

A Note from Our President...

What a wonderful year NAMI-FL has experienced...our first full year as an incorporated not-for profit. We held our Annual Meeting in January of 2007, followed by our first formal Board Meeting in March 2007. The following individuals acted as our first Board Members and Officers – Carol Booth, President; Ann Carter, Vice President; Joanne Denison, Treasurer; Stacy Oster, Recording Secretary; Louise Clarke, Corresponding Secretary; and Meyer Stolov and David Zimot, as Members at Large. We held four official Board Meetings in 2007 – March, May, September, and November. We also sponsored our 6th Family-to-Family Education class and our 1st Annual Rally to Raise Awareness about Mental Illness and Support Mental Health – a great collaborative community event. Later in August NAMI-FL held its yearly picnic and we all enjoyed meeting up with old friends down at Stewart Park. In late September, we co-sponsored an event with Cornell Minds Matter, Family and Children's Services, and others up on the Cornell campus – a dinner and lecture with Kay Redfield Jamison, famous author and clinician. It was great to see our name out there in such a big way. NAMI-FL chartered a bus to provide easier access to consumers and others up to the campus from downtown. We also did a great deal

of Outreach into the community this past year – both to human service agencies and providers and to some businesses. Many family members and close friends in the Ithaca area praised our support.

Now that we have entered 2008, we should strive to continue to provide the high quality Support, Education, and Advocacy services to family members of individuals with serious mental illnesses, as we have always provided in the past. We are gaining more of a substantial reputation and receiving many referrals from other human services agencies in Ithaca and other individuals who know of our group – and its compassion and competence in the area of mental illness. We are collaborating with others to raise the level of awareness and help to erase the **STIGMA** that is connected to these devastating illnesses. Educating family members and the public is our main priority – one of the best ways to fight Stigma and demand the highest quality treatments and services for individuals struggling with mental illness is to help all individuals understand that these illnesses are –largely **biological, no-fault, have warning signs, have treatments, and people do have opportunities to RECOVER to varying degrees.** My work with Breaking the Silence in the schools (8th year!) of Tompkins County is part of the campaign. NAMI-FL will

continue to raise awareness and erase **STIGMA** in every way possible.

I am also proud of two other initiatives – our Cayuga Medical Center collaboration and our first Annual Appeal to Members and Friends. The Behavioral Services Unit is passing out our Family Packets to those who need them and is requesting that we come up and speak to both consumers and family members about our organization on a regular basis – we plan to certainly continue these efforts in the new year. By sending out our 1st Appeal Letter, we are able to say thank you to our supporters and remind people that contributing financially to NAMI-FL is certainly one very important way to keep these extremely important services to the community viable. We also truly know that individuals contribute to our group in many different ways and we are very, very appreciative of this always.

Thank you all for your wonderful support,

Carol Booth, President, NAMI-FL

2007 TREASURER'S REPORT

Treasurers' report:

Garage Sale:

\$673 revenues - \$39.66 expenses =

\$633.34

We received a very generous donation from the Cornell fraternity, Lambda Chi Alpha, for \$5000. Many thanks for these return supporters!

2008 DUES ARE DUE NOW!!!

NAMI/FL has to pay dues to NAMI/NY and NAMI National by the end of March each year. What we are trying to achieve is

to have everyone pay their dues by March 15, 2008. Please help us to achieve this goal.

Individual membership dues \$25

Family membership dues \$35

Mail to NAMI-FL, 104 East Lewis Street, Ithaca, NY.

Thank you,

Joanne Denison, NAMI/FL Treasurer

“CANVAS” AND DISCUSSION

Canvas is a serious film about mental illness, telling the story of a 10-year-old whose mother has schizophrenia, and whose father is loyal and loving but stretched almost beyond his endurance.

Canvas will be shown twice at the Willard Straight theatre, Cornell campus. The January 24 showing at 7 pm will be followed by a panel discussion hosted by Cornell Minds Matter and Compos Mentis. The discussion will take place at 8:45 to 9:45 pm. Cornell Minds Matter invites all participants for refreshments after the panel in their Willard Straight suite.

NAMI-FL CALENDAR

Support Group: 7-9 PM, First Tuesday of each month at Jean Walter's house, 104 East Lewis Street, (607) 273-2462. Please call first if attending for the first time.

January

8th, Support Group

22nd, NAMI-FL Annual Meeting

24th, Cornell Minds Matter and Compos Mentis showing of “Canvas”

29th, Second showing of “Canvas”

February

5th, Support Group

14th, 6:30 pm, Family to Family Education
Class begins

March

4th, Support Group

18th, Kevin Nickerson, Disability Benefits
and Employment Incentives, 7 pm, 104 E.
Lewis Street

April

1st, Support Group

1st, Compos Mentis 2008 opening day

May

6th, Support Group

17th, Tentative: 2nd Annual Rally to Raise
Awareness about Mental Illness and
Support Mental Health

June

3rd, Support Group

July

1st, Support Group

August

5th, Support Group

19th, Picnic at Stewart Park

Wellness Conference, fall, 2008 – TBA

NEW IN THE NAMI-NYS OFFICE

- Trix Niernberger, Executive Director
- Jeff Keller, Deputy Director
- Deborah Ashline, Forensic Project Coordinator
- Ernest (Ted) Friers, Program Support Coordinator
- Bryana Wachowicz, Membership and Events Coordinator
- Dimicio Donley, Office Coordinator

LENDING LIBRARY

NAMI-FL maintains a lending library, adding to it as new books come in. If you would like to browse or borrow, call Jean Walters at (607) 273- 2462 or Carol Booth at (607) 272-6593 and we will arrange a time.

Jean Walters, Manager, NAMI-FL

Newest Library Books:

- Daughter of the Queen of Sheba, Jacki Lyden, 1997
- Surviving Schizophrenia, 5th Edition, E. Fuller Torrey, 2006
- Crazy in America – Hidden Tragedy of our Criminalized Mentally Ill, Mary Beth Pfeiffer, 2007
- Night Falls Fast: Understanding Suicide, Kay Redfield Jamison, 1999
- Rescuing Patty Hearst, Virginia Holmes, 2003
- I don't Want to Talk About It -- Overcoming the Secret Legacy of Male Depression, Terrance Real, 1998
- Touched by Fire, Kay Redfield Jamison, 1994
- Don't Call Me Nuts-- Coping with the Stigma of Mental Illness, Patrick Corrigan and Robert Lundin, 2001
- Recovery from Schizophrenia, edited by Hopper Harrison and Jane Santorino, 2007
- The Center Cannot Hold, Elyn Saks, 2007
- The Innocent Man, John Grisham, hardcover and audio, 2007
- Behind Happy Faces – Taking Charge of Your Mental Health, for young adults, Ross Szabo, 2007
- Telling is Risky Business – Mental Health Consumers Confront Stigma, Otto Wahl, 1999
- Crazy – A Father's Search through America's Mental Health Madness, Peter Early, 2007

- Lincoln's Melancholy – How Depression Challenged a President and Fueled His Greatness, Joshua Shenk, 2006

BOOK AND MOVIE REVIEWS:

Successful law professor Elyn Saks writes of her lifelong battle with schizophrenia in "The Center Cannot Hold: My Journey Through Madness". Intelligent, analytical, and articulate, Dr. Saks offers as full an understanding of the experience of schizophrenia as it seems possible to get without having the illness. She describes her symptoms, her decades-long refusal to believe that she is mentally ill, and her struggle to overcome schizophrenia with and without medication. She articulates the critical need for external structure to support internal stability, and illustrates her attempts to build structure for herself throughout her life, particularly through her work. Three major themes emerge: one is her aversion to taking medication, believing that she should be able to "will" herself well; this is partially a result of her unwillingness to believe that she is ill rather than "socially maladroit". A second theme is the value of "talk" therapy in understanding and managing her illness. And a third theme is the critical role that relationships, with her psychoanalysts, medical doctors, and close friends, played in her survival and recovery. This personal account of schizophrenia was extremely valuable to me in understanding the experience and the resulting behavior of family members with schizophrenia, and also in understanding the value of my role in the lives of my family members.

Deborah Grantham, NAMI-FL member

WE ARE SEEKING BOOK AND MOVIE REVIEWS. PLEASE CONTACT DEB GRANTHAM, 607-277-5148 OR DGG3@CORNELL.EDU WITH SUBMISSIONS.

EDUCATION

Family-to-Family Education Course

NAMI of the Finger Lakes is sponsoring its 7th Family-to-Family Education Course for family members and close friends of those individuals struggling with one of the Major Mental Illnesses.

Family-to-Family is a 12-week course, led by trained family members. Classes and materials are free.

Classes focus on the knowledge and skills family members need to cope more effectively and to help their loved ones manage their illnesses. The course covers the following illnesses -- Bipolar Disorder, Major Depression, Schizophrenia, Anxiety Disorders, Borderline Personality Disorder, and accompanying Addictive Illnesses.

When: Thursdays, beginning February 14, 2008 at 6:30PM

Where: TST BOCES Community School, 214 Elmira Rd., Ithaca, NY

Who: instructors Jean Poland, Janet Lynch with Joanne Denison assisting.

For additional information, call 273-2462 or 266-8079.

*****Class size is limited and registration is required.
Psychiatric Disabilities in the Workplace**

On October 12, 2007, Employment & Disability Institute of the Cornell School of Industrial and Labor Relations, the Employee Assistance Program, and NAMI-Finger Lakes held a workshop at the Cornell Cooperative Extension System Conference. *Psychiatric Disabilities in the Workplace* covered mental illness as a brain disorder and information on NAMI (Bruce McKee as speaker); the legal and human resources considerations, including the Americans With Disabilities Act; and the human experience (Carole Stone spoke about her personal experience).

The workshop was revised from a February 2, 2007, workshop held for Cornell Cooperative Extension (CCE) Administration on the Cornell campus.

CCE has approximately 1,700 employees in 56 county offices across the state and campus. The workshop drew 9 CCE employees from across the state, and was well received. We hope that it will be the basis for local work with businesses, already being undertaken by Carol Booth and Jean Walters.

Deb Grantham, NAMI-FL member

GUARDIANSHIP

In September, 2005, I took on new family responsibilities when my father became too ill to look after my youngest sister, diagnosed with mental illness. A few months after bringing my sister to live here with my husband and me, I became co-executor of my father's estate. The trusts that my parents had established were designed to protect my sister's assets in the event that she became hospitalized or had other major medical expenses. But as I

worked on the estate, I came to realize that those trusts only protected her assets while they were in trust, and that they likely would not be enough to support her for the remainder of her life. I began looking into ways to protect her inheritance, such as setting up a trust for her myself. I discovered that the only way I could protect her would be to become her legal guardian.

As I was caring for her and seeking services for her in the Ithaca area, I also realized that HIPPA and other confidentiality conventions prevented me from getting the information I needed to assure good care for her. My father had those old-fashioned personal relationships with Liz's medical providers in Connecticut that led to a good exchange of information. That wasn't going to happen here and now. Liz could sign releases, but she could also revoke them. Not likely, but my ability to advocate would still be quite limited. Guardianship again seemed to be the best answer.

I sought local legal counsel and began the process of gaining guardianship. We decided that I would seek guardianship of both her personal and financial concerns. I provided a great deal of personal information about Liz to my attorney. At times, it was quite painful, both revisiting some of her incapacities and revealing them. I worked with our other sister to make sure that she agreed to the process and decisions, and to be designated as the back-up guardian. She agreed with the understanding that I would consult her about major decisions in Liz's treatment. That worked for me, because I didn't want to do this alone and because Nori is a nurse.

I also talked to Liz a good bit about the process and the reasons for doing it. She is very trusting of me, which is an honor, and a responsibility. She had some reservations and we addressed those in the petition for guardianship, namely that she can choose her own friends and associates without my intervention or approval. She's far too savvy to need my guidance in that arena.

We filed a petition for guardianship of person and property in Tompkins County Supreme Court, whereupon (see what it did to me!) Liz was assigned an attorney who met with her some weeks prior to a hearing that was held in the TC Supreme Court. Liz liked him, he listened to her reservations, and we proceeded to a hearing.

The hearing was extremely painful, in that I had to answer questions very frankly, describing incidents that exemplify her lack of ability to live on her own or manage her own assets. We thought that since neither Liz nor the State disputed the petition, that we would not have to go through that. I relived that hearing for weeks, every night when I went to bed, cringing over what I had to say about her in public.

Finally, it was over. Not long after the hearing, I received the official notice of guardianship of person and property. It gave me the right to get information from her medical providers, as well as to share information. I can seek services for her on her behalf. I can manage her finances. I immediately set up a guardianship account that can receive her inheritance. As guardian, I have full control over that account, essentially a trust, and over her finances, but with oversight by the State. I did have to file an initial report and have to file an annual report on the services I've

gotten for her, her health, and her assets and income. I have to account for every penny in that annual report.

The process was costly and somewhat painful, but the peace of mind is well worth it. I would be happy to talk to others about my experience in more detail. NAMI-NYS has more information at <http://www.naminys.org/future.htm>.

Deb Grantham, NAMI-FL member

COMPOS MENTIS

Compos Mentis, Working Toward Wellness, has completed a successful first season on an organic farm next to the Cayuga Nature Center. The mission statement – “Compos Mentis helps adults learn to live with a mental illness, and ease the transition back to school or work by working with others, caring for living things, and sharing their experiences” – has been a guide throughout the first year.

This past spring, summer, and fall the program attracted seven apprentices and about 35 volunteers, some of whom went through profound changes in the process of transforming the fallow farm into a productive one. From the first annual report:

We grew more than 50 different fruits, vegetables and herbs, collected 2,145 eggs from our laying hens, engaged in a variety of afternoon activities, casual conversations and structured discussions, and invited family and community members to biweekly dinners. Apprentices learned to prepare and preserve the food they grew, build with wood and wire, design and paint a mural, bind journals, make soap, and more. They practiced

meditation and Pilates. Three of them accomplished educational goals. And all of them expressed satisfaction with the program, although it was not an ideal fit for two of them. In its first year, the growth of the program was robust, and this has created new opportunities.

Our seven apprentices came with a range of diagnoses, abilities, and interests. Their illnesses included histories or symptoms of depression, anxiety, panic, compulsive thinking, schizophrenia, schizoaffective disorder, attention deficit, mood and eating disorders. All of them experienced social isolation as a result of illness. Compos Mentis was for them a place to go and a way to structure time. They came to be with people who have similar experiences.

There was consensus among apprentices that taking care of living things (plants, animals and people) was very helpful in focusing on things other than themselves; and they are more accepting of the fact that they are living with a mental illness. Some but not all reported that Compos Mentis was a big help in developing realistic goals for the next steps in their lives. There was agreement, too, that being with others in a safe and supportive environment was important, and that they enjoyed being outdoors.

Our clearest challenge in the next few years is to grow in the right directions and at the right pace. We began as a seasonal program for lack of year-round quarters. This was fortunate, for it allowed us to start on a small scale. However, to be more effective as a place where people can come to terms with mental illness and ease their transitions back to school or work, we need to be available to them when they need us, at any time of the year. This would require new facilities and a more diversified work program.

In the immediate term, we enter the 2008 season eager to hire an assistant program coordinator, work more closely with volunteer staff, involve the families of apprentices in meaningful ways, improve the farmstead, and continue to welcome apprentices who request financial aid. We have a good idea, from apprentices' evaluations and staff and volunteers' observations, where the strengths and weaknesses of our program exist. We will address these in this second season.

Comments from Susan Larkin, a NAMI member, Family to Family teacher, and Compos Mentis volunteer: I worked at the farm one day a week through the summer and fall. Work varied with the seasons and I enjoyed conversations with apprentices on topics that interested them. We reviewed class notes, talked about Photoshop, photography, and learned new skills - from pickling Brussels sprouts to making soap. I hope to volunteer again next season and learn more - from other volunteers, from the staff, and especially from the apprentices. We have much to share and learn from each other.

If you would like to be on the Compos Mentis mailing list, would like to know more about the volunteer program, or how to make a donation, please let me know – Susan Larkin, SCL8@Cornell.edu, 607-539-7299.

If you would like to know more about the program, information is on the website: <http://composmentisithaca.org>.

Susan Larkin, NAMI-FL member