have experienced firsthand the trauma of criminal justice involvement, have led the charge to train police officers, institute jail diversion programs, launch mental health courts, improve transition planning from jails and prisons, and make a host of other improvements in how the criminal justice and mental health systems respond to their shared population.

Their efforts have borne considerable fruit. In nearly every community that has made strides to address the problem, advocates have been a driving force for change.

**CIT**

### **The First Annual Minnesota CIT Conference**

*Feb. 27 – Teresa Bomhoff – Part 1*

The Barbara Schneider Foundation and the Minneapolis Police Department worked together on the creation of the first CIT (Crisis Intervention Team) Unit in Minnesota.

The Barbara Schneider Foundation (BSF) was born out of a tragedy that occurred on June 12, 2000. Local police, called in on a noise complaint, shot Barbara Schneider to death in her own home. Six police officers entered her South Minneapolis apartment when she was having a mental health crisis. The police were untrained to deal with this call as a health care intervention; instead they treated her as a violent criminal. Rather than receiving the crisis intervention needed, she was shot to death.

Mental health community activists, people with mental illness, and law enforcement professionals came together to vow to do better.

As this work progressed it became clear that more than mental health crisis response needed to be reformed. Necessary reforms to the systems and procedures used in response to calls regarding a mental health crisis were identified and called for.

The current system of care by social services, health care and criminal justice gives minimal attention to the long term needs of the mentally ill. This original group determined they must broaden their mission beyond improving mental health crisis response to include reforms needed to prevent mental health crises. This at-risk population is currently without the long-term support services they need to live successfully. Barbara Schneider Foundation incorporated on February 22, 2002, and retained a part-time paid and volunteer staff to provide leadership to work to end the revolving door for people with severe mental illness.

BSF's mission states, "Eliminate the criminalization and abusive treatment of people with mental illness by improving public safety and mental health systems through proactive training and education."

BSF's primary goal is working to change the mental health crisis response framework from one of public safety to one of health care. They believe this is the root of the lack of much needed services in the community for those who struggle with mental illness.

In next month's newsletter – there will be more about the Barbara Schneider Foundation – the leadership they have put together for this widespread effort for education and to change the response to people with a mental health crisis.

Teresa Bomhoff, President of NAMI Greater Des Moines attended the First Annual Minnesota CIT Conference in Minnesota on February 27. In next month's newsletter there will be an article about the conference.

For information on the latest bills in the state legislature, go to [www.infonetowa.com](http://www.infonetowa.com).

To find legislator and committee information, go to [www.legis.state.ia.us](http://www.legis.state.ia.us)

***"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has." – Margaret Mead***

Please detach, complete, attach check, and mail to NAMI-GDM Treasurer – Don Jayne, 1291 16<sup>th</sup> St., West Des Moines, Iowa 50265

- For Renewal of NAMI – GDM dues for 2006  
 To become a NAMI-GDM member in 2006



Checks should be made payable to NAMI-GDM.

## IT'S TIME

We look forward to seeing you in 2006!!

Name \_\_\_\_\_

Address \_\_\_\_\_

City, State, Zip code \_\_\_\_\_

Phone \_\_\_\_\_ E-mail \_\_\_\_\_

Dues are as follows:

(please check one)

\_\_\_\_\_ \$35.00 Individual/Family  
 (\$10 national, \$10 state, and \$15 local)

\_\_\_\_\_ \$3.00 Consumers/Limited Income

\_\_\_\_\_ \$40.00 Professional

\_\_\_\_\_ Gift \$ \_\_\_\_\_

Be part of a movement to create awareness of the facts of mental illness – it is a human issue, a health issue, a community issue. At our meetings, you can meet, share, and care with others who are living with mental illness, as well as obtain information about mental health resources, meet speakers knowledgeable about mental illness, have access to informational resources and legislative issues.

Please help to support us whether it is through payment of dues or attending meetings or both!



Sign up for the next **“Visions for Tomorrow”** class. It is an 8 week course (1 night a week for 2-2 ½ hours) for parents, foster parents and other caregivers of children and adolescents who have serious emotional disorders.

Curriculum includes types of mental illnesses and emotional disorders as well as instruction on coping skills; dealing with schools; communication; medication; rehabilitation, recovery, and transition; and advocacy. Call the NAMI office to sign up – 515-254-0417.



**Panel Members** for **“Out of the Shadow”** Presentation on Sunday, March 12, at the Temple for the Performing Arts, 1011 Locust – 2:00 P.M.

After viewing the documentary “Out of the Shadows”, we will have a panel of experts to comment on the film and answer questions posed by the moderator and the audience. Panel members will be composed of the following:

- Psychiatrist Dr. Bruce Sieleni, M.D.
- Des Moines Mobile Crisis Unit – Larry Hejtmanek
- Polk County Supervisor Angela Connolly
- Polk Co. Health Services – Karen Walters-Crammond
- State Senator Jack Hatch
- Consumer – James Bremhorst
- Consumer – *Unconfirmed*
- Parents – Rudy and Marnie Vasquez
- Adult Child of Parent – Jeannie Harbison
- Faith Community – Cece Arnold



For a look at what's happening nation-wide in the mental health care field – go to: **Behavioral Healthcare Headlines**

<http://alt.samhsa.gov/SBHH/viecurrent.asp>

for the most current issue – or –

<http://www.samhsa.gov/news/news.html>



**Schizophrenia Digest** magazine and **BP (Bipolar)** magazine to be available at NAMI-GDM meetings

At the February 9 business meeting, the NAMI Greater Des Moines Board approved the purchase of a bulk subscription to both Schizophrenia Digest magazine and BP (bipolar) magazine.

Both magazines are printed quarterly. We will have 50 copies of each magazine available for members and others attending the Sunday affiliate and support group meetings on a first come-first served basis.

There is a limit of 1 copy per person/family.

What will be the cost to you? Please donate a \$1.00 per copy to our organization.

The decision by the Board to offer both magazines was done to enhance support to those living with an illness and for families with loved ones suffering from severe mental illness.

Each magazine offers information about the illness, latest research and legislative developments, and stories of hope. Many letters to the editor have said “Now I know I am not alone.”

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To learn more about mental illness, call NAMI Iowa (515-254-0417) or visit their office library at 5911 Meredith Drive, Suite E, Des Moines, IA 50322-1903. Check out the online resource NAMI website, [www.nami.org](http://www.nami.org), for information on research, disorders, treatments, medications and other topics.

### **Schizophrenia: The Lonely Disease**

*By a former patient – Excerpt from Pine Rest Today*

I am a catatonic schizophrenic. I am also a wife, a mother, and a social worker. All of which essentially means I am a person like other people, but one who happens to suffer from a disease called “schizophrenia”.

Schizophrenia crept up on me unexpectedly. It started one summer when I was 21. A time when life should be opening up, but without my knowing, my mind was closing down.

It began with fear – fear of the world and fear of myself. It was a fear greater than fear; it was sheer terror. I began to feel very visible and vulnerable, so withdrew from the world as I did not want to be seen. My terror only grew. And then my mind betrayed me. It is strange to lose control of one’s thoughts for they are the very essence of one’s self. If someone were to speak to me, a host of responses would leap into my mind.

My thoughts became so loud I feared everyone could hear them. They were ever-present, no longer willing to fade into the background as I went about my daily life. As though they followed the pattern of my mind, the voices took over, softly at first, then louder until they screamed through my brain leaving jagged bursts of pain behind.

Communication became difficult, for no longer were my experiences in common with the rest of the world. This, then, for me was the beginning of the long loneliness.

Muteness became a way of life for me, for how could one speak out of the blankness and the chaos going through one’s mind? And my body began to sense things it never had before. I became aware, with new senses, that if I spoke, the air around me, the very universe would shatter.

Loudness became a word with new meaning. A page in a book being turned in another room brought an agony of sound. Cats stomped noisily across the floor. The ticking of a clock was more than I could bear. My other senses were heightened to such an extent that the clothes on my body became a weight I could not tolerate. My eyes were bombarded by the colors all around.

The terror grew. My body would melt, dissolving into the rain. I found it hard to hold on to pieces of myself, as frantically as I tried. My world was falling apart around me as I fought a losing battle.

It was not a simple journey back. And how could one reach me to bring me back? For me, it was many people and the many things they did. The journey back started in a hospital. They did not give up on me. Step by step, I traveled the journey back. It was like a mountain climb, retreating only to climb a bit higher again.

In many ways there are fears in reaching out to another person - greater than those fears experienced in my illness, but assurance is there that I will not have to face it alone. What courage I have comes from this.

The journey back can take a lifetime, it is one that you never can say is completed. But with the help of God, my therapist, my husband, and friends, I am on my way.

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To witness another story of struggle, courage and love - **PLEASE JOIN US AT THE TEMPLE FOR THE PERFORMING ARTS ON SUNDAY, MARCH 12, for the film “Out of the Shadow”**. Please register by calling 254-0417. This is a free event.