2014 EDUCATION CONFERENCE

NOVEMBER 14-16
Desmond Hotel and Conference Center · Albany, NY

Lisa Dixon, MD, MPH,
Director, Center for Practice Innovations, New York State Psychiatric Institute

Marvin S. Swartz, MD,
Professor in Psychiatry and Behavioral Sciences, Division Head, Social and Community Psychiatry, Duke University

Lloyd Sederer, MD,
Medical Director, New York State Office of Mental Health

Mike Veny,
Director, Transforming Stigma

Major Sam Cochran, Ret.,
University of Memphis

Delbert G. Robinson, MD,
Associate Investigator, Center for Psychiatric Neuroscience, The Zucker Hillside Hospital

A Publication of the National Alliance on Mental Illness | New York State
President’s Message  By Irene E. Turski

It is with sadness and gratitude that we say good bye to our past NAMI-NYS president Tom Easterly, who resigned from the Board in April. With his insight and compassion, we will miss his leadership.

After an exhaustive search, we welcome our new Executive Director Wendy Burch who comes to us with a wonderful resume of accomplishments and leadership skills. I look forward to the team approach necessary to run a successful and dynamic organization.

It has been a year so far filled with tragedies and triumphs. As president of NAMI-NYS, I see one of my most important jobs is to try as best I can to unite all NAMI-NYS members to move together in the future. We all have our individual stories, history, and agendas, but we need to be respectful to other’s views and beliefs. We need to open ourselves to the ideas and suggestions from all our members to ensure a strong and effective organization.

One of our crowning jewels is our wonderful signature programs. With the ever shrinking funding all mental health organizations are experiencing, we need to aggressively campaign and fundraise not only to keep the current schedule but to increase availability for our programs.

We are a grassroots organization that started as a family movement and have evolved to include the loved ones we have worked so hard to help. This is the united NAMI I hope to represent.

All encompassing support, education, and advocacy for all our members. We need to have our voices heard not only by the medical and mental health community but by every group that touches the lives of people with mental illness. We need to advocate to our legislators and let them know of deficiencies we see and experience.

With the Office of Mental Health’s Centers of Excellence, we are all very concerned how the people we love with mental illness will be treated and prioritized. While we all know more community housing with support services are needed, let’s not forget how important it is to first stabilize our loves ones. They must have the inpatient hospital beds and mental health professionals ever present to be sure whatever treatment course and medication is given, the appropriate amount of time necessary is allotted. Too many times, (sometimes with family members protesting) they are sent out into the community too early and not stabilized. How odd when you consider a hospital would never release a heart or cancer patient into the community while still unstable. As family members, there is nothing we would love more than to have our loved ones out in the community, living their lives as unrestricted as they possibly can BUT... we will not compromise the mental and physical health of our loved ones to save money. Ironically, in the end, because many people are not given the necessary time to stabilize, they go through a revolving door of emergency hospital visits, homelessness, or arrests, and the biggest sin is, every time it happens, they may never come back mentally or physically to us the way they were due to further brain damage. This is not the most humane approach to our most vulnerable population. We must also prioritize the often forgotten people with SMI who do not advocate for themselves due to their condition.

I encourage all NAMI members to please email, write or call me to let me know your concerns or ideas regarding the future of our organization. It is only through open dialogue that we will succeed.

NAMI is here to protect and empower our loved ones and the communities we love. We cannot allow funds to be diverted away from the people who need it most. We are NAMI, we are united, we are strong and we will continue to aggressively advocate for the basic rights our loved ones are entitled to have.

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Executive Director’s Message By Wendy Burch

By the time this issue of the newsletter goes to press I will have been in the executive director position for two months. In that time I have had the opportunity to both attend a few local events here in Albany and to begin to visit the affiliates. Over the next few months I am looking forward to traveling throughout the state and meeting as many of our members as I can. I applaud the outstanding work I see going on, and I ask that our affiliates continue to keep our office informed of your activities so we can ensure that we are relaying the news of all your great work throughout the state.

The NAMI New York State office is busy planning an informative and productive Educational Conference, this year’s title being United We Stand: Shaping Our Future. I believe those of you who are able to attend the conference will find it worthwhile, and I hope you will join us in Albany November 14-16.

A little personal information about myself: after growing up in Connecticut and attending college in New York, I was commissioned as an officer in the U.S. Army. I had the opportunity to serve with some really exceptional men and women both in the United States and abroad. I completed my last Army assignment in 2003 and resigned my commission, settling in the Albany area. Since 2007 I have worked as the executive director of the county historical association. Like many of you, my life has been touched by mental illness, and I empathize with the individuals and their families living with it.

I hope you enjoy this issue of the newsletter. As a reminder, our e-news goes out weekly, and if for some reason you are not signed up to receive it, please contact the NAMI-NYS office. We are also on Facebook and Twitter, and I urge you to follow us on both to receive useful and timely information.

Have a great summer and I hope to see you all, if not during my travels around the state, then certainly at the Educational Conference in the fall!
Support NAMI-NYS through the State Employees Federated Appeal (SEFA) Campaign

The SEFA campaign allows NYS employees to designate a portion of their paycheck to be automatically donated to a charity of choice.

NAMI-NYS’s SEFA Number is: 999-00281

If you are a NYS employee please designate NAMI-NYS as your SEFA charity. If you have friends or family who are NYS employees please ask them to designate NAMI-NYS as their SEFA charity.

Community Public Service Program

We are very grateful to be participating in the Community Public Service Program through the State University of New York at Albany and to be spending it with NAMI-NYS. During the semester, all three of us have spent time individually and cohesively working on projects to directly benefit the NAMI-NYS community. Alongside Stephen Oby Jr. as our program leader, we aided non-profit affiliates to help organize their public programs and learn how they advocate for mental illness awareness. Our time with this program has given us greater knowledge of the professional settings of an office and most importantly NAMI-NYS’ contribution to the community.

Intern and Volunteer Photos and Bios

We thank the excellent team of interns and volunteers who have worked with us during the previous semester.

Caitlin Andreone – Caitlin attends the Sage College of Albany as a Business Administration major. Caitlin has helped keep email lists and the NAMI-NYS Facebook page up to date as well as helping with preparation for the education, legislative, and children's mental health conferences.

Ginai Prosper – Ginai is a senior psychology major at Siena College. She currently works along with Christine Rickeman at the Helpline and has also assisted with preparation for elections and conferences.

Karina Vega – Karina is joining us from the Albany Leadership Charter High School and is currently in her Junior year. Karina is working with NAMI-NYS to fulfill her service learning hours needed to graduate. During her time with us she has helped with clerical work in the office.

Christine Earl – Joining us from Bryant and Stratton College, and is currently working towards a degree in accounting, Christine worked with Sharon Clairmont, acquiring on the job skills and credits for her accounting program.

Laura Poulard – Laura is in her Junior year at the University at Albany as a Psychology major. She began interning at NAMI-NYS in the Spring semester assisting with the Helpline.

Sarah Wagoner – Sarah attends Mercy College in Dobbs Ferry NY as a senior. She is majoring in Psychology. Sarah volunteered with NAMI-NYS for the Summer.

Caity Gallagher - In her Senior year at the University at Albany, majoring in Psychology and Music, Caity volunteered with us over the summer.
**NAMI Syracuse**  By Karen Winters Schwartz

NAMI Syracuse held their 3rd annual Children’s Conference: Navigating Early Intervention Programs and Services for Children at the Rosamond Gifford Zoo on May 14. While eighty attendees settled in with their coffee and juice, John Wohler, PhD gave an informative talk on eating disorders. This was followed by a moving message of hope and recovery by Tanisha Wiggins and Katrina Castro. The morning ended with a well-received discussion by Stephan Glatt, PhD regarding the Breaking the Silence program and the progress NAMI Syracuse is making getting it into our local schools. The afternoon kicked off with an update on country and state services, and ended with an introduction by Seetha Ramanathan, M.D. and Julie Aspenleiter, Psy.D of an aspired and much needed Early Intervention First Break Program. Plans are already in the works for next year’s conference.

**NAMI Putnam**  By Lorraine Bushnell

Over 100 participants joined the NAMI Putnam affiliate on May 10th for their first Mental Health Awareness Walk. Karl Rohde, Director of Putnam County Veteran Services Agency led the pledge of allegiance and spoke about veterans suffering from depression and PTSD. Mary Ellen O’Dell, County Executive, and Andrew Katz, Assemblyman, James Reitz, County Judge for the mental health court, and Michael Piazza, County Commissioner for Mental Health, Social Services and Youth Bureau also joined the other supporters during this event. Judge Reitz thanked Bushnell and NAMI for its dedicated work: “It’s all about helping people. The court system must stress helping people get better rather than throwing them in jail. People deserve a second chance. My court philosophy has always been: ‘Let’s help instead of hurt!’”

**NAMI Cayuga**  By Terri Wasilenko

Partnered with the Cayuga Community College and Partnership for Results to hold a free depression screening during the campus ‘wellness week.’ This is a bi-annual event held at the college is in its third year and allows students to interact with therapists and receive referral information available for participants. Helped to facilitate Nothing to Hide: Mental Illness in the Family photo-text exhibit. This week long exhibit was held at the Weedsport High School along with educational materials on mental illness. The exhibit showed twenty photographs with accompanying texts were set up for middle and high school students to view. Educational materials were also provided for the students.

**NAMI Rensselaer County**

Held an informational night at the local library, providing materials on county resources and other local supports for individuals and family members.
NAMI Walks in Westchester
By Jennifer Jacquet-Murray

The NAMI Walks Westchester took place on Saturday May 17th and was a wonderful community event benefiting NAMI Westchester and NAMI FAMILYA Rockland. After days of torrential rains and flood warnings, the sun came out on Saturday morning just in time for the family friendly activities, inspirational speeches and gorgeous walk along the famous Rye Playland Boardwalk. The fundraising has already brought in over $94,000 and we are well on our way toward our goal of $100,000. We had over 450 people at this event, which increased awareness about mental illness and raised funds for the essential programs that both of our NAMI affiliates provide. This event wouldn’t have been possible without our partnership with NAMI FAMILYA Rockland and the combined efforts of our members, friends, mental health organizations and those people from our communities who care about ending the stigma of mental illness. We had a great time celebrating our fundraising efforts and it was a fantastic way to bring our community together during mental health awareness month.

NAMI Walks Long Island/Queens By Janet Susin

On Saturday, May 3, NAMI Queens/Nassau and other participating local affiliates, Central Suffolk, Huntington, Long Island Regional Council, Nassau University Medical Center, and North Shore walked at beautiful Jones Beach to raise awareness about mental illness and funds to support our programs and services. We were blessed with glorious spring weather, a wonderfully supportive crowd, and an outpouring of support for a cause that means so much our loved ones and our families. So far we have raised close to $230,000 and are hopeful that we will reach our goal of $250,000 when our NAMI Walk fundraising ends on July 3.
Another Successful Year for NAMIWalks NYC  By Samantha Wiener

On Saturday, May 10, 2014 New York City was home to NAMIWalks NYC, the nation’s largest mental health event, organized by the National Alliance on Mental Illness of New York City (NAMI-NYC Metro). Thousands of New Yorkers gathered along the cobblestone streets at the South Street Seaport Promenade and walked proudly together across the Brooklyn Bridge for a common cause: to eliminate the stigma surrounding mental illness and raise mental health awareness.

This year, New Yorkers walked with a special purpose: to spread the word about NAMI-NYC’s anti-stigma campaign #IWillListen, which features thousands of individuals who have pledged to listen to those impacted by mental illness and shared this promise among their social networks. #IWillListen recognizes that in order to effectively combat the stigma surrounding mental illness, we must not rely solely on the 1 in 4 Americans who will experience a mental health disorder in a given year to speak out, but we must call all Americans, the 4 out of 4, to create change.

NAMI-NYC was honored to have Health Commissioner Mary Bassett present at this year’s Walk. “If we expect to eradicate stigma, it is critical that New York City’s leaders make the commitment to speak out about mental illness and make it a priority public health issue. Dr. Bassett’s comments at the Walk were moving and showcased her understanding of the effects of stigma,” stated Wendy Brennan, NAMI-NYC Executive Director. Dr. Bassett and the other leaders in mental health that were present during the event, demonstrated to thousands of New Yorkers that mental health is part of overall health, and that New York City is committed to individuals and families impacted by mental illness.

This year’s Walk also featured a new addition: a 5k run. Given the enthusiasm of the nearly 80 runners pre and post-race, it looks like this is something NAMI-NYC will continue to host for future Walks. The Walk was followed by a wellness fair, with health screenings, massage, yoga—all free of charge—as well as raffle prizes.

“NAMIWalks NYC continues to fight the stigma of mental illness year after year, and ensures that help and hope are available for those in need,” said Brennan. “Our walkers are mothers and sons, friends and family, physicians and social workers—coming together to end the silence about mental illness and raise funds for our no-cost programs that have the power to change lives.”

2nd NAMIWalks Rochester – STOMPING OUT STIGMA!  By Lindsay Chambers

ROCHESTER, NY - NAMI Rochester and The Village Gate welcomed over 1,000 people and over 60 Teams to the Village Gate Saturday, May 17th for the 2nd NAMIWalks Rochester!
NAMI Rochester joined, for the 2nd year, over 80 NAMIWalks nationwide to increase public awareness of mental illness. Over $107,000 has been raised to date with donations still coming in!

The 1.5-mile Walk began and ended at the Village Gate, located in Rochester’s Neighborhood of the Arts. This FUN community event was a celebration! We invited and urged the entire community to come together to raise awareness, combat stigma, honor those who lost their lives to mental illness and celebrate recovery!

Entertainment was provided by musical guests Mindscape, Les Femmes of Nik Entertainment and Young Audiences of Rochester. New York State Senator, Joseph Robach kicked off the Walk. Monroe County Office of Mental Health Director, David Putney read a Proclamation signed by County Executive, Maggie Brooks declaring, May 17th as NAMI Rochester Walk Day. Local sponsors included Stern Properties, Village Gate, Wegmans, Sunovion, Unity Behavioral Health and ABR Wholesalers.

Proceeds from the walk will support NAMI Rochester’s mission—to provide support, education, and advocacy to individuals and families of all cultural backgrounds living with mental illness, including schizophrenia, bipolar disorder (manic depression), major depression, obsessive-compulsive disorder and severe anxiety disorders. NAMI is a not-for-profit, grassroots, volunteer-driven organization that provides free educational and support programs in Monroe and surrounding counties and advocates on the local, state and national level for improved services and resources for those affected by mental illness.
It is with a heavy heart that we share with you the sad news of the passing of NAMI-NYS Founding President Muriel D. Shepherd on May 11th. Muriel was a true champion for bettering the lives of people living with a mental illness as well empowering their families. She is responsible for not only founding NAMI in New York State but also guiding us towards being the formidable organization we are today.

Muriel was a true visionary, whose tireless dedication allowed NAMI-NYS to become the provider of support, education and advocacy for families touched by mental illness in communities throughout the Empire State. Anyone who was lucky enough to work beside Muriel will always remember her for her fighting spirit, keen mind, as well her kind and generous heart. The whole NAMI-NYS family mourns her loss and we will always continue to uphold all that Muriel believed in and devoted her life to as well as working to fulfill her dream of eradicating the stigma of mental illness and finding a cure for our loved ones.

Of Muriel NAMI-NYS President Irene Turski says “I’m honored to be the latest in a lineage of NAMI-NYS Presidents that started with Muriel D. Shepherd. Muriel will always be an inspiration to me. Any New Yorker that has been impacted by mental illness owes Muriel a tremendous debt of gratitude. She was a pioneer who empowered families who had been marginalized by the mental health system and let us know that we are a vital part of the recovery team and that we have an integral voice in reforming the mental health system. Muriel's legacy will not die, because we will not let it. Though we are heartbroken from the loss of Muriel her spirit and determination will always shine brightly within NAMI-NYS and all the work we do in guiding her legacy.”

NAMI-NYS Consumer Chair John Coon, II (who was the recipient of the 2009 Muriel Shepherd Award) says “Muriel was a leader, founder and educator. NAMI has lost one of the best. She helped move a movement, one that has inspired me as a consumer of mental health services. Without our founders I don't know where I'd be today. I only wish I could have learned more from her. It's up to the rest of us to carry on, remembering our humble roots and dedication of our founders and thoughts of them that carry on today. All my love and fondness, your friend John.”

NAMI-NYS sends our deepest condolences to Muriel’s two daughters Sarah Shepherd and Althea Schoen as well as all her friends and family.

Please call the NAMI-NYS office if anyone would like to donate to NAMI-NYS in Muriel’s memory or the memory of their loved one.
NAMI Programs

NAMI on Campus

Our NAMI on Campus groups held several events over the past several months, and have helped to promote their group on campus as well as strengthen relationships with local NAMI-NYS affiliates.

The NAMI on Campus group at Syracuse University held their annual Love Yourself Campaign in February. This campaign encourages students to write a positive note about themselves and take a photo of it to display. The campaign was very successful this year and provided a lot of students the opportunity to learn more about the on campus group.

The NAMI on Campus group at John Jay College of Criminal Justice had a very busy few months as they participated in several events. The group gave presentations on youth social justice and facilitated “Text, Talk, & Act,” which engaged students in discussions on mental health issues among college students. The group also co-sponsored the showing of the movie ‘Dark Light’ and ‘Raise the Age: Long-term implications of trying children as adults in criminal court and how changing the law can improve future outcomes for youth.’

The members of this on campus group also collaborated nicely with our NAMI-NYC Metro to host an ‘I Will Listen Week,’ and participated in the affiliates’ annual NAMIWalk.

Finally, we’re happy to announce a new NAMI on Campus club at Lehman College. We welcome anyone who may be interested in starting a NAMI on Campus group to contact Andrew Chakmakas at the NAMI-NYS office.

NAMI-NYC Metro continues I Will Listen Efforts

NAMI-NYC Metro has continued its efforts with their ‘I Will Listen’ campaign which began last year, through several successful events. The anti-stigma campaign was designed to help facilitate a discussion around mental health and to promote nonjudgmental listening and peer support. The affiliate hosted their annual gala back in December with the theme of the event focused on the ‘I Will Listen’ campaign. With nearly 300 attendees the event was successful and attained a record high for participation. The gala featured actress, author, and mental health advocate Mariel Hemingway who hosted the event, with money raised to be used to support the funding of this campaign.

The campaign continued in April with the NAMI on Campus group at John Jay College of Criminal Justice. The on campus group became the sixth college to join the campaign as students tabled for a week to promote the project and engage students. Students received pins, stickers, and t-shirts (provided by NAMI-NYC Metro) and participants were also able to film their own ‘I Will Listen’ videos.

The most recent success of this campaign took place in Philadelphia’s famous Love Park on June 3rd. The city declared the day, ‘I Will Listen day’ as participants took photographs and pledges to listen in the fight to eliminate stigma of mental illness. Congratulations to NAMI-NYC Metro on their continued success with this campaign.

CIT interest at University at Buffalo

By Andrew Chakmakas, information provided by Kristin Adduci.

Congratulations to the Cheektowaga Police Department in Erie County for forming the first Crisis Intervention Team in Erie County. Chief David Zack of the Cheektowaga Police Department was able to secure the funding in order to train 25 officers in Crisis Intervention Team Training. Kristin Adduci from Suicide Prevention and Crisis Services and Lt Brian Gould from the Cheektowaga Police Department became certified mental health instructors through the Department of Criminal Justice Services, in order to deliver the training. Since the initial training in May 2013, a total of 45 officers have received the training including officers from the following departments, Cheektowaga Police Department, Town of Tonawanda Police Department, Town of Evan’s Police Department, Town of Lancaster Police Department, Orchard Park Police Department, Town of Tonawanda Police Department, State University Police Department (University of Buffalo), West Seneca Police Department and SPCA Peace Officers. As of part of their training, officers shadow staff from Crisis Services Emergency Outreach Program and learn valuable skills in assessment of mental illness, securing linkages, and follow up. Crisis Services was awarded several grants, which has allowed the agency to train officers and provide support to clients in the community. One of the departments that has completed the initial training is the State University Police Department at SUNY Buffalo. They recently sent 2 officers to be trained, and are looking to work more closely with Crisis Services to provide appropriate crisis intervention to people on the University Campus that suffer from mental illness. We wish these departments continued success and hope that the SUNY Buffalo University Police Department is able to move forward with their CIT Training.

NAMI-NYS Improves Online Outreach

We are proud to report that our online resources informing readers on NAMI-NYS, NAMI, NIMH, and other mental health related matters now reaches over 7,000 people. Through our weekly e-newsletter, Facebook, and Twitter account we are able to provide our subscribers with up to date information. Please follow us on Twitter @NAMINESWORK, or on Facebook at NAMI New York State. You can also join our weekly e-newsletter mailing list by contacting our office at 518-462-2000.
What’s Great in Our State

This year, NAMI-NYS expanded our activities celebrating Children’s Mental Health Awareness Week by co-producing two events.

First, on May 6th, NAMI-NYS and our coalition of mental health and children’s advocates partnered with the New York State Office of Mental Health to produce What’s Great in Our State—A Celebration of Children’s Mental Health Awareness. The event held at the New York State Museum honored people and programs who are addressing children’s mental health issues.

The event gave NAMI-NYS the opportunity to honor our NAMI Rochester affiliate for their exemplary work in offering NAMI Basics classes and giving Parents and Teachers as Allies presentations as well as their upcoming presentation to the New York State School Nurses Association Conference. The award was presented to NAMI Rochester President Pat Sine and Program Manager Donna Leigh-Estes. The other honorees were: ACE (Adverse Childhood Experiences) Think Tank; DECA Project in New York City Early Childhood Programs; Hackett Middle School Full Service Room; Montefiore’s Pediatric Behavioral Health Services; The OnTrackNY; and the Seneca and Tompkins County Early Recognition Screening Program – The Whole Child Checkup Initiative.

During the ceremony we were presented with a proclamation from Governor Cuomo declaring it Children’s Mental Health Awareness Week in New York.

The following day, NAMI-NYS and our partners participated in the Alliance of New York State’s YMCAs Healthy Kids Day. NAMI-NYS exhibited at the event held at the New York State Legislative Office Building, giving us the opportunity to educate legislators and their staff on children’s mental health awareness. As part of the event NAMI-NYS represented the coalition at a press conference with Assemblyman Felix Ortiz, former Chair of the Mental Health Committee and Senate Co-Leader Jeffrey Klein. At the press conference NAMI-NYS’s Matthew Shapiro explained that “there is no health without mental health and a healthy brain is vital to healthy children.”

A Brighter Day

The second annual “A Brighter Day” event took place on May 16th at Glennpeter Diamond Centre in Albany. The event which was hosted by NAMI-NYS members Bob and Evelyn Keplinger, is designed to raise both awareness of mental illness and funds to advance NAMI-NYS’s mission to provide support, education and advocacy for people and families impacted by mental illness.

NAMI-NYS member Jason Paden gave an inspiring presentation detailing his recovery from severe mental illness and then engaged in an informative dialogue with WNYT (the Capital Region’s NBC affiliate) News anchor Elaine Houston. Elaine asked many of the questions that we typically hear from the public who may not be as aware of the realities of mental illness. Elaine also inquired about the role Jason’s family played in his recovery. Audience members also posed questions to Jason, who deftly provided answers as they related to his personal journey to recovery, while making sure to constantly stipulate that recovery is different for everybody. For many attendees Jason is now the face of mental illness. NAMI-NYS is grateful to have so many articulate In Our Own Voice presenters who are changing people’s perception of mental illness throughout New York State.

The event grew in its second year with attendance from NAMI-NYS affiliates in the capital region, NAMI-NYS board and staff members and friends and family of the Keplingers. NAMI-NYS wants to thank all those who attended.

NAMI-NYS is also extremely grateful to Bob and Evelyn Keplinger for once again hosting the event, Elaine Houston for emceeing, Jeff Wise and his staff at Glennpeter Diamond Centre for providing such a wonderful venue and catering and to all of the Capital Area businesses who donated for the raffle. We look forward to A Brighter Day 2015.

NAMI PROGRAMS

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This year, NAMI-NYS expanded our activities celebrating Children’s Mental Health Awareness Week by co-producing two events.

First, on May 6th, NAMI-NYS and our coalition of mental health and children’s advocates partnered with the New York State Office of Mental Health to produce What’s Great in Our State—A Celebration of Children’s Mental Health Awareness. The event held at the New York State Museum honored people and programs who are addressing children’s mental health issues.

The event gave NAMI-NYS the opportunity to honor our NAMI Rochester affiliate for their exemplary work in offering NAMI Basics classes and giving Parents and Teachers as Allies presentations as well as their upcoming presentation to the New York State School Nurses Association Conference. The award was presented to NAMI Rochester President Pat Sine and Program Manager Donna Leigh-Estes. The other honorees were: ACE (Adverse Childhood Experiences) Think Tank; DECA Project in New York City Early Childhood Programs; Hackett Middle School Full Service Room; Montefiore’s Pediatric Behavioral Health Services; The OnTrackNY; and the Seneca and Tompkins County Early Recognition Screening Program – The Whole Child Checkup Initiative.

During the ceremony we were presented with a proclamation from Governor Cuomo declaring it Children’s Mental Health Awareness Week in New York.

The following day, NAMI-NYS and our partners participated in the Alliance of New York State’s YMCAs Healthy Kids Day. NAMI-NYS exhibited at the event held at the New York State Legislative Office Building, giving us the opportunity to educate legislators and their staff on children’s mental health awareness. As part of the event NAMI-NYS represented the coalition at a press conference with Assemblyman Felix Ortiz, former Chair of the Mental Health Committee and Senate Co-Leader Jeffrey Klein. At the press conference NAMI-NYS’s Matthew Shapiro explained that “there is no health without mental health and a healthy brain is vital to healthy children.”

A Brighter Day

The second annual “A Brighter Day” event took place on May 16th at Glennpeter Diamond Centre in Albany. The event which was hosted by NAMI-NYS members Bob and Evelyn Keplinger, is designed to raise both awareness of mental illness and funds to advance NAMI-NYS’s mission to provide support, education and advocacy for people and families impacted by mental illness.

NAMI-NYS member Jason Paden gave an inspiring presentation detailing his recovery from severe mental illness and then engaged in an informative dialogue with WNYT (the Capital Region’s NBC affiliate) News anchor Elaine Houston. Elaine asked many of the questions that we typically hear from the public who may not be as aware of the realities of mental illness. Elaine also inquired about the role Jason’s family played in his recovery. Audience members also posed questions to Jason, who deftly provided answers as they related to his personal journey to recovery, while making sure to constantly stipulate that recovery is different for everybody. For many attendees Jason is now the face of mental illness. NAMI-NYS is grateful to have so many articulate In Our Own Voice presenters who are changing people’s perception of mental illness throughout New York State.

The event grew in its second year with attendance from NAMI-NYS affiliates in the capital region, NAMI-NYS board and staff members and friends and family of the Keplingers. NAMI-NYS wants to thank all those who attended.

NAMI-NYS is also extremely grateful to Bob and Evelyn Keplinger for once again hosting the event, Elaine Houston for emceeing, Jeff Wise and his staff at Glennpeter Diamond Centre for providing such a wonderful venue and catering and to all of the Capital Area businesses who donated for the raffle. We look forward to A Brighter Day 2015.
New Shift in Strategy for GOP on Mental Health Reform: Bad News for Serious Mental Illness! By Janet Reilly, NAMI Queens/Nassau

The recent news on 6-5-14, that the House Energy & Commerce Committee would divide the “Helping Families in Mental Health Crisis Act” bill into pieces is an attempt to pass individual provisions that are not controversial, and leaves serious mental illness unaddressed. This is a major blow to the bill and its author Rep. Tim Murphy (R-PA) who has argued that only dramatic and comprehensive reform would serve to help people with serious mental illness.

Republican leaders pushed for mental health reform back in 2013 in response to the school shooting in Newton, Ct. They selected Rep. Murphy, a child psychologist & chairman of an Energy & Commerce subcommittee, to craft the legislation that would reform the tangled thicket of federal rules and programs related to mental health. Taking cues from public safety advocates and families of people with serious mental illness Murphy’s bill proposed real measures that would help the seriously mentally ill (SMI). Among them HIPAA reform and AOT (Assisted Outpatient Treatment).

The defeat of Murphy’s comprehensive bill is a victory for the national mental health groups that were uneasy or opposed to it. The countless phone calls, letters, and meetings on the part of a broad coalition of consumer and survivor advocacy organizations and individuals spoke up and made sure they were heard by key legislators with the power to dismantle Murphy’s bill. Touche! But they are not the voice of people with serious mental illness, nor did they represent them. They advocated for high functioning consumers and existing programs that financially support those providers. Some argue that the bill shifts resources to the back end and ignores the possibility of early intervention before people reach serious mental health crisis. If there was some kind of way of preventing SMI, which is an organic disease, we would do it. Yes, Research is needed to find out what causes these brain malfunctions and why once under control they can erupt at any time again.

People, especially our legislators, need to understand there are 2 population groups with mental illness – severe with psychosis and the rest of the non psychotic disorders. Both groups have brain diseases, but that’s where the similarity ends. People with SMI, debilitating brain diseases, that cannot recognize their illness or agree to treatment on their own should not be allowed to go untreated. To wait until they are a threat to themselves or others can sometimes be too late and more catastrophic. With the current HIPAA laws they are allowed to keep their families from speaking with care providers and helping them to make appropriate treatment decisions and stay the course. Baffling! When my cousin was diagnosed with cancer his family decided that someone would always be with him when his doctors spoke to him about treatment options and meds so the best decisions could be made on how to proceed. My cousin is a smart, rational professional who normally would not need help making decisions. But he is very ill and not on his usual game. He does not have a brain disease, he has the wherewithal to allow and want the help. It is ludicrous, not to mention more costly, to ignore the needs of the SMI. What does it cost to repeatedly hospitalize these people, or house them in jail, or the cost to society, families, etc.

To think we need to choose who to help in this country and forget the rest of the population with SMI is inhumane and wrong on every level. We are morally decaying in this country. Our government is as broken as our mental health system. If you have a loved one with SMI the time is right now to share your story with legislators in support of the provisions in Murphy’s bill that address SMI.

Help for Mental Illness By Dr. Steve Dvorin, NAMI Rochester

The headlines are screaming at us: more school shootings. The common denominators are firearms and mental illness, and yet they should not be conflated.

Let’s consider the ways that we can help persons with serious mental illness. Congressman Tim Murphy, R-Pa., has introduced the Helping Families in Mental Health Crisis Act, which has bipartisan support. Murphy is a clinical psychologist who has experience working with individuals who have a serious mental illness. His bill focuses attention on persons with the most serious mental illnesses.

It provides for replication of New York State’s Kendra’s Law (Assisted Outpatient Treatment) across the country. In our state the application of Kendra’s Law has reduced hospital admissions, arrest rates, and incarceration for persons with mental illness who fail to recognize their need for treatment and have not been collaborative partners in their care.

Of major importance to families whose loved ones live with a serious mental illness, the Murphy bill relaxes some restrictive federal privacy requirements so as to allow more effective communication around issues of mental illness and safety.

Families are often the first to notice the emergence of mental illness or the recurrence of symptoms in a person with serious mental illness.

Sadly, these same families have not been able to effectively become involved in the treatment of a loved one because of HIPAA restrictions. This needs to change.

Murphy’s bill provides for more effective coordination of federal efforts to insure that persons with serious mental illness are identified and treated early and before tragedies bring them to the attention of coroners, the community or mental health providers.

The brain is the most complex organ of the human body. It has yet to reveal all of its secrets.

The Murphy bill supports research that will lead to better understanding of serious mental illness and better treatments.

Congressman Murphy brings attention to the needs of the most highly impaired persons who don’t always recognize their need for help.

Let’s support improved access to treatment, early intervention and coordination with families who are such an important component of the treatment team.
Building on the tremendous success of last year’s education conference, NAMI-NYS is excited to once again broaden our scope this year to present the biggest and most inclusive educational event in our history. *United We Stand: Shaping Our Future*, taking place November 14-16 at the Desmond Hotel in Albany, is designed to demonstrate how people living with a mental illness, their families and service providers must stand united to shape a future which finds, the research of today becoming the most beneficial treatments of tomorrow; a more effective system for the delivery of mental health services; and the current stigmas of mental illness being transformed to a public comprehension of these diseases and compassion for those who live with them.

The 2014 conference will feature an expanded focus with increased workshop sessions on both Friday and Saturday and plenary sessions which will educate people with a mental illness, their family members and doctors on their roles in shaping a future where recovery from a mental illness is more achievable than it has ever been before. There will also be sessions on how we as mental health advocates must work with our elected officials and government agencies to improve the delivery of mental health services. We are also excited to engage the next generation of advocates by including the first ever Young Adult focus track on Saturday.

ONCE AGAIN THIS YEAR, FRIDAY WILL FEATURE three focus tracks on mental health issues impacting children and adolescents, the criminal justice system and the military community. We have expanded to three workshop sessions for each track this year. Friday afternoon’s plenary session will feature two of the nation’s preeminent leaders in reforming the criminal and juvenile justice systems to be more responsive to people with mental health issues: Dr. Marvin Swartz and Major Sam Cochran (Retired, Memphis Police Department).

**Marvin Swartz, MD**, the Division Head of Social and Community Psychiatry at Duke University is a true pioneer in conducting research at the forefront of introducing the necessary reforms needed to make the criminal justice system, the juvenile justice system and the social service system more comprehensive to the unique needs of people living with a mental illness. His groundbreaking work includes examining the role legal tools such as Psychiatric Advance Directives may play in improving outcomes for persons with severe mental illness. Dr. Swartz has also done the most extensive evaluation of New York’s Assisted Outpatient Treatment Program (Kendra’s Law) and estimating the cost of criminal justice involvement in severely mentally ill individuals.

**Major Sam Cochran** is a national leader in introducing strategies to improve interactions between police (and first responders) and people having a psychiatric episode. Major Cochran developed the "Memphis Model" of Crisis Intervention Training which is now viewed as the most successful strategies for de-escalating situations involving people living with a mental illness or experiencing psychotic episodes.

Friday evening will feature two sessions providing updates on the newest research of serious and persistent mental illnesses. The first session will examine the NIH funded Recovery After Initial Schizophrenic Episode (RAISE) study. *Delbert Robinson*, a forerunner in the study of the benefits and effectiveness of early intervention in the treatment of schizophrenia, has played a major role in the RAISE study as part of one of the two research teams conducting the investigation. His team from the Zucker Hillside Hospital is engaged in a national study examining various early intervention strategies. Dr. Robinson will provide attendees with some of the initial insights on his team’s findings which are set to be published this fall.

**FRIDAY’S DINNER PROGRAM WILL INCLUDE** a presentation by the 2014 Connie Lieber Research Award Winner. Each year, NAMI-NYS consults with Connie Lieber, a leading public advocate and philanthropic supporter of mental illness and schizophrenia research in the United States and around the globe and founder of the Brain and Behavioral Research Foundation, to present an award in recognition of a researcher conducting innovative and groundbreaking work on understanding the brain and psychiatric illnesses. This year we are expanding the presentation by the winner in order to provide attendees with an in-depth look at some of the most cutting-edge work currently being conducted to shape the treatments of tomorrow. We look forward to announcing the winner of this prestigious award shortly.
Saturday evening will feature a lively and inspiring presentation by Mike Veny, the founder of Transforming Stigma, which will detail how being confronted with stigma is an opportunity to educate and build relationships and how to find and maintain your own personal wellness. This knowledge is tremendously beneficial for both people living with a mental illness and family members. Mike will share his remarkable story which includes being hospitalized, expelled from schools, and suicidal as a child to being a successful professional drummer, speaker, and entrepreneur as an adult. Mike provides audiences with a unique insight and understanding of mental health challenges and his firm belief that mental health challenges and people challenges go hand in hand. He works hard to constantly grow relationships and immediately resolve any conflicts. His speeches address the challenge of mental health stigma through a message that encourages simple, proactive actions. This provides a guideline for people to see their challenges in a positive light. This incredible interactive experience is something you will never forget.

Saturday evening will also feature a special tribute to NAMI-NYS Founding President, Muriel Shepherd, who passed away earlier this year. We are honored to showcase Muriel’s tremendous legacy which combined her intellect and compassion to ensure that family members of those living with a mental illness have a voice in our loved one’s care and in improving the systems that deliver mental health care and social services. The tribute will be designed to show how we are the torchbearers in her quest to improve the lives of people touched by mental illness.

Saturday will also provide attendees with more workshop options than ever before with three afternoon sessions. The first session with five workshops will focus on specific psychiatric diseases. The next two tracks (each with five workshops) will explore broader issues which impact those affected by mental illness. Saturday afternoon will also see the introduction of the Young Adult track. Saturday's lunch session will feature an update of federal legislative issues by Andrew Sperling, Director of Legislative Affairs for NAMI, followed by an overview of the NAMI Smarts program which demonstrates how NAMI members can best project their advocacy voice.

Sunday will once again find sessions from two of NAMI-NYS’s most trusted advisors, Lloyd Sederer, MD, Medical Director of the NYS Office of Mental Health and Lewis Opier, MD, the retired Medical Director of the NYS Office of Mental Health and our partner in the Ask the Doctor column in the NAMI-NYS newsletter. Dr. Sederer will present his unique insights on the importance of family involvement in both the recovery process and in maintaining wellness. Dr. Opier will lead an “Ask the Doctor” session.

We also look forward to being joined by newly appointed NYS Office of Mental Health Commissioner, Anne Marie Sullivan, MD, who will be presenting during the weekend. You will not want to miss this opportunity to learn the newest information on mental health issues and how you can play a role in shaping the future of mental health care. Information on the conference is available at www.naminy.org and registration is now open online. We will be sending out our conference brochure and scholarship information in September. We look forward to learning together with you in November.

Save the Date
2014 NAMI-NYS Education Conference
November 14-16
Desmond Hotel
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More information coming soon
We are Most Grateful to Those Who Made Financial Donations to NAMI-NYS During the First and Second Quarters of 2014.

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$100 and under  
This year the National Institute of Mental Health (NIMH) held its annual Outreach Partner Meeting on April 1st through 3rd. An NIMH Outreach Partner is a non-profit organization from each state chosen by NIMH to help deliver science-based information to communities in their respective states. NAMI-NYS is proud to serve as the Outreach Partner for New York State. Once again, this year’s meeting was held at the National Institutes of Health (NIH) campus in Bethesda, MD.

The meeting began with NIMH Director, Thomas Insel, MD, providing an overview of the state of mental health research. Dr. Insel detailed the White House Conference on Mental Health and many of the exciting initiatives coming from the federal level including President Obama’s BRAIN initiative and his desire to make the exploration of the brain the scientific priority of his administration, similar to how President Kennedy’s scientific priority was putting a man on the moon. He also explained how the White House has pledged $100 million for mental health care and praised the legislation introduced in Congress by Representative Tim Murphy.

Dr. Insel also provided information on the developments taking place on the NIH campus including the new Porter Neuroscience Center (containing 10 institutes and 85 new labs) which opened the day before the center “will serve as a premier institution for brain research, as well as forge a new model for the collaborative conduct of biomedical research across the country and around the globe.”

The keynote address followed and it was given by Sherry Glied, Ph.D, the Dean of New York University’s Wagner Graduate School of Public Service. Dr. Glied is a leading expert on healthcare reform and has done extensive work reviewing the Affordable Healthcare Act. The title of her presentation was Improving Behavioral Health in the Era of Healthcare Reform. She began by describing the previous attempts at instituting a national healthcare system made by President Nixon and President Clinton and explaining the history of parity in healthcare.

Dr. Glied also explained how parity in the coverage of mental health care can be a bit of a double-edged sword. Companies providing healthcare coverage tend to only cover evidenced-based treatments and several growing mental health therapies (such as peer support programs) are not evidenced based. This is a problem that will have to be continually monitored. In outlining the Affordable Healthcare Act, Dr. Glied said as mental health advocates we should be watching for is: Are people with mental health problems gaining coverage; How much are people with mental health problems spending out of pocket; and how much are people with mental health problems spending on premiums? The underlying question being, are these rates similar to those for people with other health problems?

New York State was represented again the next day with a presentation by Lisa Dixon, MD, MPH, Director of the New York State Psychiatric Institute’s Center for Practice Innovation. Dr. Dixon presented on Implementing First Episode Psychosis Services in the Community: Life After RAISE Connection. Dr. Dixon provided the findings of her research team which conducted one half of NIMH’s Recovery After Initial Schizophrenic Episode (RAISE) study and detailed the positive outcomes that derive from early intervention. She also discussed the next steps in implementing early intervention strategies. The main example she used was OnTrackNY. Dr. Dixon explained how she shared her findings from the RAISE study with the New York State Office of Mental Health (NYS OMH). NYS OMH was so encouraged by this that they green lighted OnTrackNY to be run through the Center for Practice Innovation.

OnTrackNY is an innovative treatment program for adolescents and young adults who are experiencing their first episode of psychosis. The program helps people achieve their goals for school, work, and relationships by using a shared decision making approach. Participants work actively with the entire treatment team to identify meaningful goals and services that can make a difference. OnTrackNY offers a comprehensive array of services that are individualized to meet the needs of each participant. These include: Psychiatric treatment including medication; Cognitive-behavioral approaches including skills training; Individual placement and support approach to employment and educational services; Integrated treatment for mental health and substance use problems; and Family education and support. Dr. Dixon will be making a more in-depth presentation on OnTrackNY and other programs conducted at the Center for Practice Innovation at this year’s NAMI-NYS Education Conference.

Each year at the meeting NAMI-NYS participates in the Partner Sharing program, where Outreach Partners detail unique programs designed to educate the community and disseminate NIMH information. This year we focused on our Build it Together campaign designed to connect with and engage multicultural communities. We detailed the 2013 highlights of the program which included producing the country’s first training of Bases y Fundamentos de NAMI-the NAMI program for families of children and adolescents with mental illness conducted in Spanish (which was produced in collaboration with fellow NIMH-Outreach Partner, NAMI-New Jersey), as well as a special NAMI Family-to-Family course held in Far Rockaway comprised of predominately Haitian families who were impacted by the devastation of Super Storm Sandy.

Other topics covered at the meeting included: the use of technology in mental health interventions (which detailed telepsychiatry and the growing number of “apps” designed to address mental health issues); communicating mental health successes; the role of peer support; and an update from the National Action Alliance for Suicide Prevention.

NAMI-NYS looks forward to incorporating NIMH and their researchers at our annual education conference and will provide you with weekly NIMH updates through our e-newsletter and through the NIMH news widget on our website.
Youth Programming  By Sharon McCarthy, NAMI Westchester

NAMI has several Signature Programs that address the issue of children and adolescent mental health. Unfortunately, all too often we are hearing media stories of children and adolescents suffering from a mental illness and not getting the services and support. Our society needs to be aware of warning signs and how to get help.

NAMI Basics is an education program similar to Family-to-Family but geared for parents and caregivers for children under the age of 13 who have been diagnosed with or experience symptoms of a mental illness. In addition to covering the types of conditions, medication, communication and problem solving, the classes provide an environment where parents and caregivers can lift the heavy burden of the isolation they often experience. This past year NAMI Westchester started a support group for parents and caregivers. We are hoping through this support group we will be able to launch more NAMI Basics classes, something many affiliates have struggled with statewide due to stigma and lifestyle limitations of parents taking care of children and adolescents. We continue to market the program whenever we talk to schools and medical professionals and we also would like to pursue providing the program to social workers and case workers similar to the great work that NAMI NYC Metro is doing.

NAMI Westchester has long felt that educating school principals, counselors and staff on the warning signs of mental illness was needed and we were grateful when NAMI developed the Parents and Teachers as Allies program. Since initiating this program in our county in 2012 we have been able to complete six presentations. The presentations discussed the warning signs of mental illness, how families can be helped and the services that not only NAMI can provide but what is also available in the community. We emphasize that we do not expect educators to diagnose but to be aware of what certain behaviors can indicate. We also stress that we understand the difficulties they face in talking with families when they sense a child may show symptoms but how important it is for the child

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Mid-Hudson Programs  By Jo Ann Brown and Tina Lee, NAMI Mid-Hudson

NAMI Signature Programs are the heart of a NAMI affiliate. It is a vehicle to fulfill NAMI’s mission of support, education, and advocacy, and to leave a footprint in the community as a valuable resource. NAMI Mid-Hudson is a perfect example of this.

NAMI Mid-Hudson covers two large rural counties: Dutchess and Ulster. When an affiliate is faced with limited financial resources and manpower, such as we are, creative approaches and diligence were needed to expand our Signature Programs to achieve sustainability and increase our visibility in each of these counties. Most importantly, NAMI Mid-Hudson recognizes the strengths of a NAMI affiliate: we are a peer-run group and we are willing to develop relationships and work collaboratively with the community.

This can be seen in our implementation of a NAMI Family-to-Family course in the eastern part of Dutchess, a large enough county that we have two of these courses running at a time. It became evident to us that even though we were holding a support group as well as the class right at the town’s high school that the staff was unaware of NAMI and the services available right in their school district. We contacted the superintendent directly and asked if he could please help us get the word out. He then had the class posted on the school website and sent a letter to the faculty and staff. He also posted the class flyers right in the lobby of the elementary, middle and high school.

We have shown similar commitment to networking and persistence in our implementation of NAMI Basics. We asked a local school to send the Basics flyer home with students from grades K through 8. This was very effective in reaching families. Even through our first attempt to run the class was unsuccessful we persisted, moving the next class closer to Poughkeepsie. The hosting school district has not been as receptive to NAMI as of yet, but we believe the success of this course will be a good in-road.

We recognize that networking proved to be a game changer for our affiliate. When we reach out to a potential partner, we do not believe it is effective to leave information or a folder with information without personally speaking with someone. When something is mailed or e-mailed it is not considered; we always look to personally speak with someone, as that’s what makes an impression.

After meeting with the upper management of an agency or potential partner we then obtain their e-mail and ask if, when the next flyer for a Signature Program is prepared, whether we can send it so that they can provide it to staff or families, display it in their office, and forward to anyone else who could help reach the families in our community. We often receive phone calls and find out which agencies are displaying our flyers in their waiting rooms or telling their clients about NAMI. Many times we have not even contacted the agency that is displaying the flyer but instead learn that it is being forwarded to others.

This networking is an effective way to give NAMI Mid-Hudson a defined identity and promote our Signature Programs. In another example, we recently joined the Dutchess County Regional Chamber of Commerce. With a cost of just over a $1 a day, our affiliate is able to network with other local businesses and nonprofits to establish relationships and promote our Signature Programs. Membership includes monthly Contact Breakfasts with attendance of 200 members, free radio air times, and the ability to use the Chamber’s website. As a Chamber member, we are also listed in the directory of over 312 members.

Reaching out to local businesses has proven to be another valuable asset to NAMI Mid-Hudson and our Signature Programs. For example, Gold’s Gym Fishkill and Lagrange have collaborated with NAMI Mid-Hudson to bring mental health information and NAMI Signature Program information to the gym members for the past year. We have set up tables in the gym regularly. Gold’s is also holding a fundraiser for NAMI Mid-Hudson, again promoting our affiliate and our Signature Programs at no cost.

Offering seminars to the community is also an effective way to promote our Signature Programs and establish professional relationships. Recently, NAMI Mid-Hudson sponsored a very successful SSI-SSDI workshop at Dutchess Community College. We were able to promote NAMI and also introduce our Signature Programs to the diverse audience of clinical providers as well as individuals affected by mental illness and build an important relationship with Dutchess Community College.
This relationship with Dutchess Community College has allowed NAMI Mid-Hudson to begin offering the Peer-to-Peer program on campus, launching a support group for the students as well as establishing a NAMI on campus as a resource to the students. There are also plans in place to present NAMI and the Signature Programs to all the clinical staff at Dutchess as an added resource to the students and their families.

The NAMI Peer-to-Peer program is a new one for our affiliate. We are excited to implement Peer-to-Peer not only at the college but in other locations in both counties we serve. We do believe that even though the Hudson River divides Ulster and Dutchess Counties that we should not let it divide the classes we hold. We will hold our first Peer-to-Peer class this June in Dutchess, welcoming both Ulster and Dutchess residents, and the next Peer-to-Peer will move to Ulster this fall.

The success of our programs is not due exclusively to community outreach. We recently found volunteers to update and develop our website to highlight special events, online petitions, videos, photos, newspaper links, and current information pertaining to our Signature Programs, as well. The success of the last few months with NAMI Mid-Hudson and our Signature Programs has also hinged upon the support of the community. We are a peer run group. By working collaboratively with other mental health agencies, schools, businesses, and organizations we complement each other as additional resources to the community. NAMI Mid-Hudson is dedicated to helping families regardless of whether it is through our programs or through other programs. This philosophy gives NAMI credibility and a niche to sustain our affiliate.

NAMI Mid-Hudson has seen within the last year that the growth of our affiliate and our Signature Programs is not contingent on a large budget. NAMI Mid-Hudson recognizes that it is not about doing more with less, but doing differently with less. It is evident that with some creativity, NAMI need not be the best kept secret in Dutchess and Ulster Counties.

Seventeen New NAMI Family-to-Family Co-Leaders Trained at Creedmoor Psychiatric Center  By Jeannette Wells, NAMI Queens/Nassau

NAMI-NYS held a fantastic two-day Family-to-Family training event on February 8th and 9th 2014 at Creedmoor Psychiatric Center in Queens Village, NY. The trainers, Pamela Solomon and Bonnie Goldberg, trained 17 new Family-to-Family Co-leaders over the course of the two days. The standard Family-to-Family training is usually three days but because all trainees were also F2F course graduates, Stephen Oby of NAMI-NYS and his counterparts at NAMI consented to a two-day training model.

The 17 new Family-to-Family co-leaders hailed from NAMI Central Suffolk, NAMI-NYC Metro, NAMI Queens/Nassau, NAMI Staten Island, and NAMI Westchester. They were an attentive, energetic group of men and women willing to teach other families the education they had received in their own Family-to-Family classes. We left assured that they will indeed show empathy, courage, support, love, and compassion to their struggling families in their future classes. Thank you to all our future co-leaders.

NAMI-NYS was willing and eager to work with our local affiliate to bring as many new leaders to the region as possible. This shortened, local training opportunity allowed many people to train that might not have been able to otherwise, and gave our affiliate the teachers we needed to continue growing this program in Queens and Nassau County.

NAMI Homefront Begins Launch  By Stephen Oby, Jr.

NAMI-NYS is honored to be participating in the launch of a new program designed to provide education and support to families of Military Service Members and Veterans affected by major mental health conditions. The program, called NAMI Homefront, is a six-session adaptation of the evidence-based Family-to-Family program, which NAMI affiliates of New York State have been running in several U.S. Department of Veterans Affairs (VA) facilities statewide in recent years. We are thrilled to have engaged six of our strongest affiliates statewide to begin delivering this important resource, which adapts to the of military and veterans’ communities, such as post-deployment and post-discharge transitions.

The issue of mental illness experienced by veterans and military has surged to the national forefront in recent years, and it is a tremendous problem. More than 100,000 combat veterans sought help for mental illness since the start of the way in Afghanistan in 2001, and about one in seven of those have left active duty since then, according to VA records collected through 2007. Mental health cases reportedly grew 58% from 2006 to 2007, and 25% of Operation Enduring Freedom/Operation Iraqi Freedom (OEF/OIF) veterans seen at VA health care facilities reportedly received mental health diagnoses. The need for education and support is clear.

We’re proud to report that 13 teachers from six affiliates of NAMI-NYS have trained to teach NAMI Homefront: NAMI Buffalo & Erie County, NAMI of Central Suffolk, NAMI NYC Metro, NAMI Rensselaer County, NAMI Rochester, and NAMI Syracuse. The very first course in New York State, taught at the Manhattan VA by Geraldine Burton and Pamela Solomon, began June 23rd.

The other five participating affiliates have been very active in pursuing outreach and engaging parties who may potentially be interested in the course, and we fully expect each of our six affiliates to have run the course by year’s end.

NAMI-NYS remains committed to contributing to the education and support of all individuals experiencing mental illness and their families, including our veterans and military. We’re thrilled to offer this unique and valuable resource to families in need across New York State.
NAMI-NYS Gains Ten New State Trainers

NAMI-NYS is proud to be nominating ten candidates to attend NAMI’s Train the Trainer event in Arlington, Virginia this summer. Our candidates are diverse both programatically and geographically, representing Signature Programs such as Basics, Connection, Ending the Silence, Family-to-Family, Family Support Group, In Our Own Voice, and Parents and Teachers as Allies, and areas such as Albany, Long Island, New York City, Orange County, Rochester, and Westchester County. We’re eager to put these new state trainers to work preparing new program leaders statewide in our ongoing mission to educate and support New Yorkers around the issue of mental illness.

**Congratulations to our new State Trainers**

- Geraldine Burton, Family-to-Family
- Mary Crowley, Family Support Group
- Nivia Dones, Ending the Silence & Parents and Teachers as Allies
- Chris Hagel, Connection
- Pat Hillenbrand, Basics
- Mary Beth Honsinger, Family Support Group
- Sharon McCarthy, Ending the Silence & Parents and Teachers as Allies
- Bill Perun, In Our Own Voice
- Beth Ramme, Basics
- Jodie Terhune, Ending the Silence & Parents and Teachers as Allies
In 51 weeks NAMI changed my life By Kate Hewlett, NAMI Otsego

Thirteen years ago when I was seeking peer services in my community, I realized the lack of availability in Oneonta, NY. I was determined to find a support group that myself and others could benefit from. Two years ago I co-established the Peer Alliance League (PALS), which is an open support group for anyone struggling with any mental health issue. The facilitator of the local NAMI support group heard about PALS and invited me to be on the NAMI Otsego County board of directors.

Soon after I was encouraged to participate in the NAMI In Our Own Voice (IOOV) training. IOOV are speaker stories that illustrate the individual’s realities of living with mental illness. I really didn’t know what I was getting myself into, but looking back I am so glad I did it. I love spreading the word, encouraging others that there is hope, healing, and recovery.

The facilitator of the local NAMI support group called PAL. Then we learned about In Our Own Voice. This program gave us the training and the vehicle to reach many more people with our own stories of recovery, in order to make people aware that recovery is possible. Kate and I took this opportunity and ran with it. We presented 6 times in the next 6 months.

Because of my experience with NAMI over the past year, my personal recovery has skyrocketed. My professional life has also been greatly furthered. I have been hired as a peer specialist, I am the team leader for the Mt. View Social Club in Oneonta. I was super excited to be working! The social club used to be a place to hang out and watch television. Now the transformation into more of a wellness and recovery center is in process. I facilitate therapeutic groups and activities such as, Open discussion, Wellness self-Management, mindfulness/meditation, creative writing, and walking. Other activities are currently in the works.

My position at Mt. View led to an invitation to be on the Mental Health Sub-committee, as well as the Regional Advisory Committee. I am currently taking part in a training to facilitate WRAP.

I am now certified to be a Peer-to-Peer education mentor and am planning on teaching my first class this September. I am also looking forward to taking part in the training for NAMI Connection, a weekly recovery support group for people living with mental illness as well as Ending the Silence, an in-school presentation about mental health designed for high school students. The past 51 weeks have been the greatest adventure of my life and I have NAMI to thank!

My Year with NAMI By Tammy Burrows, NAMI Otsego

On Memorial Day weekend of 2013, I participated in In Our Own Voice training in Greenville NY. I wasn’t prepared for the year of growth that this training would begin. My colleague Kate and I had similar stories of mental health diagnosis, although the diagnoses themselves were very different. We both were told at a relatively young age that our lives were effectively over, and were given a long list of things that we would never be able to do. We each began our own recovery journey, and met each other about 2½ years ago in Oneonta NY. We had each reached a certain level in our own recovery where we felt comfortable reaching out to other consumers of mental health services to support them in their recoveries. We started a support group called PAL. Then we learned about In Our Own Voice.

This program gave us the training and the vehicle to reach many more people with our own stories of recovery, in order to make people aware that recovery is possible. Kate and I took this opportunity and ran with it. We presented 6 times in the next 6 months.

Because of my experience with NAMI over the past year, my personal recovery has skyrocketed. My professional life has also been greatly furthered. I have been hired as a peer specialist, I am the team leader for the Otsego County Warm Line, I have been appointed to a seat on the Otsego County Mental Health Sub-Committee, I am currently awaiting appointment to a seat on the board of Opportunities for Otsego, and I participate in the Regional Advisory Committee, which provides input into NYS OMH policy under NYS OMH Commissioner John Allen.

My NAMI IOOV experience was so personally and professionally galvanizing that I recently returned to Greenville NY to participate in NAMI Peer-to-Peer training. I feel confident that facilitating Peer-to-Peer classes will be equally enhancing to my personal recovery, and will allow me to support many other consumers of mental health services in their recovery.

Thank you for the experience!
NAMI Westchester and NAMI Mid-Hudson
Complete Successful Ribbon Campaigns

Congratulations to NAMI Westchester and NAMI Mid-Hudson on completing successful Ribbon Campaigns during Mental Health Month.

NAMI Westchester in their second year with the campaign was able to work with
- 30 municipalities,
- 5 schools
- 4 agencies
- 4 hospitals
- Hold a flag raising ceremony at Yonkers City Hall

NAMI Mid-Hudson, who worked closely with NAMI Westchester throughout this campaign held a successful first outing as they were able to bring the campaign to
- 10 municipalities
- 10 organizations
- 7 Mental Health Agencies
- 7 schools including one college
- 4 businesses

The hard work both of these affiliates showed throughout this campaign have allowed for new relationships to grow and most importantly for more people to learn about NAMI and all we have to offer. We wish both affiliates luck in next year’s campaign and hope other affiliates look to host a campaign in their area to reproduce the success these two affiliates have had.

NAMI Westchester County-Wide Ribbon Campaign May 2014
Find Help. Find Hope.

APPROVED MUNICIPALITIES
- Village of Ardsley
- Hamlet of Armonk
- Hamlet of Bedford Hills
- Village of Bronxville
- Village of Croton on Hudson
- Village of Dobbs Ferry
- Village of Elmsford
- Town of Greenburgh
- Town of Greenwich, CT
- Town of Harrison
- Village of Hastings on Hudson
- Village of Irvington
- Hamlet of Katonah
- Village of Mamaroneck
- Town of Mamaroneck
- Town of New Canaan, CT
- City of New Rochelle
- Hamlet of North White Plains
- Village of Ossining
- City of Peekskill
- Village of Pleasantville
- City of Rye
- Village of Rye Brook
- Village of Scarsdale
- Town of Somers
- Village of Tarrytown
- City of White Plains
- City of Yonkers
- Town of Yorktown

AGENCIES
- Andrus
- Department of Community Mental HEALTH
- MHA
- Volunteer NY

SCHOOLS
- Croton on Hudson Septa
- Horace Greeley High School
- Mamaroneck Union Free School District
- Mamaroneck-Larchmont Septa
- Yonkers Board of Education

HOSPITALS
- Montefiore Hospital Medical Center, Bronx NY
- New York Presbyterian Hospital/ Westchester Division
- St Joseph’s Medical Center
- St. Vincent’s Hospital

NAMI WESTCHESTER FLAG RAISING AT YONKERS CITY HALL
- Mike Spano, Mayor City of Yonkers
- Stamata Pappas, NAMI Westchester Board President
- Bernadette Kingham-Bez, Sr. Vice President St Joseph’s Medical Center and Executive Director St.Vincent’s Hospital
- Mimi Clarke-Corcoran, President and CEO Andrus
- Stephen Ferrando MD, Associate Medical Director and Vice Chair of Clinical Programs NY Presbyterian Hospital
- Shelley Mayer, Assemblywoman New York State Assembly District 90

NAMI-MH County-Wide Ribbon Campaign May 2014
Find Help. Find Hope.

APPROVED MUNICIPALITIES
- City of Beacon
- Town of Lagrange
- Town of Dover / Wingdale
- Town of Poughkeepsie
- Town of Woodstock
- Village of Fishkill
- Village of Millbrook
- Village of Millerton
- Village of New Paltz
- Village of Rhinebeck

MENTAL HEALTH AGENCIES
- Cornell Cooperative Extension
- Dutchess County Healthy Families
- Family, Woodstock NY
- Mental Health America, Poughkeepsie
- NYMHA of Ulster County
- Rockland Psychiatric Facility, Dutchess Clinic
- Taconic Resources

HIGH SCHOOLS
- Arlington High School
- Dover Elementary School
- Dover Middle School
- Dover High School
- Roy C. Ketchum High School
- Spackenkill High School

COLLEGES
- Dutchess Community College

ORGANIZATIONS
- Arlington Professional Fire Fighters, Local 2393
- Arlington Fire Fighters, Red Oaks Mill Fire Station 3
- Arlington High School Friends of Rachel Club
- Beekman Fire Department, Poughquag NY
- I Am Beacon
- J.H. Ketcham Hose Company, Dover Plains NY
- J.H. Ketcham Hose Company, Wingdale NY
- John Jay High School, Believer’s Club
- North East Community Center, Teen Team
- Spackenkill High School, Leo Club

BUSINESSES
- Apple Valley Shopping Center, Lagrange NY
- M&T Bank, Fishkill NY
- United States Post Office, Fishkill NY
- United States Post Office, Lagrange NY
So far, 2014 has been active and eventful on legislative issues impacting mental health and the delivery of mental health services on both the state and federal levels. During this momentous period NAMI-NYS has been on the forefront in projecting our advocacy. We are pleased that the voice of NAMI-NYS and our grassroots members have led to several positive outcomes during this legislative session, including NAMI-NYS’s number one legislative priority issue; preventing the closures of state psychiatric hospitals while ensuring that savings from reductions of beds are reinvested in community services.

This reflects NAMI-NYS’s belief that people living with a mental illness should receive the treatments most appropriate for their recovery, whether they can benefit from a community-based recovery or if there illness is so severe that only the intensive care exclusively available through a hospital is right for them. NAMI-NYS believes that both options must be available and that the state should not have to cut one to support the other.

As 2014 approached it appeared as if the state would be reducing the number of psychiatric hospitals from 25 to 16 and the savings from the closures would be reinvested into community based services which would be managed through the Office of Mental Health’s Regional Centers of Excellence, which would be set-up throughout the state. NAMI-NYS vehemently opposed the closures of any hospitals or combining children’s psychiatric hospitals with adult psychiatric hospitals as recommended in Buffalo. On February 11th, NAMI NYS President Irene Turski, Government Affairs Chair Sherry Grenz and Crisis Intervention Training (CIT) Chair Barbara Biasotti testified before the Joint Legislative Public Hearings on the 2014-2015 Executive Budget Proposal Mental Hygiene.

Irene and Barbara both gave their harrowing stories which provided evidence of why the need for beds and assisted outpatient treatment is so important.

Our advocacy efforts on both fronts proved successful as New York announced that there will be no state hospital closures in the upcoming budget year (though all the hospitals targeted for closure will see reductions) and there will be a true reinvestment in community services. The state will move ahead with its planned $25 million dollars investment in community services, which will be annualized to $44 million in the budget for this year. The original reinvestment capped bed savings at $70,000 a bed. This new reinvestment caps the savings at $110,000 bed.

The centerpiece of NAMI-NYS’s advocacy efforts was our annual Legislative Conference which took place on Tuesday March 18th. The conference allowed the membership of NAMI-NYS to meet with their legislators to advance the 2014 Legislative Action Agenda, which consisted of:

1) Reinvestment in Community Services,
2) Safe and Affordable Housing,
3) Sustained Support of NYS Research Institutions,
4) Expansion of Crisis Intervention Teams, and
5) Increased Mental Health Services for Veterans and the Military Community.

Along with flexing our advocacy voice, the conference saw NAMI-NYS present two special awards which gave us the opportunity to showcase two achievements related to our Action Agenda.

First, NAMI-NYS recognized one of New York’s two research institutions, the Nathan Kline Institute (NKI), which had recently been named in the top 1% of the world’s research facilities. This demonstrates that the investment the state is making in our two research institutions, (New York State Psychiatric Institute being the other) is paying dividends now. NAMI-NYS was joined by NYS Senator David Carlucci, Chair of the Senate’s Mental Health and Developmental Disability Committee and Anne Marie Sullivan, MD, Acting Commissioner of the NYS Office of Mental Health, in presenting the award to NKI Director, Donald Goff, MD and several high ranking staffers. Then NAMI-NYS awarded Senator Lee Zeldin for his work on securing funding for the Joseph Dwyer veteran peer-to-peer mentoring programs. In 2012, NAMI-NYS testified before a special hearing called by Senator Zeldin and former Senate Mental Health Chair Roy McDonald to address the PTSD and other mental health issues impacting veterans. It was from this hearing that funds for the peer mentoring were allocated. This year’s budget includes the re-appropriation of $1.85 million for the program.

NAMI-NYS won another victory on one of our Legislative Action issues when the Legislature
President Irene Turski and Government Affairs Chair Sherry Grenz have met with the mental health chairs in both the Assembly and Senate. Acting OMH Commissioner Anne Marie Sullivan, recently met with several board members and Executive Director Wendy Burch. Sherry and Wendy along with Criminal Justice Chair Jayette Lansbury had an off-the-floor meeting with Assemblyman Daniel O’Donnell, Chair of the Correction Committee to discuss reforms necessary to make the penal system more responsive to the needs of inmates who have a mental illness. CIT Chair Barbara Biasotti and members of her committee have also had several meetings with key legislators to advocate for increased CIT trainings in the state. Finally, on May 19th, NAMI-NYS participated in Legislative Disability Awareness Day allowing us to inform legislators and their staff about mental illness.

On the national front, the biggest piece of news was the introduction in the House of Representatives of the “Helping Families in Mental Health Crisis Act.” NAMI-NYS immediately endorsed this bill, which has received bipartisan support, and sent a memo of support to the entire New York State congressional delegation. A few of the aspects of the bill that NAMI-NYS find especially beneficial are:

1) It would create exemptions in HIPAA and FERPA that will help families access information necessary to provide care to loved ones,

2) It would return the Protection and Advocacy for Individuals with Mental Illness (PAIMI/P&A) to its original focus of working to improve care for the most seriously mentally ill,

3) It would increase NIH funding so that they can discover the causes and develop new treatments for serious mental illnesses,

4) It would funds pilot Assisted Outpatient Treatment Programs proven to reduce homelessness, hospitalization, arrest and incarceration of the most seriously mentally ill, and

5) It would fund mental health courts so more people with serious mental illnesses would be redirected to treatment rather than to jail and prison. Recently, Irene Turski, Sherry Grenz, and Wendy Burch, along with NAMI Schenectady President, Roy Neville, met with Congressman Tonko to explain why this bill is so important and why NAMI families are so concerned about reforming the HIPAA Laws.

While NAMI-NYS is proud of our accomplishments this session, there is still much work to be done. The advocacy voice of our members will be needed more than ever in the coming months as we continue to fight against future hospital closures, advance CIT across the state and work with our federal leaders to pass true reform. NAMI-NYS looks forward to the NAMI National Convention held in Washington D.C. in September as we will be making advocacy visits to many in the New York State congressional delegation. We will continue to inform you and ask for you to participate in Action Alerts via our E-Newsletter.

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Ask the Doctor

By Lewis A Opler, MD, PhD

If you have a question for Dr. Opler please submit it to Andrew Chakmakas at the NAMI-NYS office.

Q: I am wondering whether doctors treating patients for mental illness are aware that advanced-stage Lyme disease often mimics symptoms of mental illness? I would recommend Dr. Richard Horowitz’s book “Why Can’t I Get Better” which discusses the symptoms of neurological Lyme disease. My daughter was treated for anxiety and depression for 10+ years. She was on numerous medications and involved in talk therapy. She received no relief and was suicidal. In June she was diagnosed with advanced stage Lyme with co-infection Babesia. With treatments, she is feeling better. I don’t know if she would still be in my life if she continued down the path of being treated for mental illness without the antibiotic treatments she received to address the Borrelia Burgdorferi bacteria.

Brian Fallon, MD, and colleagues at Columbia University Medical Center have written extensively about neuropsychiatric symptoms in persons where Lyme disease has affected the central nervous system (CNS).

We also have much to learn about viruses and neuropsychiatric disorders, such as Borna virus, and I recommend a book edited by Kathryn M. Carbone titled Borna Disease Virus and Its Role in Neuropsychiatric Disorders. E. Fuller Torrey and Robert Yolkin’s work suggests that the parasite toxoplasma gondii may cause neuropsychiatric disorders, including schizophrenia. If Torrey and Yolkin are correct, toxoplasma gondii is not mimicking mental disorders, it is causing them.

Q: Are there specific treatments for someone with schizoaffective disorder who seems intractable on his meds? The individual is a 33 year old male, 13 years ill and is taking injectable Haldol (200 mg). Seroquel and Lithium (dosage unknown). Clozapine is often effective in patients with either schizophrenia or schizoaffective disorder when other medications are ineffective. Additionally, clozapine is the only antipsychotic that is FDA approved for suicidality. If clozapine has not been tried, find out why not, and if there is no good reason, then it is time to request (demand?) that it be tried.

Q: What do you know about high doses of folic acid to ease symptoms of voices?

Roffman et al. (JAMA Psychiatry 2013 May;70(5) 481-489) report results of a randomized, double-blind, placebo-controlled trial in which they found improvement in negative symptoms in persons with schizophrenia with a particular genetic profile when given folic acid plus vitamin B12. Subjects without the genetic profile described in their paper did not benefit in negative symptoms. No change was found in severity positive symptoms, including on hallucinatory behavior.

Youth Programming

Continued from page 16

when they do. The presentation from the person living with a mental illness is very powerful and sometimes an “eye opener,” especially when the presenter discusses the teacher who made a difference in their life. The demands on school districts make it difficult to find the time to provide this two-hour program and we have adapted it, when necessary, to a 90-minute program. We have found networking and having people with connections in the schools extremely helpful. For example, one of our board members is a principal. She made the initial contact with her district’s staff training director and, after discussing the program in depth, she brought us in. We now do the program annually for that school district. The feedback we get after these presentation is always positive and one of gratitude.

Ending the Silence is a new program that NAMI is rolling out to help educate middle schools and high school freshmen and sophomores. This presentation is done by a parent and individual in recovery. The presentation, with the help of a power point video, describes the various mental health conditions. The individual in recovery tells their story on how they lived with their mental illness while attending school. The emphasis is on how there is help and the importance of seeking that help. The program lets students realize the need to be supportive of those suffering from a mental illness. The hope is that through this program students will open up the dialogue with their families, and because New York State is adding three state trainers in this program in 2014, affiliates all over New York will have the chance to bring Ending the Silence to their local schools.

It is often said it “takes a village” and we, who have had mental illness touch our lives, all know too well the impact that individuals can have on someone’s recovery. As a parent of a daughter whose illness surfaced while in high school, I know how the understanding and compassion of her school’s professionals, staff and students made a difference in her obtaining her diploma and ultimately her recovery. We are very fortunate that NAMI has developed these programs that will hopefully help improve the lives of children and adolescents suffering from a mental illness as well as their families.
**Lending Library**

**CHECK OUT OUR NEW ADDITIONS TO OUR LENDING LIBRARY.**

We currently have 134 books and 28 DVD’s that are available to borrow. Go onto [www.naminys.org](http://www.naminys.org) and go onto the Lending Library link and fill out and submit the request form. The book or DVD can be borrowed for up to 30 days.

**We’re happy to offer the following books and DVDs:**

*Reis’s Pieces: Love, Loss, and Schizophrenia* and *Where Are All the Cocoa Puffs? A Family’s Journey Through Bipolar Disorder* by Karen Winters-Schwartz

(see more from Karen on page 5)

*Living with OCD… The Raw Truth* by Vicki Moorehead.

(Vicki tabled at A Brighter Day, see more on page 10)

*Nothing to Hide: Mental Illness in the Family* by Jean J. Beard and Peggy Gillespie

(See more on this topic on page 5)

*The Family Guide to Mental Health Care* by Dr. Lloyd Sederer MD

(Dr. Sederer recently spoke at an affiliate event, see page 5).

We’re happy to offer ‘Call Me Crazy’ a Five film that was discussed heavily by NAMI in the past months and the 60 Minutes piece ‘Imminent Danger’ which looks at how the mental health and criminal justice systems are failing those with severe mental illness.

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**SAVE THE DATE**

**2014 NAMI-NYS EDUCATION CONFERENCE**

November 14-16

Desmond Hotel and Conference Center

Albany, NY

*More information coming soon*