The Road Less Traveled

_Ian Walks America to Honor His Brother’s Memory_

When Ian Cummins lost his younger brother Ryan to suicide, he felt compelled to act. So he made the decision to walk across the country to share Ryan’s story in a nationwide effort to both honor his brother and to battle mental illness by raising awareness and inspiring a more open dialogue.

“I am seeking to make a positive impact on our country’s constant struggle with one of the most debilitating diseases in the world: suicide,” Ian writes on his website, ianwalksamerica.com.

“According to NAMI, suicide claims approximately 30,000 lives in America each year. Over the past four years, my brother Ryan had been clashing with the pain of a suicidal thought process on a daily basis. He was but one of the thousands of Americans fighting to preserve the fragile balance of their minds. On Nov. 9, Ryan’s battle ended when he took his own life in the final attempt to overcome a sickness we know so little about.”

Ian describes his brother as an intelligent, energetic young man with a gifted mind who was a talented musician, active in numerous sports, and skilled in technological analysis and problem-solving. During his sophomore year in high school, the bright future everyone anticipated for Ryan began to turn with the onset of powerful negative emotions he was unable to control. In the years to come, he was first diagnosed with major depression, followed by bipolar disorder and then attention deficit disorder.

After high school graduation in 2012, Ryan enrolled at the University of Pittsburgh at Greensburg campus and performed well initially, but soon struggled to function. He transferred to Pitt’s main campus for his sophomore year to be able to commute from home, but was unable to fight through his pain. He switched majors with the hope that a less intensive workload might help.

Ryan was prescribed numerous medications over four years of treatment which worked to varying degrees and caused many side effects. During the last four months of his life, he refused to take his medications because they made his thoughts foggy and unfocused. Ryan first attempted suicide in 2011. He completed suicide in November 2013.

continued on page 4
I recently celebrated one of those milestone birthdays that make you sentimental, reflective and philosophical. My primary focus is the future of the mental health system and what is going to happen. Where are we headed? Who will be the advocacy leaders for our members with mental illness and their families? This edition of the newsletter introduces you to some of our future champions: Ian Cummins, Nicole Campbell, Kevin Hines, Stacy Pershall and Dana DeFonso.

In our feature article, read about Ian Cummins walking across the United States in honor of the memory of his brother Ryan, whom he lost to suicide in 2013. You will feel his grief but ultimately you will experience the hopefulness Ian is spreading coast-to-coast, “battling mental illness through awareness.”

Nicole Campbell, a college student and NAMI volunteer is featured in our In the Spotlight column. Nicole, wise beyond her years, reflects on NAMI’s Strategic Plan, mission, diversity and making connections with other young people.

Read about Kevin, Stacy and Dana, all three presenters at our 14th Annual Education Conference, Mental Illness and Young Adults: Voices for Hope. They are truly “voices of hope” for today’s young people and their families. The shared theme in Ian’s journey and Nicole’s volunteerism, along with our conference presenters, is the powerful message of hope we all feel when we hear the words, “You are not alone. We are not alone.”

Please take some time and read about NAMI Southwest Pennsylvania earning the Seal of Excellence by completing the Pennsylvania Association of Nonprofit Organization’s Standards for Excellence accreditation program. It has been a busy and exciting past couple of months. We are now busy getting ready for our 8th Annual NAMI Walk on October 5, 2014.

Have a safe and relaxing summer and always remember that NAMI is here for you!

Christine Michaels, MSHSA
Executive Director, NAMI Southwestern Pennsylvania
PA Budget Update

In May, Pennsylvania’s Independent Fiscal Office reported that there will be $1.3 billion less revenue available to fund Gov. Corbett’s proposed 2014-2015 budget. Now (early June), the legislature is beginning to negotiate this shortfall. We are advocating against a “cuts only” budget and advocating that mental health funding cannot be cut. We support regular Medicaid expansion and seeking other revenue sources. It is time to reinvest in human services!

NAMI staff will attend the RCPA (Rehabilitation and Community Providers Association) Capitol Rally on June 17. In Harrisburg, we will visit our government officials and advocate for mental health funding.

House Resolution (HR) 226 called for “the Joint State Government Commission to study PA’s Mental Health System, particularly as to how criminal defendants with mental illness are addressed by established procedures and progress.” The Joint State Government Commission report suggests a “robust” approach to mental health treatment and recommends more funding for mental health services. The report is available at www.jsg.legis.state.pa.us.

Medicaid Expansion in PA

NAMI continues to support regular Medicaid expansion not Healthy PA. A NAMI Action Alert in April encouraged supporters to provide comments on Healthy PA, which is Gov. Corbett’s alternative program currently being reviewed by the Centers for Medicare and Medicaid Services (CMS).

National News

As an alternative to the controversial Murphy bill (HR 3717), Rep. Ron Barber from Arizona introduced HR 4574, the Strengthening Mental Health in Our Communities Act of 2014. While there are several similar, positive provisions in both bills, the Barber bill does not change the structure of the Substance Abuse and Mental Health Services Administration (SAMHSA) or include changes to DRN. The negative provisions regarding SAMHSA and DRN in the Murphy bill were previously opposed by NAMI Southwestern Pennsylvania.

Our Executive Director Chris Michaels and Associate Director Debbie Ference visited Sen. Bob Casey and Rep. Tim Murphy during legislative visits on May 7 in Washington, D.C., advocating for the Mental Health First Aid Act of 2013.

2014 Organizational Supporters

NAMI Southwestern Pennsylvania’s Organizational Supporters have taken part in our membership based program to form a group of organizations that, together, provide a natural network of caring peer support and invaluable community resources.


To become one of our Organizational Supporters, contact Darcey Garda at dgarda@namiswpa.org.
“My brother was simply existing in a world he felt little purpose in,” Ian describes. “How can somebody have the capacity to make so many positive impacts on so many lives without having a clue to the basic fundamentals of his own existence? Through my sadness, rage and despair, I gained solace in an object found in his possessions the night he took his life. In the front photo pocket of his wallet rested a small card with a quote by Mahatma Gandhi. On that card was a wish never answered — a light that reminded me what Ryan and those like him were fighting for. Happiness is when what you think, what you say and what you do are in harmony.”

On Jan. 1, Ian resigned his job as a Registered Nurse in the Medical Intensive Care Unit at UPMC Mercy Hospital in Pittsburgh, put his schooling to earn a bachelor’s degree on hold, and began to make preparations for his walk across America. He spent countless hours training physically, even doing a 23-mile preliminary walk to experiment with how he should best load and carry his supplies (he credits an expert at REI for offering great advice), which shoes would best protect his feet (he was fitted with better walking shoes and orthotics after the test!) and if he should consider hauling a small trailer (he is). He also invested considerable time mapping his route across the states, factoring in seasonal weather conditions, locating roads that were the safest to walk on, contacting local law enforcement for permission to walk across bridges and stretches of road typically closed to pedestrian traffic, and ensuring that he could almost always reach a town within 20-30 miles to find a safe place to spend each night and stores to re-stock his supplies.

After two months of careful preparation and planning, Ian began his walk from Neptune’s Park in Virginia Beach, VA on March 1. As of the writing of this article, he was traveling through the nation’s heartland - Kansas - anticipating reaching the halfway point of his journey within a few days. Just moments before his roadside interview began, a couple stopped their car to offer Ian a ride. When he explained his mission, they, too, had a story of mental illness and heartache to share.

“These people were just two of the hundreds I have encountered so far on my journey,” Ian reflects. “My initial hope was that if I could meet just one person who was suffering in silence from the pain of suicide, all of this effort would be worth it. Instead, I have experienced hundreds of personal encounters during the past three months, and I have thousands of followers online. People with mental illness are so often living in such a scary place of loneliness. I believe that by talking about it, the awareness that they are NOT alone is the first step toward healing and hope.”

When Ian reaches the Pacific Ocean in San Francisco, CA, with a planned arrival date by late summer/early fall, he will have traveled approximately 3,000 miles. He is not walking away from his grief, but using his walk as therapy to move through the grieving process and to cope with the tragic loss of his only sibling. He carries Ryan’s ashes with him as he walks toward acceptance and allows the beauty of nature around him to calm his mind and spirit.

“Every day, my mission grows,” Ian reflects as the sounds of cars rush by him on the road. “I want my brother’s life and struggle and death to be a catalyst for others to ask for help. We not only need additional resources to assist those whose minds have more to share with us, but we need to bond together as a nation to make it happen. The resources do not have to be limited to using funds to increase support programs. Instead, each and every person in this country can be their own resource for someone in need. It starts with taking any misconceptions surrounding mental illness and throwing them to the ground.”

“Mental illness is as real as the person who lives with one,” Ian continues. “I guarantee that no person would want to share their inner most feelings and thoughts out loud to a society that deems their struggle as a weakness or inadequacy. I know I wouldn’t; however, we must continue to spread awareness and bury stigma to eliminate fear in those with mental illness. We just might be able to learn more about mental illness and how to better treat it when we first learn more about the individuals living with it.”

Ian concluded his interview with the message that if you have lost a loved one to suicide or are experiencing suicidal thoughts on a regular basis, you are NOT alone. Do not be afraid to share your story with others. Your personal experiences and/or association with mental illness will be the key for the future of awareness and understanding.

To support Ian on the second half of his journey across the nation, please visit ianwalksamerica.com, or go to the NAMI Southwestern PA website at www.namiswa.org and click on the Ian Walks America link. Proceeds will help benefit NAMI Southwestern PA in its continuing commitment of spreading education, hope and support to those with mental illness and their family members. The site also includes opportunities for visitors to post their personal stories or messages of encouragement to Ian.
14th Annual Education Conference Offers Voices of Hope for Today’s Young Adults

NAMI Southwestern Pennsylvania’s 14th Annual Education Conference on Saturday, April 12 marked the first time in its 14-year history that the conference sold out before the event. Was it the relevant theme of young adults and mental illness? The exceptional speakers who traveled to Pittsburgh to share their stories of recovery? Or the agenda that featured topics like addiction among young adults, suicidal thoughts, body modification as treatment and using modern technology in recovery?

It may have been all of the above, starting with a warm and informative welcome from NAMI Southwestern Pennsylvania Executive Director Chris Michaels, who gave an overview of “Who is the Millennial Generation?” referring to the 20-something group of young adults that were the focus of this year’s conference.

Soon after the introduction, our first keynote speaker, Stacy Pershall, engaged the audience with her very personal and difficult tale of growing up with borderline personality disorder (BPD). Stacy spoke openly of her struggle with being different and bullied in school; her diagnosis of BPD and an eating disorder; her experience with body modification as treatment; her much publicized online suicide attempt; and ultimately how DBT (Dialectical Behavioral Therapy) saved her life. Stacy’s openness and humor touched everyone in the room. She gave us each a greater understanding of BPD and a renewed appreciation for the many courageous people in recovery.

Next was speaker Dana DeFonso, a supervisor for behavioral health rehabilitation at SPHS Behavioral Health, who gave the morning plenary session, The Voice of Addiction: Substance Use Among Young Adults. Both a clinician and a family member, Dana was able to provide a unique perspective of addiction, particularly among young adults, and what can be done to help.

Our Pittsburgh-style luncheon featured the NAMI Southwestern Pennsylvania annual meeting, conducted by Board President Charma D. Dudley, PhD, FPPR, followed by the presentation of the Dick Jevon Advocacy Award to two longtime advocates Anne Handler and Eleanor Slater. Both women were present to graciously accept the well-deserved award and share the day with us. We are sorry to report that Eleanor passed away on May 24.

The much anticipated presentation from international suicide prevention advocate Kevin Hines came next on the agenda. Kevin shared his heartrending story of growing up with bipolar disorder and the suicidal thoughts that plagued him as a young man. He shared the painful details of his suicide attempt from the Golden Gate Bridge, and how surviving it changed his perspective on life and made him into the advocate that he is today. Kevin’s story gave us great insight and reaffirmed our belief in recovery.

At this point in the day, our attendees chose one of six workshops, including Ask the Doctor by Dr. Roger Haskett; Treatment in the Millennial Age: Using Modern Technology in Recovery by Jen Lukondi and Nicole Campbell; Eating Disorders and Young Adults by Dr. Liz McCabe; Exploring Gender Identity and Sexual Orientation by Sarah Rosso; How Young Adults Can Afford the Affordable Care Act by Jennifer Grybosky; and The Most Astounding Fact: A Writing Workshop for Recovery by Stacy Pershall.

Evaluations and forms for Continuing Education Credits were collected as the day came to an end. We were pleased to see such positive reviews on one of our best and most attended NAMI conferences ever. Thank you to the sponsors (listed on page 6) who made this educational and inspiring day possible! ☺
Not too many decades ago, doctors believed that if a child had a mental illness, it was the fault of the parents -- particularly the mother.

That was the world Eleanor Slater entered, but it wasn’t the one she left. Mrs. Slater, a longtime advocate for families affected by mental illness, died May 24 at her home in East Liberty of ovarian cancer. She was 89.

It was the 1960s when Mrs. Slater, who had never met anyone with a [a child with mental illness], learned she was the mother of a daughter with paranoid schizophrenia. In terms of knowledge about mental illness, the 1960s were “the dark ages,” said her other daughter, Catherine Desjardins of Arlington, Mass.

“There was really such a lack of understanding, that people couldn’t talk to their friends about it, they couldn’t talk to relatives about it, because there were so many misconceptions and misunderstandings,” Ms. Desjardins said.

Mrs. Slater needed support, and she knew others did, too, so she started the Pittsburgh Alliance for the Mentally Ill. “She was really a pioneer,” said Anne Handler, her friend and a fellow advocate for families.

It was work she pursued for decades, helping families and their loved ones cope with a diagnosis that was often isolating and difficult to comprehend.

Much of her life was devoted to making sure families affected by mental illness] received support and that information about mental illness was available -- work that continued until her last days, her daughter said. “It was very brave of her to take this on,” Ms. Desjardins said.

NAMI Southwestern Pennsylvania extends its deepest condolences to the family of Eleanor Slater. We share the grief and sadness of her many friends and fellow advocates. We’re grateful that Eleanor was a longtime NAMI volunteer, supporter and friend.

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2014 NAMI Education Conference Sponsors

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Allegheny HealthChoices, Inc.  Staunton Farm Foundation

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This conference is co-sponsored by Allegheny County Department of Human Services, Office of Behavioral Health.
New Location!!

8th Annual NAMI Walk
Sunday, October 5, 2014
Steel Valley Trail
Waterfront Homestead

Join NAMI Southwestern Pennsylvania for the 8th Annual NAMI Walk

Introducing...

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Walk with us to raise awareness of mental illness. Together we will spread the word that treatment works and recovery is possible!

Information and Registration:
www.namiwalks.org/swpa
When did you first learn about NAMI Southwestern Pennsylvania?

I was introduced to NAMI in 2013 during an *In Our Own Voice* (IOOV) presentation at the Community College of Allegheny County South Campus. I knew right away that I wanted to become involved with the organization. I have lived with symptoms of mental illness since childhood and received a number of diagnoses while in high school and college. The lack of helpful resources and support for people my age inspired me to pursue a bachelor’s degree in Psychology and a career in the mental health field - working with young people - after I graduate in 2016 from Penn State University. Volunteering with NAMI has shown me that I don’t need my degree to start making a positive difference in my community right now.

Why did you feel such an immediate connection with NAMI Southwestern Pennsylvania?

One of the four objectives in NAMI’s Strategic Plan for the next three years is to create a culture of transformation by focusing on the relevant needs of children and youth in our region. I feel very connected to this endeavor because I know firsthand what it is like to struggle with mental illness as an adolescent. I recognize how early intervention can dramatically improve recovery efforts for young people with mental illness and the importance of providing parents with easier access to effective resources that can help them support their children. NAMI Southwestern Pennsylvania’s commitment to children and transition-age youth by training educators, providing support services to parents and advocating for improved mental health services for young people like me is a mission that I can embrace.

What resources and treatments have been most effective for you?

I struggled with anxiety and depression and was diagnosed with Bipolar II Disorder during my freshman year of college. As a student, my quest for perfection overwhelmed me. I have learned how to become more aware of my thoughts and how to focus them in more positive ways before they lead to certain negative behaviors and actions. I am also grateful for the resources that have helped to bridge the gap of understanding between my family and me and appreciate that they understand better what I am going through and how to encourage me.

What activities have you participated in to promote NAMI’s work?

I served as both a volunteer and a fundraiser for NAMI Walks in 2013 and am already getting ready for this year’s Walk. I co-presented in a workshop for the NAMI 2014 Annual Education Conference *Young Adults and Mental Illness: Voices for Hope*. Along with NAMI staff, I have presented to parents, educators and para-professionals about anxiety and how it is presents itself in school-age children. I also participated in a NAMI IOOV presentation at North Allegheny High School. It was great to connect with high school students and offer encouragement.

Why is it so important for young people to become active NAMI volunteers?

We have age on our side! We can make faster, stronger connections with other young people because it’s easier to build trust and a rapport with people our own age. When young people who are living with mental illness have the courage to speak out, it inspires other youth who are struggling on their own to ask for help. When you find that help at a younger age, it puts your life journey on a better, healthier path. NAMI needs a large, diverse group of volunteers of all ages, races, cultures and backgrounds because mental illness doesn’t discriminate, and people with serious mental illness won’t feel as alone if they see people just like them who are in recovery and full of hope.
NAMI Southwestern Pennsylvania is proud to announce it has been awarded the Seal of Excellence by the Pennsylvania Association of Nonprofit Organizations (PANO) for successfully completing the Standards for Excellence accreditation program. NAMI Southwestern Pennsylvania earned The Seal of Excellence in January 2014 at the culmination of a rigorous months-long review process conducted by PANO and a team of independent peer reviewers. They evaluated all of the organization’s operations, work and accomplishments and determined that NAMI demonstrated successful compliance in meeting the high standards set forth in PANO’s Standards for Excellence: An Ethics and Accountability Code for the Nonprofit Sector.

“The quality of our work matters, and we want to be excellent,” says NAMI Southwestern Pennsylvania Executive Director Chris Michaels, MSHSA. “Pursuing the Seal of Excellence required us to examine our organization from the inside out, revealing how NAMI was built on a strong foundation and validating that our work is of the highest quality.”

Of the approximately one million nonprofits operating today in the United States, only about 200 have earned the Seal. NAMI Southwestern Pennsylvania is one of just 15 nonprofits in southwestern PA to have earned this distinction.

“The Seal of Excellence is granted to well-managed, responsibly governed organizations that are deserving of the public’s trust,” explains Patricia Mogan, Standards for Excellence Officer for PANO. Anne Gingerich, PANO’s Executive Director, adds, “NAMI can focus even more fully on advancing its mission of improving the lives of individuals and families affected by mental illness, as staff will be less likely to get bogged down in the issues that can arise due to faulty internal systems. The Seal of Excellence is truly one of the ways that organizations can better position themselves to reach their fullest potential.”

“It has been very rewarding to work through this process to achieve the Seal of Excellence distinction,” says Michaels. “The recognition has inspired our staff to a new level of motivation, and we hope that the accreditation will open new doors to us in the fundraising community. We also believe that the Seal shows that we are a worthy partner, and we look forward to establishing additional collaborative relationships with other organizations in our region who have similar missions.”

NAMI staff accepted the Seal of Excellence award at a special event held at PANO in Harrisburg, PA on April 29.

### PANO Standards for Excellence

Only organizations which demonstrate their compliance with the Standards for Excellence are given permission to use the Seal of Excellence.

- **The Seal of Excellence is a symbol for trust.** Organizations that display the Seal go beyond simply obeying the law and government regulation – they demonstrate their willingness to earn the public’s trust.

- **The Seal of Excellence is a symbol of excellence in nonprofit management.** Organizations that display the Seal are guided by a well defined mission, have evaluation systems in place to measure the effectiveness of their programs and adhere to sound financial management policies.

- **The Seal of Excellence is a symbol of excellence in leadership.** Organizations that display the Seal are led by a volunteer Board of Directors that accepts responsibility to oversee the organization’s mission, policies, programs, human and financial resources.

- **The Seal of Excellence is a symbol of openness and disclosure in nonprofits.** Organizations that display the Seal have information available to the public, provide truthful responsible stewardship of all donations and provide a voice for their constituents.
CART (Consumer Action & Response Team) of Allegheny County is a program of NAMI Southwestern Pennsylvania. In addition to conducting satisfaction surveys with Allegheny County residents about the behavioral health services they receive, CART also interviews family members to get their input. CART is funded by Allegheny County Department of Human Services and Community Care. The purpose for these interviews is to provide quality improvement information to the providers and payers of services.

If you would like to be interviewed as a family member or as an individual who receives services, please call CART Tuesday through Thursday from 9 a.m. to 4 p.m. at 412-348-0126 or 1-800-300-6026. The interviews are confidential but they will need to know the name of the service provider, the service type (i.e. Outpatient, Partial Hospitalization, C.R.I.R.) and the location.

What is the NAMI Family-to-Family Education Program?

NAMI Family-to-Family is a free, 12-session education program for family, partners, friends and significant others of adults living with mental illness. The course is designed to help all family members understand and support their loved one living with mental illness, while maintaining their own well-being. The course includes information on illnesses such as schizophrenia, bipolar disorder, major depression and other mental health conditions. Thousands of families describe the program as life-changing. The program is taught by trained teachers who are also family members and know what it is like to have a loved one living with mental illness.

NAMI Southwestern Pennsylvania, the local organization of the National Alliance on Mental Illness, offers the NAMI Family-to-Family Education Program throughout the year in various locations. Visit the [www.namiswa.org](http://www.namiswa.org) to learn more about Family-to-Family and NAMI’s Signature Education programs.

Participant Perspectives

“This course overall was the single most, without a doubt, helpful and informative thing ever offered in all my years searching for answers... It has helped me to understand better and communicate more effectively with my brother.”

Contact NAMI Southwestern PA to register for September 2014 classes! 1-888-264-7972 or email info@namiswa.org
NAMI Support Groups...

Visit the NAMI Southwestern PA website, www.namiswpa.org, and click on the “Support” link at the top of the homepage for a complete listing and meeting dates of support groups.

**Allegheny County**
NAMI Parent Support Group - Youth and Transition-Age East Liberty Carnegie Library, 5 - 7 p.m. Contact: Linda Thornhill, 412-403-9539 for more information.

NAMI Pittsburgh South - Mt. Lebanon
Contact Email: nami.south@gmail.com

NAMI Pittsburgh North - Ross Township
Contact: Tom/Janet Ammons 724-443-4422

NAMI Pittsburgh East-FAMILIAS - Churchill
Contact: Anne Handler 412-421-3656

NAMI Spouse Support Group - Churchill
Contact: Mim Schwartz 412-731-4855

NAMI McKeesport, Penn State McKeesport
Contact: Violet Ludwig 412-373-7977

NAMI Western PA Borderline/Personality Disorders Family Support Group - Ross Township
Contact: Jo Burkholder 412-776-5974

Minority Families of the Mentally Ill - Oakland
Contact: Wilma Sirmons 412-327-4890

NAMI W.P.I.C. Family Support Group - Oakland
Contact: Merle Morgenstern 412-246-5851

**Butler County**
NAMI PA Butler County - Butler MHA
Contact: Butler NAMI Office 724-431-0069

NEW: Teen Peer Support Group
Contact: 412-304-8521 for meeting information
Location: Guthrie Paganie & Associates, 162 Brickyard Road, Ste 100, Mars PA 16046

**Fayette County**
NAMI-C.A.R.E. Fayette County
Contact: Carol Warman 724-439-1352

**Indiana County**
NAMI Indiana County - Third Tuesday each month, 5:30 p.m., Community Guidance Center, Contact: Autumn 724-422-4718

**Lawrence County**
NAMI Lawrence County
Contact: Sandi Hause 724-657-0226

**Washington County**
NAMI Washington County - Washington, 4th Thursday of the month
Contact: Jim Gleason 724-225-1607

**Westmoreland County**
NAMI Alle-Kiski - New Kensington, 2nd Wednesday of the month
Contact: Thad Kaminski 724-339-1339

NAMI Mon Valley - Contact: Harriett Hetrick (724) 872-2186 for more information regarding the following locations:
- Monessen, 2nd Monday of the Month, 7-8:30 p.m.
- Irwin, 2nd Tuesday of the Month, 7-9 p.m.
- West Newton, 3rd Thursday of the month, 6:30-8:30 p.m.
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.

- Individual/Family/Friend $35.00
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Please make check payable and mail to:  NAMI Southwestern Pennsylvania, 105 Braunlich Drive, McKnight Plaza, Suite 200, Pittsburgh, PA 15237

You may also join or donate via the website at www.namiswpa.org.