



### Letter from a Co-President

What a good year we have had—busy and productive! Since the last Newsletter in February, our local affiliate has become incorporated and has confirmed its I.R.S. Tax Exempt Status, allowing us to apply for grants to do more of our good works. We held our 5<sup>th</sup> Family to Family Class, taught by Ann Carter, Joanne Denison, and myself, and graduated 22 participants—the largest ever. Now we have more wonderful friends and new members to add to our group.

We applied for a mini-grant from NAMI-NYS and just received a check for \$1100 to be used for operating funds. We are hoping to sponsor another fund raiser sometime later this year.

We had a special program in May, organized by Susan Larkin, about Special Needs Trusts and Guardianships. Thanks to Tom Witmer of MetDESK for an excellent presentation.

I have been asked to be on the Lakeside Nursing Home Advisory Council for its new Behavioral Services Unit. Beth Jenkins from the Mental Health Association and myself were asked to meet with Pat Deptula, the Administrative Director, and Rebecca Norman, Community Outreach, to help evaluate a new training manual that Lakeside has proposed.

We have been collaborating with like-minded agencies in the community—Loaves and Fishes, Unity House, Family and Children’s Center, Lakeside, C.M.C. Psychiatric Care Unit, etc. This is good for our organization since it increases our visibility in the community, and strengthens our standing among the other non-profits.

I hope that this Fall will bring more community outreach with our information table at the county library at the end of September, an *In Our Own Voice* presentation by Rachel Greco from NAMI-NYS, and our Schizophrenia Simulator event in mid October. We are exploring a possible collaboration with Cornell’s student group, “Minds Matter”, sometime next Spring.

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We hope to begin talking about a major fund raiser, and to continue our collaboration with the hospital on family support groups and welcome folders for families.

I hope I can entice NAMI-FL members to attend the NAMI-NYS Education Conference at the beginning of November, being held in White Plains. We need representation. Besides, this is a magnificent conference.

Let’s continue our strong support for the wonderful work of NAMI of the Finger Lakes—with the support of all of you, we can educate the community and erase stigma, improving the quality of lives for those we love.

Thanks.

*Carol Booth*

Many thanks to Carol for a job well done!

*Jean Walters and Susan Larkin*

### **Fifth Family-to-Family Education Course**

NAMI-Finger Lakes completed its fifth Family-to-Family Education Course. The course—taught by Carol, Ann, and Joanne—ran from March 1–17, and had a record 22 students.

Family-to-Family will be offered again this Spring, probably starting in late February. Class size is limited to 20 people, and pre-registration is required—call 273–2462 or 272–6573 for more information.

Anyone who has already taken the Family-to-Family class and is interested in becoming a teacher or support person for future classes should call Jean Walters at 273-2462.

### **Talks With Cornell Sociology Class**

On April 26 NAMI-FL co-president Bruce McKee gave a talk on “Mental Illness as a Family Stressor” to one hundred undergraduate students of Cornell’s “Families and the Life Course” (Human Development/Sociology 250). Bruce discussed how major mental illnesses affect families, and how families are forcing the U.S. mental health care system to change.

Course instructor Dr. Kristi Lekies invited our co-president because the course textbook did not contain any information on how mental illness impacts families. Dr. Lekies was pleased with the presentation, and sent us the following note:

“I wanted to thank you again for coming to speak to my class this spring. The semester is now over, and a number of students commented on their evaluations how interesting your presentation was. I learned a great deal and have a much greater appreciation for the challenges faced by families dealing with mental illness. You were realistic, but also hopeful”

### **“Out of the Shadow”**

At the invitation of Sandra Ferreria from Loaves and Fishes, Jean Walters, and David Bulkley from the Tompkins County Mental Health Association attended a dinner, and then responded to questions about the video *Out of the Shadow* at the Tompkins County Public Library. Nearly twenty people attended.

### **We Become a Not-for-Profit Corporation**

NAMI-FL owes a big thank you to co-president Bruce McKee, who devoted an incredible amount of time and effort to achieving not-for-profit status for our organization. Below is a short summary of who we are, which can be found on our web page: [www.namifingerlakes.org](http://www.namifingerlakes.org). NAMI-FL owes Bruce thanks also for his work on putting the web page together and keeping information on it current. Thanks—and offers to help with the web page—may be sent to Bruce at [bwmckee@twcny.rr.com](mailto:bwmckee@twcny.rr.com).

*Susan Larkin*

NAMI-Finger Lakes—a New York State not-for-profit corporation—was granted IRS 501(c)(3) status on July 19, 2006.

Our new 501(c)(3) status brings many benefits to NAMI-Finger Lakes:

- We have additional credibility in the eyes of community;
- We can now write grant applications to fund our educational and outreach activities;
- People who donate money to us can write it off on their taxes;.
- We are exempt from federal taxes (the effective date is March 26, 2006).

We give special thanks to NAMI-NYS, which sponsored a special low-cost program that helps local NAMI affiliates like ours obtain both New York State not-for-profit status and IRS 501(c)(3) status.

We also thank Sean Moran (NAMI-NYS) for organizing this program; paralegals Jennifer Lockwood and Melissa Mackey for helping us with the forms and paperwork; and Attorney Michael West of the Council of Community Services of New York State for shepherding the paperwork through the state and federal systems.

Now that we have the federal 501(c)(3) status, we are applying for New York State tax exemption, and we hope to have this completed before Christmas.

### **On-line Video and Audio**

We have recently discovered a number of on-line radio and video programs about mental illness. These high-quality productions are an excellent and free way to educate family and friends about mental illness.

There are links to them in the Events section of our [www.namifingerlakes.org](http://www.namifingerlakes.org) website. Note that you'll need a fast Internet link to comfortably run the videos.

*Reaching Out.* This excellent on-line video was produced by the Schizophrenia Society of Canada. It intertwines two stories—a dramatization about a high school student developing schizophrenic symptoms, and a series of interviews with adults who have learned to successfully manage their illness.

The film's purpose is to educate students (and adults) about the early warning signs of schizophrenia; the importance of early diagnosis and treatment; and that there is hope for recovery and a full, productive life. The video is approximately 22 minutes long, and the web page includes instructional material for teachers.

*Living with Manic Depression.* This is a 49-minute N.P.R. *Talk of the Nation* interview conducted by Jacki Lyden with psychiatrist Dr. Kay Redfield Jamison. Ms. Lyden talks about growing up with a mother diagnosed with bipolar disorder, and Dr. Jamison discusses how her bipolar disorder has affected her personal and professional life.

*Dark Glasses and Kaleidoscopes: Living with Manic Depression.* This is a 33-minute video about bipolar disorder (manic depression). It includes interviews with people in recovery, and dramatizations of how the illness affects both the ill individual and the family. Note that this video starts a bit slow, but gets better as it goes along.

### **Need for Support**

Due to extended efforts at publicity, well-attended Fall programs, and the yearly offering of the Family-to-Family course, NAMI-Finger Lakes is receiving many inquiries for help and information. Expenses will be rising as our visibility continues to increase. Although dues to a non-profit do not count as a charitable donation (we've checked), all donations beyond the yearly dues are now officially tax deductible. If you can offer financial assistance, checks should be made out to NAMI-Finger Lakes and mailed to

NAMI-Finger Lakes  
104 E. Lewis Street  
Ithaca, NY 14850

Dues—\$25 per person and \$35 for a family—for our local group are due in January. Checks should be made out to NAMI-Finger Lakes and mailed to the office at the address listed above. Note that we can waive dues for individuals and families with challenging financial situations. Please call the office at 273-2462 if you have any questions.

### **Support Group**

Our support group continues to be well attended by six to twelve people each month. We meet the first Tuesday of each month, year round at Jean Walters' home at 104 East Lewis Street from 7:00 to 9:00 p.m. All family members, relatives, and friends of people with major mental illnesses are welcome to attend. However, we suggest that you meet at least once with Jean Walters, the support group coordinator, before attending the established support group. If you'd like to set up such a meeting, please call 273-2462 and leave a message. The next meeting will be on October 3.

Respectfully submitted,

Jean M. Walters

### **Good News**

On July 11 the city of Ithaca's Board of Zoning Appeals gave unanimous approval for converting Verle's physical therapy office to the NAMI-Finger Lakes office. It took six months to accomplish but was well worth the effort. Now 104 E. Lewis Street is officially recognized as our office.

Respectfully submitted,

Jean M. Walters

### **Fall Education Program**

This year's Fall Education Program, (September 18 through October 19), is themed around "Empathy—What is it like to live with a mental illness?"

Our goal is to educate ourselves and the Ithaca community about how mental illness affects the lives of our loved ones, the challenges they face in living a normal life, and their courage in persevering against personal pain and societal stigma.

NAMI-Finger Lakes will host three education programs (described in the next three articles) in support of this goal: an information table at the county library, a talk by Rachel Greco as part of the *In Our Own Voice* series, and a virtual-reality simulation of the effects of schizophrenia.

## At the Tompkins County Library

Through the efforts of Joanne Denison, a special table will be on display at the Tompkins County Library during the weeks of September 18–29. Information, booklets and brochures with information on mental illnesses will be available and free to the public.

## In Our Own Voice

Our Mental Illness Awareness program begins with a talk by Ms. Rachel Greco on living with mental illness. Ms. Greco is the Program and Outreach Manager for NAMI New York State. She will talk about how bipolar disorder has affected her life, and the challenges she faces in managing her illness while maintaining a successful personal and professional life.

Ms. Greco is giving her talk as part of NAMI's *In Our Own Voice: Living With Mental Illness* program, an education program that encourages mental health consumers to become actively involved in education about severe mental illnesses.

Rachel's talk will begin at 6:45 p.m. on Tuesday, September 19 at the Borg Warner Room East, Tompkins County Public Library. The talk is free and open to the public; refreshments will be served; and NAMI-Finger Lakes will have an information table set up in the lecture hall.

## Schizophrenia Simulator

Empathy is defined as "feeling concern and understanding for another person's situation and feelings".

However, it can be difficult to empathize with our ill relatives because we would have to have a mental illness to truly "walk a mile in their shoes".

However, with one major mental illness—schizophrenia—virtual reality technology can give us a hint of the unquiet and disturbing world of untreated schizophrenia.

October 17–19 we will sponsor showings of Janssen Pharmaceutica's Schizophrenia Symptom Simulator to families, police, social workers, doctors, and the general public.

The simulator is a virtual reality machine that uses a computer, video goggles and headphones to simulate the frightening auditory and visual hallucinations associated with untreated schizophrenia.

Janssen originally developed the simulator to help doctors appreciate the difficult inner world of their schizophrenic patients. The simulator was developed in close consultation with individuals suffering from schizophrenia, and it simulates the paranoia and the visual and auditory hallucinations that they experienced before treatments brought their symptoms under control.

By showing this to Ithaca residents and officials, we hope to generate empathy for the challenges that people with schizophrenia face in living with their illness—and admiration for their bravery.

N.P.R. did an excellent story on the simulator. You can listen to it at [www.npr.org/programs/atc/features/2002/aug/schizophrenia](http://www.npr.org/programs/atc/features/2002/aug/schizophrenia).

Because only one person can use the simulator at a time, we ask that you make a reservation by contacting the event coordinator, Bruce, at 257-7662 or at [bwmckee@twcny.rr.com](mailto:bwmckee@twcny.rr.com).

## Out-of-town Events

October 4: 9:00 a.m.–3:00 p.m. The NAMI Promise Educational Conference, *Community Intervention in Psychiatric Emergencies*, will be held at the Empire Room, New York State Fairgrounds, Syracuse. The registration deadline is September 25. Check the NAMI-Promise Web Site for more information at [www.nami-promise.org/events.html](http://www.nami-promise.org/events.html) or call (315) 487-2085. One of the speakers at this conference will be Terry Garahan, M.S.W., who will be talking about the Tompkins County Emergency Outreach Program.

November 3–5: The NAMI-NYS 24<sup>th</sup> Annual Educational Conference, *From Research to Recovery*, will be held at the Crowne Plaza, White Plains, NY. Check [www.naminys.org](http://www.naminys.org) for more info or contact Gina Bartosiewicz at (518) 462-2000, x208, or contact [gbartosiewicz@naminys.org](mailto:gbartosiewicz@naminys.org).

## More News From Albany

NAMI-NYS has had several legislative priorities on its agenda for a number of years—Timothy's Law, Boot the SHU (Special Housing Units in Prisons), and the housing waiting list—and this year, *finally*, all of these bills have moved closer to final passage. Just prior to the end of June, each of these bills moved through both the Assembly and the Senate. Another legislative priority comes from the problem of having sexual predators in our psychiatric



centers after they are released from prison. NAMI-NYS has additional concerns—housing, research, the 10% rate increase for providers of services, and to hold harmless the dual-eligibles as the new medicare drug system settles in.

Advocacy is tremendously important—crucial—for improving the quantity and quality of services for individuals with mental illnesses and their families.

Let me say a few words about the first three priorities I mentioned. New York is one of a few states that has no insurance parity law—which means that services and treatment for mental illnesses are still not treated the same as other physical illnesses. There are higher co-pays, lower limits on regular services and hospital stays, and little payment for needed medications. This is certainly discrimination. The Assembly passed an insurance parity law several years ago, but the Senate has refused, until this summer.

For too long prisoners struggling with severe mental illnesses and who cannot abide by the prison rules have been put into solitary confinement (special housing units) where they decompensate tremendously and quickly. NAMI-NYS has pushed for elimination of this practice for years and now both the Assembly and Senate have passed a bill.

The housing waiting list bill—long overdue and implemented many years ago for the mental retardation and developmental system—also passed both the Assembly and the Senate. This bill would allow for accountability in the housing availability system.

Now Governor Pataki has vetoed both the legislation to ban the use of solitary confinement for prisoners with psychiatric disabilities and the legislation to establish a mental health housing waiting list.

The Senate is expected to return to Albany September 15. Mental health advocates are hoping that the Senate will use this opportunity to address a number of issues of importance to New Yorkers living with psychiatric disabilities. We are hopeful that the Senate will pass the version of Timothy's Law that they agreed on with the Assembly at the end of the legislative session in June. At this time, the Assembly has not publicized any date to return to take up this important measure.

Therefore, we are encouraging everyone to contact their Senator before the Senate returns to Albany. Please tell your Senator that you want him to pass Timothy's Law. Tell your Senator to override Governor Pataki's vetoes of the following bills:

(A.3926-a / S.2207-c) to "Boot the SHU" by banning the use of solitary confinement for prisoners with psychiatric disabilities and making prisons safer;

(A.2895-a / S.3653-a) to establish a mental health housing waiting list.

You can contact your Senator's office by calling the Senate switchboard at (518) 455-2800 and asking to be connected with your Senator's office.

### **Lost and Found**

We have a beautiful serving bowl and a slotted spoon at Jean's house. They were accidentally left after the picnic. Give us a call if you think in might be yours. 273-2462.

### **Brochures**

We have new brochures and would like help distributing them. I will leave a pile on Jean's side porch (104 E. Lewis Street, Ithaca), and you can always contact me about this matter at 272-6573.

*Carol Booth*

### **The Andrea Yates Verdict**

A statement by Michael J. Fitzpatrick, M.S.W., Executive Director, National Alliance on Mental Illness, July 26, 2006.

"Justice has been served by the finding of a Texas jury today that Andrea Yates is 'not guilty by reason of insanity' (N.G.R.I.) in the tragic deaths of her children five years ago.

"Too often, tragedies are only compounded by tragedies. In this case, the National Alliance on Mental Illness (NAMI) trusts that Andrea Yates will get the treatment she needs in a secure and appropriate psychiatric hospital. Even if she is released at some future point in time, she will likely be subject to continual court monitoring.

"Andrea Yates was sick. We praise the jury for recognizing that fact.

"NAMI hopes the two trials and ultimate verdict in the case have contributed to a broader public recognition and understanding of severe mental

illnesses, particularly postpartum depression, psychosis, hallucinations, and delusions.

“N.G.R.I. defenses are rarely raised and rarely succeed. The criminal justice system usually is ill-suited to address issues involving mental illness as it tries to impose legal logic on biological irrationality.

“Human tragedies must lead not simply to individual trials. Broader inquiries are needed, particularly to determine where the mental health care system may have failed prior to those tragedies that do occur.

“Whatever else happens to Andrea Yates, her children will have died in vain, unless we as a society address that fundamental concern.”

### Premonition

*It began in the cacophony of the O.B. ward;  
My angel came to me, all softness and dimples.*

*So unprepared was I for motherhood  
A dream eclipsed the reverie of her first day:  
A nightmare train snatched her from my arms,  
into the creaking wheels.*

*Awakening, came the boundless tears and sudden fear  
Oh, God, I can't abide so precious this new love!*

*Fairest, most beautiful, my silver angel grew  
Showering delights like snowflakes with each new gift  
Lovely, through the early growing years.*

*And yet, the recurrent doubt, the cry—  
Oh, God spare me in my vulnerability;  
Anticipating, and later remembering the  
Heartbreak of patience too short—the hand too swift.  
The foibles of a mother too young to treasure  
all the moments.*

*Only much later, the fear realized  
In a way too cruel to predict,  
Too soon the bonds cut with harsh words, swift blows.  
A turn of events agonizing to endure.*

*My angel turns on me with devastating verbiage and  
hopeless disobedience.  
Too soon she flees to others unworthy of her gifts.*

*And naught to do but watch, despair  
And suffer beyond endurance of the soul.*

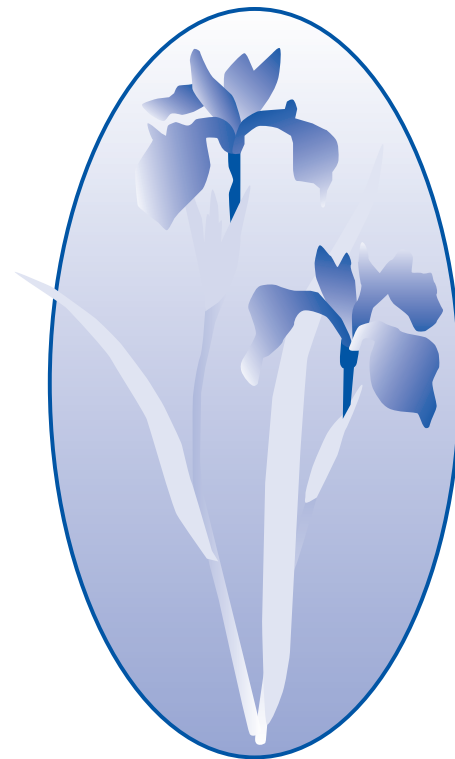
Anonymous

### newlife.com

A web site that I have found most helpful is [newlife.com](http://newlife.com). It has a wealth of information on topics such as depression, anxiety, mood swings, health & wellness, and relationships. This Christian web site offers encouraging and practical tips on how to deal with emotional struggles. Whether you are helping a loved one with mental illness, or need help dealing with stress, I recommend this site.

Stella M. Sill

horselover3@usadatanet.net



## NAMI-FL Calendar

[Times in *italic* are A.M.]

Date	Time	Location	Event	
September				
5	7:00	104 E. Lewis Street	NAMI-FL Support group	If you haven't come before, call Jean Walters at 273-2462
18–29		Tompkins County Public Library	Table with information on mental illness	
19	6:45.	Borg Warner Room Tompkins County Public Library	<i>In Our Own Voice</i>	
October				
1–7			This is Mental Illness Awareness Week	
3	7:00	104 E. Lewis Street	NAMI-FL Support group	If you haven't come before, call Jean Walters at 273-2462
4	9:00 –3:00	NY State Fairgrounds	NAMI Promise Educational Conference	See article on page 4.
17	6:00 –9:00	104 E. Lewis Street.	Schizophrenia Simulator	NAMI members, support group members, and Family-to-Family graduates are especially encouraged to attend at this time.
18	10:30 –9:00	Borg Warner Room Tompkins County Public Library	Schizophrenia Simulator	For media, law enforcement, social and mental health workers, and attorneys.
	5:00 –9:00	Borg Warner Room Tompkins County Public Library	Schizophrenia Simulator	For the general public.
19	10:30 –3:30	Cayuga Medical Center and other locations.	Schizophrenia Simulator	For doctors and nurses.
November				
3–5		Crowne Plaza, White Plains	NAMI-NYS 24 <sup>th</sup> Annual Educational Conference	See article on page 4.
7	7:00	104 E. Lewis Street	NAMI-FL Support group	If you haven't come before, call Jean Walters at 273-2462
December				
5	7:00	104 E. Lewis Street	NAMI-FL Support group	If you haven't come before, call Jean Walters at 273-2462

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