



National Alliance on Mental Illness

# The Voice

The Newsletter of NAMI Southwestern Pennsylvania

Volume 15, Issue 3 January 2010

## NAMI Southwestern PA Serves as a Lead Partner in Mental Health Advanced Directives

Stakeholders educate people about the benefits of Mental Health Advance Directives

Pennsylvania lawmakers – in an effort to further ensure that those with serious mental illness have the same basic rights as everyone else regarding informed consent for mental health treatment – passed a law that became effective Jan. 29, 2005. Act 194 permits adult Pennsylvanians who have capacity to make mental health decisions to write and sign a Mental Health Advance Directive (MHAD).

A MHAD—which can include a declaration, a mental health power of attorney or a combination of the two—is a written document that when signed, dated and witnessed by two adults becomes legally binding. The document allows a person to make choices about mental health treatment while the person has capacity in case there is a later time when the person lacks capacity and is in need of treatment. It also allows an individual to include information that, although not legally binding, may be helpful to address barriers that prevent a person from seeking treatment, such as designating someone to take care of pets, hospital preferences and whom to notify. The document does not need to be notarized.



are clearly documented for others to follow. The issue today is that too few people are utilizing this vital benefit.”

Since the law became effective nearly five years ago, many stakeholders in the behavioral health system in Allegheny County have recognized that people have not been taking advantage of the opportunity to develop and sign MHADs. NAMI Southwestern Pennsylvania, in collaboration with the Disability Rights Network of Pennsylvania, Mental Health America of Allegheny

“This document is an essential component of a wellness and recovery plan,” explains Sharon A. Miller, Director of Education and Community Relations for NAMI Southwestern Pennsylvania. “It prompts open communication among consumers, loved ones and providers about important decisions regarding mental health treatment. And, it helps to lessen fears for everyone involved when a crisis occurs because personal decisions have already been made and

*continued on page 13*

### In This Issue...

From the Desk of the Executive Director .....	2
News Around the Region .....	3
2009 NAMI Walk Feature .....	5
Family-to-Family: A Participants Point of View .....	8
<b>In The Spotlight:</b> Denise Macerelli, Senior Director for Community and Government Relations, WPIC .....	12
Creating a Mental Health Advance Directive .....	14
NAMI Provider Education Enlightens Mental Health Professionals .....	15



## *From the Desk of the Executive Director...*

**T**hanksgiving always marks the beginning of the holidays and the countdown to the New Year. It is time to look back, take stock and reflect on the past year. And, "Oh my, what a tremendous year we have had at NAMI Southwestern Pennsylvania."

In March, NAMIPedia went online for testing and tweaking. April brought a very wonderful annual conference followed by our most successful NAMI Walk in October. (You can see lots of walk photos in this newsletter.) In between our two major events, we did a couple of TV shows and held a very newsworthy rally against the budget impasse at the State Office Building.

The highlight of my year was being part of the teaching team presenting the Provider Education course for the very first time. (You can read about the course on page 15.) My team became my friends, people who matter to me a great deal. And the group of people we taught were experienced professionals who care very deeply about their work... real jewels, so to speak.

In class, we—consumers, family members and provider staff—became the collaborative model we were teaching. As the system is being transformed, a consumer- and family-centered system is evolving. Our featured newsletter article on Mental Health Advance Directives is an example of an empowering self-advocacy tool for individuals anchored in a collaborative model that embraces "open communication among consumers, loved ones and providers about important decisions."

Learning from one another, sharing our experiences and feelings, Joyce Burland Ph.D. writes, "Reinforces the principle that our shared humanity must govern every domain of mental health care." Shared humanity, compassion and empathy for one another, mutual respect and equality, beginning person to person, as people first!

My warmest wishes for the happiest of New Years!

Take Care,

A handwritten signature in cursive script that reads "Christine".

Christine Michaels, MSHSA  
Executive Director, NAMI Southwestern Pennsylvania

### NAMI Southwestern Pennsylvania MISSION STATEMENT

NAMI Southwestern Pennsylvania is a regional grassroots organization dedicated to helping families and individuals affected by mental illness achieve lives of quality and respect, through education and advocacy that supports recovery.

# News Around the Region

## Updates on Legislation and Policy Impacting the Mental Health Community

Sharon A. Miller, Director of Education and Community Relations, NAMI Southwestern Pennsylvania



### Impact of Healthcare Reform: What will happen sooner rather than later when Congress passes a final healthcare bill?

In a party-line vote on Nov. 21, 2009, the Senate Democrat leaders claimed success by moving their healthcare bill to the Senate floor, wherein much wheeling and dealing over as yet unresolved and divisive issues likely will continue to shape the legislation before the final language emerges. The Senate bill includes the merger of separate bills that cleared the Finance and Health, Education and Labor (HELP) Committees earlier this year. The Senate action follows passage of House legislation (The Affordable Healthcare for America Act-HR 3962) on Nov. 7 by a vote of 220-215.

As this issue of *The Voice* goes to print, the Senate vote paves the way for a December of debate, and perhaps even carrying over into a January struggle that is sure to influence the 2010 mid-term wrestle for control of Congress. Should the debate continue, please consider the following:

I urge NAMI members and others in our broader disabilities community who believe our healthcare system must see reform to continue contacting Senators Specter and Casey and your member of Congress to ensure your voice is heard.

Given data suggesting that individuals with mental illness die 25 years younger than the general population, NAMI Southwestern Pennsylvania supports healthcare reform initiatives that are inclusive of individuals with mental illness and addictions.

We must stress that, whatever the mechanism within the final legislation that expands coverage for the uninsured, it must be required to have mental health benefits and cover those benefits at parity. This would expand the 2008 federal parity law into the individual and small group market in many states.

Insurance reform must ensure that people with mental illness could not be denied health insurance benefits on the basis of a pre-existing condition or could not be dropped from existing coverage due to their medical condition.

Many individuals with mental illness and substance use disorders are uninsured, many of whom are well below

the poverty level.

Approximately 22 percent of adults with mental illness and/or substance

use disorders are underinsured. In addition, about 30 percent of individuals with co-occurring mental illness and substance use disorders lack any insurance. One in three uninsured adults with mental illness and/or substance use disorders is under 100 percent of the federal poverty line.

To hear the cacophony on both sides of the aisle, you'd think that the reforms proposed in the Senate and House would change our healthcare system overnight. In reality, the bulk of proposed changes—such as the new health insurance exchanges or whatever version of a public option might emerge, and the new insurance mandates for individuals—will not take place until 2014 (or 2013 in the House version). However, a few provisions are scheduled for implementation as soon as the legislation is signed into law. If the bill passes as currently written, immediate measures include:

- \* **Insuring high-risk citizens.** Both bills would create a \$5 billion fund for temporary insurance for citizens with pre-existing conditions who have not been insured for at least six months. The program would end once the insurance exchanges begin in 2013 or 2014.
- \* **Extending insurance for adult children.** The House bill would allow parents to keep unmarried adult children on their health insurance until their 27th birthday; the Senate bill, until their 26th birthday. This would reduce the number of uninsured young adults.
- \* **Extending insurance for the recently unemployed.** Under current law, laid-off workers are allowed to continue buying their existing insurance through the COBRA program for up to 18 months. The bills would extend that coverage until the insurance exchanges begin.
- \* **Beginning to close the “doughnut hole.”** Both bills would begin closing the so-called “doughnut hole” in Medicare Part D prescription drug coverage by providing an additional \$500 in coverage starting in 2010. Over several years, the gap would be reduced until it was closed entirely.

*continued on page 4*

- \* **Ending rescission.** Insurance companies often cancel policies for consumers who require expensive medical care because they made honest mistakes on their medical histories. Both bills would prohibit insurance plans from canceling coverage except in cases of fraud.
- \* **Ending lifetime limits on benefits.** Both bills would end the lifetime caps on insurance coverage which have sometimes been used to deny payments to consumers with particularly expensive treatments. Both bills would also restrict annual limits on healthcare benefits.

Continue to visit [www.namiswa.org](http://www.namiswa.org) and click on **Inform Yourself** for updates on the federal healthcare reform progress and to view comparisons of the Senate and House bills.

**PA Budget Recap: House Appropriations bill was passed by the Senate and signed by Gov. Rendell Oct. 9, 2009**

**This action ended the 101 days of budget impasse.** Still unresolved, however, is the fate of a bill legalizing table games in Pa. casinos. House and Senate negotiators are still wrangling over the tax rates and the one-time license fees that casino operators would be required to pay. This bill must pass for the anticipated revenue to be collected—revenue required to balance this budget.

*Thanks to all who utilized our “Call to Action Alerts” and through your tireless efforts repeatedly contacted Gov. Rendell, legislative leaders and respective local legislators from June throughout the 101 days. Your successful advocacy urging for the passage of a budget that protects essential services and supports for people living with mental illnesses and the broader disabilities community proves that our collective voice can make a difference. Visit*

*[www.namiswa.org](http://www.namiswa.org) for a chronology of our budget advocacy activities and for photos and media coverage from the August rally.*

The enacted budget reduces overall state spending by one percent from 2008-09 levels of \$28.3 billion and includes both recurring and new one-time only revenue enhancers plus \$2.6 billion in federal stimulus money.

**Mental Health Funding**

The budget plan restored the flow of funding to non-profits including state-county funded human service providers. Counties ought to have received their allocations the second week of November. The state budget total for mental health services in OMHSAS is \$728.730 million, down from the Governor’s revised request of \$730.589 million. This line item funds both the community mental health programs and the state operated psychiatric hospitals. The budget includes a two percent across the board reduction to the county allocation, about \$3.055 million. This amount is expected to be absorbed within OMHSAS administrative costs and through reductions in the state hospital appropriations.

There is an increase of \$1.5 million to support post-closure programs related to the Mayview State Hospital closing, funding that is essential to ensuring people can live meaningful lives in the communities of their choice. The budget funds Behavioral Health Services Initiative (BHSI) at \$55.331 million and includes (with a two percent reduction) the restoration of \$12.1 million in lost Intergovernmental Transfer funds.

NAMI 2010 advocacy efforts will focus on initiatives designed to prevent another budget impasse while also preparing for transition within OMHSAS as the Rendell Administration comes to a close. 🌐

---

---

## Meet the 500 Striders

Congratulations to the outstanding individuals who each raised \$500 or more for the 2009 NAMI Walk. Thanks and way to go!

Jim Ehrman (Jim’s Jocks)\*

Ray Baum (Leo’s Team)

Mary Catherine Macik (UMPC Health Plan)

Deborah Waslichak (Community Care)

Graceanne Stafford (Mercy Behavioral Health)

Sharon Hicks (Community Care-Walking for Awareness)

Kathy Testoni (Erin’s Walkers)\*

Skip Alberts (Go CART!)

Jeanne Yohn (Pfizer)

Eileen Lovell (South Hills Stampede)\*

Denise Macerelli (Western Psychiatric Institute & Clinic)

Jim Bycura (Western Psychiatric Institute & Clinic)\*

Erin McManus (Residential Care)

Mim Schwartz (Walk the Walk)\*

Sharon Vogel (NAMI North Hills Support Group)

Paul Cannon (Community Care-Walking for Awareness)

Anne Bell (Pictionary Crew)

Nancy Hohl (Pictionary Crew)

*\*Indicates Board Member*

3rd Annual  
NAMI Walks for the Mind of America  
Sunday, October 4, 2009  
SouthSide Works & Three Rivers Heritage Trail



Over 2,000 People Walked to:

- Raise Awareness
- Erase Stigma
- Promote Treatment



# Third Annual NAMI Walk A Success

*NAMI Walk Draws Over 2,000 People, Attract Media and Raises \$128,000*

The air was cool, and the energy level was high on Sunday morning, Oct. 4, at the 3rd Annual NAMI Walk at the SouthSide Works in Pittsburgh.

Participants were in high spirits as they arrived. Wearing creative team T-shirts, walkers smiled for team photos and enjoyed entertainment provided by DJ Sean Russell of Big Day Entertainment, the Pittsburgh Pierogies and Mike the Balloon Guy.

Bubbles filled the air as children jumped inside a large moonbounce, their faces painted and arms colored with tattoos from our Children's Tent.

Honorary Chair Michelle Wright of WTAE-TV greeted participants and got the day rolling. She introduced

NAMI Southwestern Pennsylvania's Executive Director Chris Michaels and our Business Team Chair John Lovelace, President of *UPMC for You*.

At 10 a.m., over 2,000 walkers lined up in Town Square, and Michelle led the way for the 3.1-mile walk along the Three Rivers Heritage Trail.

In addition to being featured in the *Pittsburgh Post-Gazette* the week before the walk, the NAMI Walk appeared on Channel 4, Channel 11 and PCNC news on Walk Day, helping us raise awareness of mental illness and recovery.

Thanks to our phenomenal volunteers, generous sponsors and donors, and dedicated participants, the 2009 NAMI Walk raised \$128,000! 

---

## NAMI Walk Chairs Make It Happen

We are happy to introduce a new chairperson this year for the NAMI Walk: Business Team Chair John Lovelace, President of *UPMC for You*. Not only did John facilitate UPMC Insurance Services' Presenting Sponsorship, he also coordinated a UPMC "Superteam" comprised of Community Care, UPMC Health Plan and Western Psychiatric Institute & Clinic. Together his team exceeded its fundraising goal by raising a whopping \$23,238!




*John Lovelace*




NAMI Southwestern Pennsylvania's Darcey Garda, Manager of Development and Marketing, and Executive Director Christine Michaels pictured with Honorary Walk Chair, Michelle Wright, WTAE-TV (center)



*Michelle Wright* 

also posted clips of the NAMI Walk on her blog at [www.pittsburghchannel.com](http://www.pittsburghchannel.com).

We were thrilled to welcome back Honorary Chair Michelle Wright, News Anchor of WTAE-TV. With Michelle's support, WTAE-TV covered the walk and the kick-off luncheon, spreading our message of hope and recovery to its viewing audience. Michelle

Our dedicated Family Team Chair Jim Ehrman outdid himself this year! Single-handedly raising \$8,475, Jim was the top individual fundraiser for the third year in a row. Additionally, his family team earned the #2 spot on our Top 10 Teams list. Thanks for your passion and support. 



*Jim Ehrman*

## Team T-Shirt Contest

The winner of this year's NAMI Walk Team T-shirt Contest is...

### Family Services of Western Pennsylvania

Front and back design of winning T-Shirt



## Top 10 Teams!

Our Top 10 Teams exemplify team spirit in support of the NAMI Walk mission. Thank you to these outstanding teams!



**1. Western Psychiatric Institute & Clinic \$11,000**  
Team Captains: Denise Macerelli, Kelly O'Toole & Vicky Dix

**2. Jim's Jocks \$9,550**  
Team Captain: Jim Ehrman

**3. Community Care - Walking for Awareness \$8,303**  
Team Captain: Paul Cannon

**4. UPMC Health Plan \$3,995**  
Team Captain: Mary Catherine Macik

**5. Go CART! \$3,544**  
Team Captains: Alan Corn & Brian Rayne

**6. Leo's Team \$3,288**  
Team Captains: Harriet & Ray Baum

**7. Team Mon Yough: "We Walk For Hope" \$2,729**  
Team Captain: Kathy Fowler

**8. South Hill's Stampede \$2,440**  
Team Captain: Gerry Dugan

**9. TSI Titans \$2,202**  
Team Captain: Jennifer Mullins

**10. Allegheny HealthChoices \$1,780**  
Team Captain: Lea Ann Gerkin

#### Honorable Mention

The Pictionary Crew \$1,670  
Team Captain: Anne Bell

## Top 5 Fundraisers!

These five people single-handedly raised over \$16,000!  
Hats off to these superstar supporters of NAMI Southwestern Pennsylvania.

1. **Jim Ehrman** (Jim's Jocks) \$8,475
2. **Mary Catherine Macik** (UPMC Health Plan) \$2,670
3. **Ray Baum** (Leo's Team) \$2,318
4. **Deborah Wasilchak** (Community Care - Walking for Awareness) \$1,470
5. **Graceanne Stafford** (Mercy Behavioral Health) \$1,155

See page four for a list of other top fundraisers known as "500 Striders."



# NAMI Walk Volunteers

Whether you volunteered on Walk Day, at one of the pre-walk events, or as part of the planning committee, we thank you - our phenomenal NAMI Walk volunteers!

Skip Alberts  
 Tom Baxter  
 Eva Bednar\*  
 Anne Bell  
 Ed Bell  
 Lindsay Booley  
 Bob Boyer  
 Jim Bycura\*  
 Donna Broderick  
 Charlie Brown  
 Megan Bursic  
 Jack Cahalane\*  
 Mary Christensen  
 Trisha Collings  
 Alan Corn  
 Cathy Corn  
 Mindy Crawford  
 Steve Dzurilla  
 Jim Ehrman\*  
 Marianne Farmerie  
 Ralph Farmerie  
 Michael Ference

Janet Finlay  
 Tara Finlay  
 Kathy Fowler  
 Chuck Fowler  
 Elizabeth Gilarno  
 Girl Scouts Cadette Troup  
 #51163  
 Girl Scouts Junior Troup  
 #50254  
 Jenn Gore  
 John Hermann  
 Carol Horowitz  
 Irv Horowitz  
 Sean Hutchins  
 Lisa Issac  
 Debbie James  
 Dick Jevon\*  
 Loretta King  
 Cliff Krey  
 Alexis Krey  
 Barb Lopez  
 John Lovelace

Violet Ludwig  
 Jen Lukondi  
 Matt Lyons  
 Beth Martin  
 Amberly Mason  
 Edna McCutcheon\*  
 Cindy McHolme\*  
 Donna McManigle  
 Lester McManigle  
 Corey Michaels  
 Damien Michaels  
 Damien Michaels, Jr.  
 Shawna Miller  
 Myrn Montalvo  
 Camille Naylor  
 Phyllis Nettles  
 Elizabeth Pacheco  
 Meredith Paterson  
 Shawn Paterson  
 Amanda Santmyer  
 Kim Sarnowski  
 Paul Scanlon

Sharon Shaw  
 Jeff Spengler\*  
 Laurie Spengler  
 Graceanne Stafford  
 Cyndi Stewart\*  
 Erin Testoni  
 Kathy Testoni\*  
 Hope Tinker  
 Kim Todd  
 Lisa Tokich  
 Cindy Turacy  
 Curtis Upsher  
 Laura Karl Vincenti  
 Sharon Vogel  
 Kristen Volosky  
 Peter Walker  
 Roberta Walker  
 Deb Wasilchak  
 Sally Whitcomb  
 Michelle Wright

\*indicates Board Member

For more pictures visit  
[www.flickr.com/namiswpa/sets](http://www.flickr.com/namiswpa/sets)







# NAMI Walks



National Alliance on Mental Illness

## 2009 Sponsors

Our sponsors lay the foundation for a successful walk each year. We thank them for their generosity and continued support!

### Presenting Sponsor:

*UPMC Insurance Services*

**Integrating care for improved health**

*UPMC for You | Community Care Behavioral Health | UPMC for Life Specialty Plan*

### Gold Sponsor:



### Kick off Luncheon Sponsor:

Norman and Cindy McHolme

### Silver Sponsors:

Dollar Bank    Staunton Farm

### Start/Finish Line Sponsors:

Allegheny HealthChoices    AstraZeneca    NHS Human Services, Inc.

Value Behavioral Health of PA    Western Psychiatric Institute and Clinic

### Bronze Sponsors:

Bristol-Myers Squibb    Eli Lilly and Company    Janssen    Mercy Behavioral Health    Pepper Hamilton LLP

The Testoni Family    Westmoreland Casemanagement and Supports, Inc.

### Supporters:

Allegheny Family Network    Americhoice of Pennsylvania    Bookminders    Caribou Coffee-SouthSide Works

Family Resources of PA    Tom & Cindy Jevon    Kaufman House    Clifford A. & Dr. Cynthia Krey

Mr. & Mrs. Ira J. & Beverly Schulman    RG Johnson Company Inc.    Trust-Franklin Press    Wesley Spectrum Services

*For a complete list of our sponsors (including Kilometer Sponsors) and donors, visit [www.namiswa.org](http://www.namiswa.org) and click the NAMI Walk button.*

*Thank you to the Testoni Family for donating the prizes for our raffle tickets, which were a great team fundraiser, and for a box of seats to a Pirates game for our online registration contest.*



# A Participant's Point of View...

## NAMI's Family-to-Family Program

Jennifer Lukondi, Fall 2009 Family-to-Family Graduate

With the onset of a mental illness, family members are often plunged into a murky and unfamiliar new world. Their first contact with the mental health system may be through a psychiatrist who, because of patient confidentiality, may not be able to give them any specific information. It may be through a case worker, who is overworked and underpaid. In some cases, it may even be through law enforcement or the judicial system, and these professionals are not responsible for educating and supporting the family. Additionally the family often loses touch with their usual social supports, extended family, neighbors and friends in part because of the stigma of mental illness.

So, in the midst of this bewildering world, the family is isolated, even though it is usually the family that is responsible for providing for their loved – the family

who must try to coordinate care without information, who must house their loved one when released from the hospital or jail, and who must provide financial support when their loved one cannot work.

NAMI's Family-to-Family course addresses this enormous crack in the system by compiling the wisdom of families that have dealt with mental illness and providing it to others in need of information, support and strength. From one family member to another, across all boundaries: age, race, economic status, education, gender and more, this empathetic approach breaks down the barriers of isolation by letting family members know that they are not alone, that there

*continued on next page*

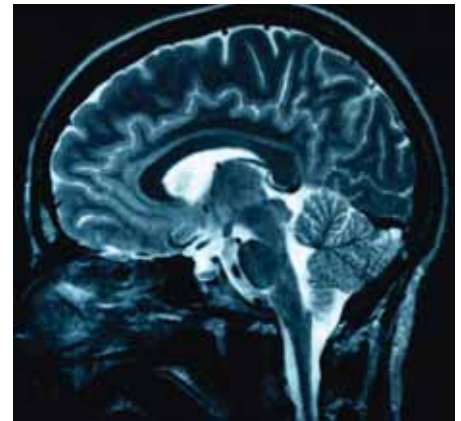


## Family-to-Family Education Program

Free Education & Support for Families who have Relatives with Serious Mental Illness

### Course Topics include:

1. Family responses to the trauma of mental illness.
2. Schizophrenia, major depression, and mania: Diagnosis and dealing with critical periods.
3. Depression and Bipolar subtypes; Panic disorder; Obsessive Compulsive Disorder (OCD); Borderline Personality Disorder; Co-occurring brain and addictive disorders.
4. The biology of the brain: emerging scientific discoveries.
5. Problem solving workshop
6. Medication review
7. Understanding the inner experience of having a mental illness.
8. Communication skills workshop.
9. Self-care, relative group testimony.
10. Rehabilitation, services available.
11. Advocacy, fighting stigma.
12. Celebration & certification ceremony.



**Pre-Registration Required – Space is limited and classes fill quickly!**

The next session of Family-to-Family Classes will begin in March 2010.

Contact NAMI Southwestern Pennsylvania to reserve a space today. Call 412-366-3788 or email [info@namispwa.org](mailto:info@namispwa.org).

is help for them, and above all, that there is hope for their loved one.

A 12-week commitment may seem daunting to people juggling busy lives, especially if life includes caring for a loved one with mental illness. However, after taking the class, there is not a single one I would say was expendable. Each class held new insights, sometimes provided by the material, but often as not, they came from our co-teachers (family members, of course) or class members.

The first classes focused on the more clinical aspects of mental illness, defining the various types, detailing the symptoms of each, and tracing the behavioral expression of the illness back to the regions of the brain that are impaired. This foundation of clinical understanding is essential to accepting the person with mental illness as just that, as a person with an illness.

Later sessions expanded on this knowledge and perspective by describing the feelings that a person with mental illness experiences as, in their view, the world around them inexplicably changes and they begin to lose touch with themselves, their family and everything that has made them feel secure and safe.

The Family-to-Family class also incorporates workshops that teach useful tools: problem solving skills, communication methods and coping skills. The open and safe environment of the class gave us the opportunity to rehearse these skills so that we were better prepared to put them into practice in our daily lives. Another very practical aspect of the class was the section on medications—an often bewildering brain and tongue twister to family members and consumers alike. Our co-teachers brought in a psychiatrist to answer our medication questions directly. How often do you think family members have an opportunity like that?

When you look at it all together, Family-to-Family is a combination of the information in a Psych 101 class, delivered from the unique perspective of experienced family members and consumers, and provided in the community-feel of a support group. It is particularly suited for addressing the needs of family members who often must cope with the daily effects of their loved one's illness while also working, supporting and caring for the rest of their family and themselves in their "off" hours, without the benefit of formal psychiatric training, knowledge of the mental health system, the public welfare system, courts, jails, substance abuse programs and so on.

Most importantly, I think, was that the class was centered on the model of Recovery. Mental illnesses may be chronic illnesses without a "cure," but there is always hope for recovery. Recovery is different for everyone, and it is not a "cure," or a complete return to the former self. It is an adjustment to and improvement of the situation as it exists in the here and now. It is a way for both the consumer and their family to deal with the issues of mental illness so that the mental illness becomes part of their lives rather than dominating them. ●

*Each class in the 2009 fall Family-to-Family session at The Children's Institute has been chronicled in the NAMI Blog ([www.namiswa.blogspot.com](http://www.namiswa.blogspot.com)).*

## NAMI Wins Exceptional Employer Award

The Howard Levin Clubhouse recently named NAMI Southwestern Pennsylvania one of the recipients of its 2009 Exceptional Employer Recognition Award.

A proclamation passed in Pittsburgh City Council on Oct. 20 states, "These employers continually demonstrate the utmost respect for the Clubhouse community and the ongoing initiative to combat the stigma associated with mental illness."

The Howard Levin Clubhouse held an Employer Recognition Reception on Monday honoring the winning organizations. Paul Freund, C/FST Services Director at NAMI's Consumer Action & Response Team (CART), accepted the award from CART Interviewer Brian Rayne, who nominated NAMI for the award.





## *In the Spotlight...*

Denise A. Macerelli, ACSW, LSW, *Senior Director for Community and Government Relations, Western Psychiatric Institute and Clinic (WPIC)*

### **How long have you been working in the mental health field?**

I have been focused on the needs of those with serious mental illness since the beginning of my professional career. My background in social work has led me to work experiences in inpatient mental health care, as well as residential care and community mental health services. I have been employed by UPMC for 12 years, nine of those at WPIC. For more than 60 years, WPIC has served the needs of individuals in our community by providing a comprehensive range of behavioral health services and treatment for mental health and substance use disorders.

### **What gives you the most hope for recovery for those with serious mental illness?**

The resiliency of the human spirit amazes me and gives me great hope. People who have struggled through significant difficulties related to their mental health often find ways to celebrate life again. I strongly support the current movement toward community integration, where individuals are empowered to live lives of potential within their communities, aided by vital support services. And, I am thankful for organizations like NAMI, which continue to champion the needs of family members as they advocate for the health and successful independence of their loved ones.

### **Why is the work that NAMI does so important to our community?**

In my work, I have long understood the value of giving individuals a voice in their own recovery, balanced with the pivotal role families play in the recovery process. NAMI's role continues to evolve from an organization that began as a support to family members to one of advocacy for consumers and families. They are a positive force that challenges mental health professionals and other leaders in the behavioral health system to find more effective ways of serving consumers and their families. Many, many people who work with me at WPIC know the importance of NAMI in the lives of those we serve. And

now, because of the NAMI Walk, we have a way to say "thank you" for the work they do. Southwestern Pennsylvania is a better community for all of us because NAMI has given a voice to our friends and neighbors who didn't have a voice in the past.

### **How did WPIC get involved with the NAMI Walk?**

I live by the personal philosophy that those who have and are able should give back to those who don't and cannot. And I work with a team of passionate, dedicated people who feel as I do. To be honest, it hasn't been hard for the WPIC Team to raise funds for NAMI. WPIC created a team to participate in the inaugural NAMI Walk, raising \$3,000. Last year we more than doubled that amount, and in 2009, we were recognized as the #1 fundraising team for the second straight year, raising \$11,000. WPIC is honored to stand beside NAMI as a partner in their work to advocate for lives of respect, without stigma and discrimination, for those with mental illness and their loved ones.

### **Why is the NAMI Walk so effective?**

When people see us walking, we look like the folks who walk for breast cancer, diabetes, or any other physical disease. When people hear us talking, they know we are not ashamed, embarrassed or afraid of mental illness. The NAMI Walk is comprised of a diverse group of advocates, grassroots supporters, providers, consumers, family members and friends from every culture and socio-economic background. Mental illness does not discriminate, and neither does NAMI. Anyone who wants to walk is made to feel welcome, whether you come on your own, with a small family group or a large corporate team. And fundraising isn't NAMI's main goal—it's to encourage people to stand together and be counted, to come alongside one another in encouragement and replace fear with understanding and acceptance. Every person leaves the Walk with the message that their personal effort matters, and they share their experiences and inspire others to become involved. I anticipate this event will continue to grow for years to come, with WPIC as a major champion of their efforts.

The advocacy, education and support services provided by NAMI Southwestern Pennsylvania's staff and dedicated volunteers give hope for recovery and a future filled with promise for the nearly 80,000 people in our region who cope with mental illness. *In the Spotlight* is one way NAMI recognizes the people who so diligently work to promote improvements in our behavioral health system while championing the needs of our constituents. If you wish to nominate someone to be featured in *In the Spotlight*, send an email to [dgarda@namiswpa.org](mailto:dgarda@namiswpa.org).

***Mental Health Advanced Directives*** continued from page one

County, the Peer Support and Advocacy Network and a core group of community providers and other stakeholders, came together through the invitation of the Allegheny County Office of Behavioral Health in early 2009. The charge to this working group was to identify and overcome barriers to providing an increasing number of people with meaningful opportunities to create their personal MHAD.

“What our working group has discovered is that many people are still unaware of the opportunity to create a MHAD” Miller explains. “We also acknowledge that there is a great deal of confusion about how these documents work to protect those with mental illness during a crisis situation. This is a powerful tool that actually promotes effective treatment more efficiently, which may prompt a faster recovery.”

“There is clearly great interest in MHADs for people who become aware of what they are and the many benefits they offer,” describes Carol Horowitz, Esq., Managing Attorney for the Disability Rights Network of Pennsylvania. “The initiative in Allegheny County is working to get the word out and encourage people to take action. In addition, as people who have used their MHADs recover and then share their positive experiences with others, more consumers will gain confidence and a sense of empowerment that they can play a greater role in their recovery. People know what does and does not work for them, and they may be more willing to seek treatment if they know their decisions will be respected.”

This initiative has identified three core needs, which are currently being implemented throughout Allegheny County:

- Education for both consumers and providers on the benefits of MHADs.
- Consistent information distributed to stakeholders to let people know that MHADs exist and why they are important.
- Technical assistance provided through customized workshops and one-on-one meetings to help people complete their MHADs.

Mental Health America of Allegheny County has created a hotline for residents who have questions about how to write their own MHAD: 1-877-868-2195. NAMI Southwestern Pennsylvania continues its ongoing MHAD initiative throughout the region and can offer assistance at 1-888-264-7972.

There is also a state-wide initiative supported by the Office of Mental Health and Substance Abuse Services (OMHSAS). “One of our goals for the near future is to develop a statewide registry by which consumers can complete their MHAD and store it online where it can be easily accessed by mental health professionals during times of crisis,” Horowitz explains. “As part of this registry, we hope to include a tool that will notify people when their MHADs are about to expire so they can validate a new one before a crisis occurs.”

“The process by which the legislation was drafted and signed into law really brought the entire mental health community together. NAMI affiliates, advocates, consumer organizations and professional associations all became involved in the process to advocate for comprehensive legislation to protect the rights of those with serious mental illness,” Miller concludes. “Now, we are mobilized to provide expanded education, awareness and training in Allegheny and surrounding counties so that more people can take advantage of the many benefits this valuable tool has to offer.”

*For more information on Mental Health Advance Directives and to download the documents, visit [www.namiswpa.org](http://www.namiswpa.org). See page 14 for instructions on how to create a MHAD.*



**Save the Date!**

**NAMI Southwestern Pennsylvania's  
11th Annual Education Conference**

**Friday, April 23 &  
Saturday, April 24**

**Pittsburgh Airport Marriott**

**Our First Ever  
Two-Day Education Conference**

**Visit [www.namiswpa.org](http://www.namiswpa.org)  
for upcoming details.**



# Creating a Mental Health Advance Directive

**A** Mental Health Advance Directive (MHAD), when properly executed, is a legally binding written document that allows a person to

make choices regarding mental health treatment before that treatment is needed. It addresses both informed consent and the right to refuse treatment. It is an important component of recovery and wellness planning. A MHAD applies to mental health treatment only and should not be confused with any other legal documents.

A MHAD provides an effective way for a person to communicate a lot of information to doctors, mental health providers, support professionals and loved ones. In addition to making treatment choices such as those concerning medication, electroconvulsive therapy and research studies, a person can state whom they want to be notified in the event of hospitalization and other information regarding treatment history. The document also allows people to include preferences regarding crisis management and those unrelated to treatment, such as who should care for children or pets and dietary concerns.

Pennsylvania's law allows a person to make a MHAD that is a declaration, a power of attorney or a combination of both. A **declaration** contains instructions regarding consent and withholding of consent to treatment choices and information on preferences and treatment history. This option is more defined and less flexible. **Power of attorney** allows for the designation of a trusted, accessible friend or relative – known as an agent – to make treatment decisions for a person as they would have made them for themselves. This option is more flexible to address situations and choices that can not be accounted for in advance.

The following criteria make a directive valid in Pa.:

- Must be signed *and* dated
- Must be witnessed by two adults
- Must include treatment choices and preferences
- Individual must be at least 18 years old or an emancipated minor
- Does not need to be notarized, but the person must have capacity at the time it is written. (Pennsylvania law presumes everyone has capacity unless legally determined otherwise.)

This document becomes valid at the time it is signed and dated, but will only go into effect when a psychiatrist and another mental health treatment professional declare a person's incapacity to make mental health treatment decisions. Capacity is the basic ability to understand a diagnosis, the risks and benefits of treatment related to mental health care and the consequences of refusing treatment. It does not have an impact on the voluntary and involuntary commitment provisions of the Mental Health Procedures Act in Pennsylvania. What may be affected is the treatment a person will receive upon admission.

People need to distribute their MHAD to treating physicians, mental health providers, their agent (if one is named within the document), family members and others who play a key role in their lives to ensure they will know where to quickly find it in the event of a crisis situation. People are encouraged to carry a card in their wallet stating they have a MHAD, and who should be called if they are hospitalized.

As MHADs are legally binding, providers must carry out the treatment decisions documented unless they cannot in good conscience comply because the instructions are against accepted clinical practice or medical standards. Providers may not provide any treatment without consent unless it is an emergency response. Providers do not have to follow instructions in a MHAD when policies do not allow for compliance, such as what treatments may or may not be covered by insurance. The provider is also excused from following the instructions in a directive if the treatment documented is physically unavailable; however, all reasonable efforts must be made to transfer a person to a facility that would comply. Providers must keep a copy in a person's mental health treatment record for at least two years and update the file with any revocation or changes to the document.

A MHAD is valid for two years from the date it is signed, unless it is revoked or a new one is created. All or part of a MHAD can be changed or revoked at any time, as long as the person has capacity. It is important to create a new MHAD when it expires or after revoking the old one so that decisions will be recognized and followed in the event of a mental health crisis. Always remember to distribute the new document to everyone who received the expired version.

*Pennsylvania provides many helpful resources to assist people with creating a MHAD. For more information, call 1-888-264-7972 or visit [www.namiswpa.org](http://www.namiswpa.org).* 🌐

# NAMI Provider Education Enlightens Mental Health Professionals

There is a vast body of research that provides strong evidence that family involvement improves recovery, decreases relapse and sharply decreases re-hospitalization. NAMI National's signature education program, Provider Education, emphasizes a collaborative model based upon shared understanding, mutual respect and compassionate engagement.

A five-member teaching team consisting of two consumer teachers, two family member teachers and one mental health professional is required for Provider Education. Each week, the teaching team tackles a different topic from a fairly complex academic and scientific proprietary curriculum. The course work is presented through the lived experience of the presenters. By design, the team demonstrates the collaborative model of understanding, respect and compassion as each teacher shares their personal experiences. Whether the topic is the family adaptation model, consumer stages of recovery, empathy, secondary interventions, brain disorders, medications, stigma or advocacy, the impact of honest,

raw emotions and pain articulated in relation to didactic, academic material is powerful and behavior changing.

NAMI'S Joyce Burland, Ph.D., creator of the Provider Education Program, writes "Recounting our lived experience has demonstrated that recovery and resiliency can be achieved; it has reinforced the principle that our shared humanity must govern every domain of mental health care. This model of training is a potent catalyst of transformative empowerment—of advocacy-through-education—enabling consumers and family members to take their rightful place as frontline experts and legitimate instructors on the subject of living with mental illness."

Mental Health workers who have completed the Provider Education course described it as: "Educational, informative, enlightening and supportive for mental health workers. Absolutely necessary!"

Any provider agency interested in the Provider Education course should call the NAMI Southwestern Pennsylvania office at 412-366-3788.

**"The principles of Recovery and responsible psychiatric care mandate that whenever possible families should be engaged in collaborating with the treatment in some way and offered support for their well being and needs as caregivers."**

*-The Family Committee of the Pennsylvania Psychiatric Leadership Council position paper on Family Care Training for Community Psychiatry Fellows for use in the Centers of Excellence.*

## NAMI Online

Check out our NAMI Blog:  
[www.namiswa.blogspot.com](http://www.namiswa.blogspot.com).

Follow us on Twitter:  
[www.twitter.com/namiswa](http://www.twitter.com/namiswa).

See event photos on Flickr at  
[www.flickr.com/namiswa](http://www.flickr.com/namiswa).

Find answers on NAMIpedia at:  
[www.namiswa.org](http://www.namiswa.org)



NAMI Southwestern Pennsylvania  
105 Braunlich Drive  
McKnight Plaza, Suite 200  
Pittsburgh, PA 15237-3351

412-366-3788  
1-888-264-7972

e-mail: [info@namiswpa.org](mailto:info@namiswpa.org)  
[www.namiswpa.org](http://www.namiswpa.org)

Non-Profit Org.  
U.S. POSTAGE  
**PAID**  
Pittsburgh, PA  
Permit No. 4359

Address Service Requested

## NAMI Southwestern PA : Join Today – Let Your Voice be Heard!

Annual dues include access to our regional lending library, resource and referral information, newsletters, conference information, and membership in NAMI Pennsylvania and national NAMI.

- |                                                                        |                                                          |
|------------------------------------------------------------------------|----------------------------------------------------------|
| <input type="checkbox"/> Individual/Family/Friend \$35.00              | <input type="checkbox"/> Professional \$50.00            |
| <input type="checkbox"/> Consumer (minimum of \$3.00) \$_____          | <input type="checkbox"/> Additional Contribution \$_____ |
| <input type="checkbox"/> Restricted Income (minimum of \$3.00) \$_____ |                                                          |

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY \_\_\_\_\_ STATE \_\_\_\_\_ ZIP \_\_\_\_\_ COUNTY \_\_\_\_\_

PHONE (H) \_\_\_\_\_ PHONE (W) \_\_\_\_\_ FAX \_\_\_\_\_

E-mail \_\_\_\_\_ Number of family members in membership \_\_\_\_\_

- I would like my copy of the Voice electronically. (provide email) \_\_\_\_\_
- I am interested in receiving Call to Action alerts via email and participating in legislation and policy advocacy.  
(provide email) \_\_\_\_\_

**Please make check payable and mail to:** NAMI Southwestern Pennsylvania, 105 Braunlich Drive,  
McKnight Plaza, Suite 200, Pittsburgh, PA 15237