



WINTER 2009

Notes from the President...

2008, our second full year as an incorporated not-for-profit, was another productive year for NAMI-FL. In terms of our organization, we held 4 Board Meetings and elected 4 new Board Members – Linda Duttweiler, Deb Grantham, Rebecca Schwed, and Sherry Scott. At our Annual Meeting in January, 2009, we elected Bruce McKee, Barbara Anible, and Bill Staffeld to the Board. Officers elected for 2009 are: President – Carol Booth, Vice President – Deb Grantham, Treasurer – Joanne Denison, Recording Secretary – Sherry Scott, and Corresponding Secretary – Barbara Anible.

Last year, we sponsored a Rally to Raise Awareness of Mental Illness and Support Mental Health – with Tom O’Clair -- and a Wellness Event in October with John Allen, Director of Recipient Services with OMH in Albany. We also had several social get-togethers for our members and friends – an August picnic at Stewart Park and a December social – both with great music by members and friends.

Now that we have entered 2009 and rather difficult economic times, we must take time to prioritize our most important financial needs in order to continue providing support, education, and advocacy. We formed two important committees, Fundraising and Technology, to work toward our 2009 goals. We did not receive the typically large donation from our Cornell Fraternity Fund Raiser that we have been the appreciative beneficiary of for many years, so we are seeking other sources of income. I was able to find money (Transitional Living Services in Syracuse) to purchase a new computer monitor and some new software – so our second priority will be to upgrade our use of this new technology along with our website. We will transfer our finances to Quicken and update all of our mailing lists –Members, Friends, and others. Joanne, David, Sherry, Ann, Bruce, and several others of us will all learn how to use this new software effectively.

We continue to gain the reputation of providing quality services to family members and recipients and being a necessary partner to other service providers. We will certainly continue to fight STIGMA at all levels – through our Family to Family education course, through the free media, through our many outreach attempts in the community, and through our connections to

other Advocacy Groups. I will also continue to consult with and teach *Breaking the Silence* to children in schools around Tompkins County.

My work as Secretary of NAMI-NYS for the last three years allows me to network with other advocates from all over the state and keep up with important issues facing those heroic individuals struggling with these devastating illnesses and their courageous families and close friends. I have been involved with Children and Adolescents, Wellness, and Educational Program Committees. One thing I know for sure – the treatment and services that we have here in the Ithaca Community and Tompkins County are of very high quality. We have housing and case management for those who need it. We also have a very short waiting list for County Mental Health Services, in contrast to many other parts of NYS. We have much work ahead of us, but we have excellent partners with whom to collaborate to help our loved ones have the best quality of life that is possible in such difficult circumstances.

Thank you all for your wonderful support throughout the years.

Carol Booth, President, NAMI-FL

FINANCE

2008 Membership is due. Part of your annual membership dues are forwarded to NAMI National and NAMI-NYS to pay for your national and state publication subscriptions. We are billed according to our membership roster, so when someone misses paying their dues, we have to absorb the cost of their national and state membership from other revenue services. If you wish to continue to receive national and state NAMI newsletters, please help us by submitting your membership in a timely way each year.

Please forward your payment to NAMI-FL, 104 East Lewis Street, Ithaca, NY 14850.

Single membership dues \$25
Family membership dues \$35

Thank you,
Joanne Denison, NAMI-FL Treasurer

MENTAL HEALTH AWARENESS MONTH OCTOBER 2008

Approximately 80 people attended our major annual educational event held on October 22, 2008, *Mind and Body: Integrated Health*, featured keynote speaker John Allen, Director of Recipient Affairs, NYS Office of Mental Health. Mr. Allen was an inspiring speaker, talking about NYS efforts and the need to focus on integrated health care, and his personal efforts at achieving good mental and physical health. A panel of local speakers included Dr. Henry Gerson, Cayuga Medical Center; Susan Spicer, Clinical Supervisor, Tompkins Mental Health Services; Nancy Peckenpaugh, Registered Dietician; and Deb Siegart, Registered

Dietician, Cayuga Medical Center addressed the need for a holistic approach to health, requiring exercise, nutrition, medical and dental care, and mental health care to be effective. Local services and opportunities were identified. Nikki Bonanni, Exercise Physiologist, Island Health & Fitness and Liz Grantham, Recipient, described Liz's challenges and accomplishments as she worked with Nikki for the previous 8 months. Stamina, balance, weight management, and confidence were among the benefits, and Liz particularly noted that competitions and incentives offered by Island Health were motivating.

Exhibitors included The Yoga Center in Community Corners, Cayuga Heights; Trish Engelhard, massage therapist; Rasa Spa; and Cayuga Medical Center.

2009 ANNUAL MEETING

Beth Jenkins, Executive Director of the Mental Health Association of Tompkins County, offered updates on several issues coming from our change in New York State government and budget issues. We discussed the practice of placing sexual predators in psychiatric institutions and the impact that has on stigma experienced by mental health consumers, as well as the budgetary impact of shifting the cost of incarceration to the Office of Mental Health. Children's mental health issues were also discussed, particularly the availability of services specifically for children. She suggested we write to our state government officials asking them to not cut any funding from the mental health services in New York State.

We recognized Liz Grantham with a "Special Friend" Award for her inspiring work with NAMI-FL and her humor. She has been a wonderful asset to our membership.

FUNDRAISING

2008 NAMI-Finger Lakes Garage Sale

Our fall garage sale was held at 104 E. Lewis St, Ithaca on Saturday, October 11, 2008. The sale ran from 8:00 – 2:00 and netted about \$600 for our affiliate. We are most grateful to all who helped. Planning began in June, and we started receiving excellent donations soon after the first garage sale announcement. The number of people who helped kept the task from becoming too much for any one person. Anna and Hermann Moratz provided helpful notes from last year's sale. Trisha Engelhard worked on publicity, and Andrea Staffeld designed a beautiful flyer. Jean's neighbor, Gabe McCarthy reassembled, set up, and later took down the wooden tables stored in her basement. Trish Engelhard and Linda Duttweiler (among others) assisted Jean with setup and pricing the day before the sale. Jean received help during the sale from Andrea Staffeld, Janet Lynch, Gail Murphy (who also supplied coffee and doughnuts!) and others. Everything was picked up and taken away by 5:00 with the help of Jean Poland, Steve Little, and the folks from the Endfield Blessing Shop. Susan Larkin helped with garage sale updates to members and general cleanup. You might notice how often Jean Walters' name has been mentioned in this article. Her efforts were what held the sale together. We are most grateful to Jean, and all who helped in this fundraising effort.

SAVE THE FIRST WEEKEND OF OCTOBER FOR OUR 2009 GARAGE SALE!

Community Partnerships:

We plan on partnering with local businesses who will contribute a percentage of a day's sales to NAMI-FL. If you are willing to recruit a local business with which you have a connection, please call or email Deb Grantham (607-277-5148; dgg3@cornell.edu).

2009 CALENDAR

*Support Group meets first Tuesday of each month – 7-9PM, 104 E. Lewis St, Ithaca

January 20: NAMI-FL Annual Meeting

February:

Meetings with new Family to Family Members
First Fundraising Committee Meeting – March 5, 2009

March:

Family to Family Class begins – March 5, 6:30-9PM
Board Meeting – March 18; all are welcome
DUES!!!

April: Special Program “Tompkins County Single Point of Entry and Housing Options” – for NAMI members and friends

May:

Board Meeting — May 19; all are welcome
Final Class and *dish-to-pass* for Family to Family Course — May 20
Tompkins County Mental Health Board Recognition Event – May 27, 5 – 7PM at Holiday Inn (downtown Ithaca)

August: Picnic at Stewart Park – date TBA

October: Garage Sale

December: Alternative Gift Fair

BUILDING A CARE KIT

A one page summary of your loved one's psychiatric history can be very useful for professionals who may not have time to review a complete set of medical records. Keep at least 5 copies of this important document in your CARE kit – Critical Advocacy Resources for Emergency – so it can be easily and quickly shared. Keep it current and short and make sure it contains the most critical information, including the following:

- Full Name
- Current Age
- Psychiatric Diagnosis
- Age at Diagnosis
- Town or City of Residence
- Current symptoms and concerns – suicidal, homeless, missing, vulnerable, violent, abusing substances, etc.
- Psychiatrist's Name and Number
- Local Service Providers' Names and Numbers
- Dates of Previous Hospitalizations
- Dates of Previous Arrests or Jailings
- Current Medication Names
- Past Medications that have Helped
- Past History of Symptomatic Behavior – car accidents, debts, threatening family members, etc.
- Full Name and Contact Numbers and Address for Emergency Contact Person

Also: include in your Care Kit Recent Photo and Description, List of Emergency Numbers, Copies of Important Criteria for Emergency Evaluations and Civil Commitments, Involuntary Commitment Petition Forms, and a signed Medical Release.

Being well prepared to address a crisis for a loved one suffering with severe mental illness is very important. This information was included in an article from the Treatment Advocacy Center's "Catalyst."

BOOK REVIEW

The Lives They Left Behind: Suitcases from a State Hospital Attic, Darby Penney and Peter Stastny, 2008, Bellevue Literary Press, New York

In the Winter 2007 newsletter, Carol Booth described the museum exhibit, *Lost Cases Recovered Lives: Suitcases from a State Hospital Attic*, composed of the contents of suitcases belonging to patients of the Willard Psychiatric Center, found in the attics of the institution buildings upon the closing of the institution. The authors of *The Lives They Left Behind: Suitcases from a State Hospital Attic* chose 10 of the owners of those hundreds of suitcases and chronicled their lives in depth, based on the contents of the suitcases, Willard Psychiatric Center records, and other historical records. The 10 patients selected cover the entire history of the institution, from its foundation in 1869 to its closing in 1995. The book also documents trends in

psychiatry and attitudes toward mental illness in this country for that time period, contrasting it at some points with more progressive and effective practices in Europe and other parts of the world. The experiences of these 10 people in the mental health system in the United States are another indictment of American attitudes towards mental illness and its treatment. This is a disturbing story that is not yet over. In an epilogue, the authors question whether we are treating sufferers of mental illness any more effectively and respectfully today than in 1869. They challenge our modern mental health system, including the foundation of treatment on medication. Recent movements in peer advocacy and peer treatment are praised. All advocates for effective, equitable and empathetic treatment of mental illnesses should read *The Lives They Left Behind: Suitcases from a State Hospital Attic*.

Deb Grantham, NAMI-FL

SPEAKERS BUREAU

The new Fundraising Committee has dubbed our outreach/speaking efforts the “Speakers Bureau” for the purpose of seeking funding for NAMI-FL. Below is a description of the first 2009 speaking engagement.

Ithaca College Personal Health Class: Liz and Deb Grantham were invited Nikki Bonanni to speak on Liz’s experiences with schizoaffective disorder and on the effects on their family to an Ithaca College class on personal health. Liz started off the presentation by explaining a bit about her illness and giving a synopsis of her life and her progress towards recovery. Liz and Deb went on to talk about how the family coped with Liz’s illness. The class of 41 students was very engaged, with many questions about symptoms, medications and particularly side effects of the medications. Deb followed with a presentation on mental illness originally developed by Bruce McKee. Finally, Deb lead the class through a very powerful exercise used in Family to Family to simulate internal stimuli, and then lead a short discussion about how that exercise made the class feel. Liz talked about how it made HER feel, as well. Several students asked questions from very personal perspectives and one student disclosed that her twin sister has mental illness and wondered if she herself is likely to develop a mental illness.

Have you been diagnosed with Schizophrenia or Schizoaffective Disorder?

Do you have symptoms that have persisted despite treatment with at least 3 different antipsychotic agents? Are you between the ages of 18 and 55?

If you answered to yes to all of these questions, then you may be eligible for a treatment study now being conducted at the NYS Psychiatric Institute. This study compares the efficacy of intravenous placebo (normal saline) to intravenous antibiotic therapy for patients with ongoing psychiatric symptoms. Eligible patients will be hospitalized for 8 weeks at the NYS Psychiatric Institute at no cost for participation in the study. **If interested, call Amanda Carson, M.A., (Study Coordinator) at 212-543-5422.**

A PERSONAL EXPERIENCE

Washington Irving's story of Rip Van Winkle is an interesting tale of a man who loses years of his life to time. Mental illness has to some degree the same affect. Imagine going into what is supposed to be the beginning of life with ambition and excitement only to be lost to time indefinitely. That is very much what has happened to me. Like Rip Van Winkle I seemed to wake from a long sleep two years ago, eager to experience a new world.

After a hospital stay in March of 2006 I was determined to make changes in my lifestyle, but change would come slowly and sometimes with difficulty. It took six months after my discharge to find the right medications. Implementing effective medication is trial and error, and it changes constantly. It was at this time I found a highly regarded psychiatrist in Ithaca, but the problem now was I had to teach myself how to drive once again. Then I started attending church for the first time in 28 years. This was no easy chore. I was losing weight rapidly and my size 50 jeans were being held around my waist by a belt with notches carved into its center.

I was not satisfied with my accomplishment thus far even though I had made tremendous strides in my recovery, I wanted much more from myself. I became disabled in 1978 and had not worked since then, but I now wanted a job. I knew I had to prove to myself I could maintain employment, so I began volunteering at the library in McGraw. I worked hard cleaning, shoveling snow and anything else they asked me to do. It was not long before I received the respect of my supervisor, but even more important from myself.

And just as it was before, I was not satisfied with my spot in society. I longed to be a productive citizen. I knew I had to find employment, so I tried Catholic Charities and was hired immediately. It is my responsibility to get individuals to their appointment whether it is with a doctor or court appearances. Now along with driving I substitute at a halfway house as a resident advisor.

At present I am a freshman at Tompkins Cortland Community College, and I manage a part time job with Catholic Charities. Plus I still attend church on a regular basis. It has only been two years since my reawakening, and like Mr. Winkle I am making every effort to make up for the life time I have lost.

Ed Hazel, NAMI-FL

EVENT ANNOUNCEMENT

The Community Mental Health Services Board is planning a CELEBRATION on Wednesday, May 27, 2009 from 5-7Pm at the Holiday Inn downtown. In keeping with our Mission the goal of this event is to take this opportunity to highlight the disability services in our own community, to recognize the accomplishments and service of individuals and agencies, and celebrate our successes.

Call Carol for more info -- 272-6573

AARP ON RETURNING VETERANS

The July/August 2008 issue of The AARP Magazine (American Association of Retired Persons) reports that the advocacy and long-term, intensive care that seriously injured war veterans need is being fulfilled by their parents. Many of these injuries are physical in nature, but AARP's report echoes comments made by Tom O'Clair at the NAMI – Finger Lakes May 2008 rally: many veterans are returning home with mental illness, increasing the need for mental health services nationwide. Military screeners found psychological symptoms in 31% of Marines, 38% of soldiers, and 49% of National Guardsman returning from war. Other statistics cited are that 13.8% of troops returning from Iraq, or 226,000, have PTSD; 13.7% or 225,000 have major depression; and the two-year cost of treating PTSD and major depression is estimated at \$4 billion to \$6.2 billion. The magazine is in the NAMI – Finger Lakes library, or you can visit www.aarp.org/iraqvets for more information.

MY BROTHER

One moment, my brother is standing next to me, watching his son play and is joyfully sharing his life, and the next moment he is confiding in me, telling me, whispering his fears.

I lean in close to give him my support and attention and he reveals that someone, everyone is after him.

I look up at him expecting to see his "I got you" grin. I look for the joke in the insane, unimaginable comment but there is no humor in his eyes, only fear and horror.

He continues on in a breaking, halting voice that borders on furious, unrelenting anger, telling me that where ever he looks, wherever he goes, whatever he does, people are trying to harm him. Before I can act, before my eyes, he is spirited away to an unreachable place of pain and self-torture. He tells me that in this place, birds sing messages of hate to him. Cars veer off the road to hit him. He says he has been able to take evasive measures to survive, but that he's tired, angry and in pain. He speaks with clenched teeth and fists.

The FBI is his constant companion hidden in anyone, everyone, passing by on the street. Hidden cameras are everywhere.

"They" threaten, "I'm watching you".

When I ask him, he can not coherently identify who "They" are. I take a chance and ask if "They" are from another planet. His body stiffens and his anger rises as he hisses that I insult him.

I'm now afraid and am begging him to show me reason, to give me reasons that others would want to harm him.

Suddenly he seems rational and calm. He states in a reasonable way, "I know, it seems unlikely, but it is true".

I grasp at this rational statement for a moment, with growing hope of pulling him from the abyss

when suddenly his voice and demeanor shift.

He is moving away toward another place that I can't see. He screams, "No matter what you say, I will not believe you".

He says he knows The Truth about me.

That I am also "They".

And in that moment, I am spirited off into his paranoid fantasies where my every word, every effort, every movement is tainted with bad intention.

It is in the way I hold my head, move my hands, a catch in my voice, a look in my eyes.

I silently begin to doubt my own awareness of reality.

Are there mysteries in the world at work, of which he is aware and I'm not?

Do others seek to harm him in another dimension of what is real and I not only do not protect him from danger, but I place him in mortal danger with my denial?

Am I unwittingly a part of a conspiracy, a threat?

I look at him and feel sweeping loss and hardened grief.

My brother is gone.

He can't see me now as he cries out, "my life has been stolen from me and I can never get it back"!

Yes, his life is gone.

He is lost to us.

He has lost himself in a place of constant threat.

He doesn't see that the danger, the harm, is coming from within.

MJ

SYMPATHY

NAMI-Finger Lakes' members extend our deepest sympathy to Peter Harriott and his Family on the death of his Wife and their Mother last December. She was a long time member and supporter of NAMI-FL and also a strong leader and member of the Upstairs Art Gallery for many years. She will be greatly missed by all who knew her. A memorial service in Mary Lou's honor will be held at Anable Taylor Hall on the Cornell Campus Saturday, April 18th, 2009, at 2:00 pm in the afternoon.

LEGISLATIVE ALERT

Timothy's Law will expire this year unless the legislature acts! Call your legislative leaders and urge them to pass S.1646/A.5659, to make Timothy's Law permanent. We must end the discrimination against people in need of mental health services through their private health insurance.

Assembly Speaker Sheldon Silver (518) 455-3791

Senate Majority Leader Malcolm Smith (518) 455-2701

LEAVE THE FOLLOWING MESSAGE: "I'm a registered voter from (your locality) calling to urge you to pass Senate bill 1646 and Assembly bill 5659 to make Timothy's Law permanent!"