



# The Voice

The Newsletter of NAMI Southwestern Pennsylvania

Volume 17, Issue 2 December 2011

## Translational Research

### Transforming Scientific Knowledge into More Effective Disease Treatment and Prevention

Research that yields discovery is the backbone of modern medicine. But, scientific breakthroughs will only improve human health if those discoveries can be translated into practical applications, such as medications, therapies and other interventions to prevent or treat disease. This method of transforming scientific research results into tangible improvements in healthcare is called translational research.

Traditionally, basic scientific research has most often been initiated at the molecular level in the laboratory. This type of research has resulted in a wealth of scientific knowledge, but that knowledge has not translated into the same level of increased clinical progress and improved health outcomes for patients. On the other hand, medical treatments for psychiatric illness have often been discovered serendipitously without an understanding of the underlying disease process. For example, through trial and error, medications have been found to reduce certain symptoms of a disease, but it is unknown why the disease occurs in the first place, or how and why the medication is working in the body to have an impact.



develop a solution, followed by the clinical studies and processes that refine the solution to be effective in patients. The phrase often used to describe this process is “from the bedside to the bench and back.”

David A. Lewis, MD, chair of the Department of Psychiatry and medical director of Western Psychiatric Institute and Clinic (WPIC) of the University of Pittsburgh Medical Center (UPMC) School of Medicine, is considered a leading translational researcher in the field of neuroscience. He explains, “Translational research has been slower to take hold in neuroscience than in other medical fields because the brain is much more complex to study than any other organ in the body.”

The concept of translational research is to transform traditional research practices by reversing the order of analysis: start with the patient, and then move to the laboratory. The first step involves conducting clinical observations of patients to identify a medical problem, followed by translating those observations into hypotheses about the cause of the problem. That information is then taken to the laboratory as the basis for conducting research to

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## *From the Desk of the Executive Director*

Christine Michaels, MSHSA  
Executive Director, NAMI Southwestern Pennsylvania

**T**his edition of our newsletter always heralds in the winter holiday season, beginning with Thanksgiving Day. It's not the holidays but the feelings—the “feel good” feelings—that I savor. And, right now I am craving the emotional feel good sustenance that comes this time of year.

Surprisingly to me, I found that holiday “feel good” feeling reading this edition of our newsletter. Both the “In the Spotlight” and the “NAMI Conference Attendees Help Create First Public Artwork in Kazakhstan” articles pack an emotionally powered wallop of heartfelt, soulful goodness. Whether it's our NAMI Walk, our Conference or just a regular day in the office, the return on our emotional investment in others comes back to us and to our organization exponentially, in ways we can't even begin to measure.

With the holidays comes New Year's Day, and we optimistically welcome a new year, a new beginning, the future. That is the fundamental underlying message of our feature article, “Translational Research: Transforming Scientific Knowledge into More Effective Disease Treatment and Prevention.” The future-thinking, hope-inspiring idea is that scientific research can be transformed to have a recovery focus and that research can be “translated” into tangible improvements in the system and in the lives of people with mental illness. As research goes through a systems transformation like community mental health services to focus on recovery, can we not help but think about prevention, about preventing mental illness? Talk about “feel good” feelings!

Not only is this our holiday edition, it is our special “Walk” edition. To everyone who participated in our 2011 NAMI Walk, we thank you from the bottom of our hearts. And to those of you who came out on Walk Day despite the cold, the rain and the wind: we, NAMI Southwestern Pennsylvania, will always Walk with you, no matter what.

Have a wonderful holiday season, and best wishes for the New Year!

Sincerely,

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

### **NAMI Southwestern Pennsylvania Mission Statement**

**NAMI Southwestern Pennsylvania is dedicated to improving the lives of individuals and families affected by mental illness through recovery focused support, education and advocacy.**

# News Around the Region:

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

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



### Deputy Secretary of the Department of Public Welfare Announced

On Sept. 29, Department of Public Welfare (DPW) Secretary Gary Alexander announced the appointment of the deputy secretary of the Office of Mental Health and Substance Abuse Services (OMHSAS).

Blaine Smith was appointed deputy secretary for OMHSAS and began his tenure on Nov. 15. Smith most recently was the executive director for the Central Pennsylvania Behavioral Health Collaborative in Blair County. He previously served as director of finance, Home Nursing Agency, Altoona and chief fiscal officer, Blair County Mental Health/Mental Retardation and Drug & Alcohol Offices. He is a lifelong resident of central Pennsylvania.

We at NAMI Southwestern Pennsylvania welcome the new deputy secretary and look forward to working together to improve the lives of our citizens of all ages and their families affected by mental illnesses. We urge Deputy Secretary Smith to actively seek the input of consumers and families prior to making policy decisions that can so significantly impact lives. We are also pleased to share that former Acting Deputy Secretary Sherry Snyder remains with OMHSAS. Through meaningful dialogue and collaborative efforts, we can continue the transformation to true recovery oriented community mental health treatments and supports that are the signature of prior Deputy Secretary Joan Erney's tenure.

### Some Medicaid Eligible Pennsylvanians Lose Benefits

As widely reported, the County Assistance Offices (CAOs) had a backlog of 154,000 Medicaid cases overdue for Re-Determination as of July 1. DPW/Office of Medical Assistance Programs ordered the CAOs to review these cases in a shortened timeframe with reduced staffing and an already high volume of every day workloads. The results of the clearing of the back log were that 77,000 people lost their benefits; that is more than double the average case closings for the prior 18 months.

Of those people who lost benefits: 82 percent did not provide the required verification, 14 percent were determined to be no longer eligible, 2.5 percent voluntarily closed their cases and 2.5 percent failed to show up for their CAO appointment scheduled after they properly responded. As of Oct. 20, there had been a net closure of 105,000 Medicaid cases. OMHSAS states the overwhelming majority of the terminations are legitimate; however, advocates continue to hear from eligible people who had their benefits terminated.

### What to Do if You or Your Family Member Believes Benefits Were Wrongly Terminated

- File an appeal to the advance termination notice within 13 days on the postmarked date (make a copy to keep).
- Mail the appeal via certified mail and request a return receipt or hand deliver the appeal to the CAO and ask for a receipt.
- Contact the OMHSAS Western Operations Field Office in Pittsburgh at 412-565-5226.
- Contact your respective state legislators to inform them of your situation.

Please contact the NAMI Southwestern Pennsylvania office as we are attempting to track the number of people living with mental illness that are affected. People needing assistance with filing appeals or who have other questions related to benefits can contact the PA Health Law Project Helpline at 1-888-274-3258.

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Alex and Lauren in front of mural

## NAMI Conference Attendees Help Create First Public Artwork in Kazakhstan

Сәлеметсіздер ме  
Қазақстандан! Hello  
from Kazakhstan!

**M**y name is Alex M. White and I am a Peace Corps volunteer living and serving in Kyzylzhar, a 2000-person village in northwestern Kazakhstan, the largest country in Central Asia. I was the keynote speaker at NAMI Southwestern Pennsylvania's 11th Annual Education Conference, "Embracing Diversity: Cultivating Respect and Inclusion for a Stronger Mental Health System."

For those of you who weren't in attendance at the conference last April, what happened still seems like a fairy tale. During the Q&A after my keynote, an audience member asked what my next plans were. I shared that I was working on a grant to paint a mural on the front of my village school. Someone else asked, "How much are you trying to raise?" I answered apprehensively: \$300. "I've got \$5!" "I've got \$10!" A bowl was fetched from another room and passed around. In a matter of minutes, \$200 had been given. By the time I boarded the plane back to Kazakhstan, over \$500 had been donated. I was shocked and moved beyond words. I still am to this day.



Lauren and student begin mural

When I returned to Kyzylzhar, the first thing I did was run to school and tell my school director what had happened. He didn't understand at first, because that kind of monetary generosity is somewhat of a foreign concept where I live. After I explained again, he immediately called every

teacher and staff member into a meeting to announce the unbelievable news of what happened: during my 78 hour visit to the United States, 200 complete strangers donated over \$500 and now our school was going to be getting a mural!

My students got to work right away designing the mural. When all the elements and feedback were collected, my fiancée Lauren Chester flew from New York to Kazakhstan to render and implement the final design. The mural contains traditional Kazakh imagery, which centers upon the yurt and the words "Children are our future" around it. On the left is a teacher from our school with the iconic Әліпие



Finished mural in Kyzylzhar

book, which is the first book students are taught to read. On the right a first grade Russian boy and Kazakh girl hold the bell with an 11th grade student for the Last Bell Ceremony, their form of graduation. On the bottom is the river and a tree, which are fixtures in the Kyzylzhar landscape. The Kyzylzhar tree grows into the Baiterek, the symbol of not only Kazakhstan's capital, but its future potential as well.

This is the first public artwork ever created in the village of Kyzylzhar and the reaction has been gratifying. It's the first thing you see when you arrive in the village, and parents bring their children to the mural to tell them the stories behind the images in it.

The Peace Corps helps to promote a better understanding of Americans on the part of the peoples served, and helps promote a better understanding of other peoples on the part of Americans. The exchange of NAMI Southwestern Pennsylvania and Kyzylzhar Secondary School accomplished just that. The generosity of the conference attendees made me proud to be an American and was a tangible illustration to an entire village of international goodwill. To all those who gave, as we say in Kazakhstan, "Үлкен таудай рахмет!" – "A large mountain of thanks!"



Changing  
Minds...  
One Step  
at a Time

5th Annual NAMI WALK  
October 2, 2011



# 5th Annual NAMI Walk: A Rainy But Inspiring Day

## NAMI Southwestern Pennsylvania Celebrates Its Most Successful Walk To Date

Imagine a cold Sunday morning with rainshowers and strong winds that make it uninviting to go outside. That was the unfortunate climate for the 5th Annual NAMI Walk at the SouthSide Works on Oct. 2. The NAMI staff and volunteers set up the walk site in the early morning hours, but as 9 a.m. rolled around, there were only a handful of walkers on site and most were huddled under tents, trying to keep dry and warm. Even the mascots—the four Pittsburgh Pierogies—seemed uncharacteristically ho-hum. It was a dismal start to a much anticipated day.

Then something miraculous happened. As the 10 a.m. start time approached, walkers began appearing in droves. Before long, the site filled up with over 1,000 NAMI Walkers, some dancing to DJ Dale McCue’s lively music in the rain! Even the Pierogies perked up and joined in on the fun.

By the time singer John Tucci kicked off the 5K walk with the Star Spangled Banner, all three TV news stations turned up to film the walk. What a great news story: over a thousand mental health advocates walking in the rain to celebrate recovery!

What started as the worst event in our NAMI Walk history turned out to be the most inspiring. In addition, our sponsors, teams and fundraisers exceeded our fundraising goal of \$150,000, raising 20 percent more than last year’s walk. Wow!

With their resilience, passion and commitment to the cause, our participants and volunteers truly embodied the NAMI spirit on walk day.



## Team T-Shirt Contest Winner



Hats off to Porky the Yorkie and her fabulous team "Porky's Paws For A Cause" for winning the 2011 Team T-Shirt Contest. Way to go... RUFF!



Above: NAMI Southwestern Pennsylvania Executive Director Chris Michaels speaks to all three of Pittsburgh’s major TV news stations at the Walk. Below: Miss Pennsylvania Juliann Sheldon braves the cold weather to join us on Walk day.



## Special Thanks: NAMI Walk Chairs

### **John Lovelace, NAMI Walk Chair, President, UPMC for You & Chief Program Officer, Community Care**



John Lovelace showed his dedication to NAMI by increasing his involvement and support of the NAMI Walk this year. John gladly stepped into the role of NAMI Walk Chair and increased his organization's sponsorship by nearly 70 percent, making UPMC & UPMC Insurance Services our Walk's first ever

Premier Sponsor. He also rallied his various teams into one giant Superteam comprised of Community Care, UPMC Health Plan and Western Psychiatric, which all together raised over \$25,000! John challenged other sponsors and teams to "up" their support as well, and many of them took his words to heart. We extend our gratitude to John and his team for being a huge part of the 5th Annual NAMI Walk's record-breaking year.

### **Michelle Wright, Honorary Chair, News Anchor, WTAE-TV**

Michelle has been involved with our NAMI Walk from its inception five years ago. Each year, she has increased her

support of NAMI and made every effort to raise awareness of mental illness and the Walk. As a well-known news anchor in Pittsburgh, Michelle enthusiastically serves as the Walk's spokesperson and does an exceptional job. We cannot imagine the NAMI Walk without Michelle Wright. Thank you, Michelle!



### **Jim Ehrman, Family Team Chair & Top Fundraiser, Five Consecutive Years**

Jim is our Walk Champion. Year after year, Jim is actively involved in the planning of the NAMI Walk and works tirelessly to raise funds on behalf of his Walk team Jim's Jocks. With his unyielding persistence and commitment to NAMI, Jim has been named Top Walk Fundraiser for the past five years. Also, Jim's Jocks has landed in our Top Ten Teams each and every year. Now a NAMI Southwestern Pennsylvania board member, Jim remains an essential part of the continued success of the NAMI Walk. Thanks Jim!



## Top 10 Teams

Teams are the heart of the NAMI Walk, and this year

77 teams walked with us. These are our top teams based on overall fundraising total. We applaud and thank them for their exceptional work.

1. Western Psychiatric - \$19,100
2. Jim's Jocks - \$8,220
3. NAMI Southwestern PA - \$8,206
4. Community Care - \$5,601
5. Mercy Behavioral Health - \$3,750
6. Leo's Team - \$3,365
7. South Hills Stampede - \$3,310
8. NHS Human Services - \$3,100
9. CART of Allegheny County - \$2,723
10. J-Walkers - \$2,463

Honorable Mentions: Team Secret Agent L - \$2,240 and Allegheny HealthChoices - \$2,080



Top fundraising team, Team WPIC

## Top 5 Fundraisers

These five NAMI Walkers are the 2011 fundraising superstars! We thank them for sharing their stories with family and friends to raise awareness of mental illness and funds for NAMI Southwestern Pennsylvania.

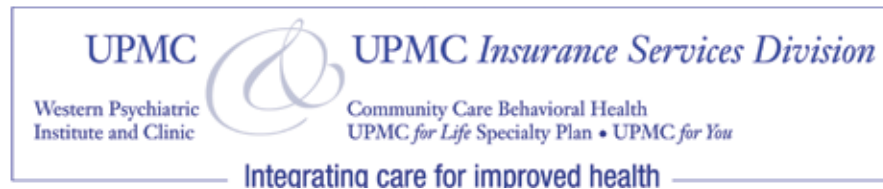
1. Jim Ehrman (Jim's Jocks) - \$8,070
2. Raymond Baum (Leo's Team) - \$2,235
3. Lora Dziemiela (Porky's Paws for a Cause) - \$2,175
4. Stephanie Sluka (NHS Human Services) - \$1,745
5. Eileen Lovell (South Hills Stampede) - \$1,565



## 2011 NAMI Walk Volunteers

We salute our NAMI Walk volunteers. Without them, it would literally be impossible to put on the NAMI Walk. Whether they served on the planning committee, volunteered at the Kickoff Luncheon or showed up bright and early in the rain on Walk Day, we thank them for their dedication and support. Visit the NAMI Southwestern Pennsylvania website at [www.namiswpa.org](http://www.namiswpa.org) for a listing of the 2011 volunteers.

## Our Sincere Thanks to our Generous 2011 NAMI Walk Sponsors



Cindy & Norman McHolme      Allegheny HealthChoices, Inc.

AstraZeneca Pharmaceuticals      Dollar Bank

Clarion Psychiatric Center      InVision Human Services

Mercy Behavioral Health      NHS Human Services      Thorp Reed & Armstrong

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Allegheny Family Network      Bookminders      Charma D. Dudley, PhD, FPPR Licensed Psychologist

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### Refreshment Sponsors

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“The brain is harder to study because it is protected by the skull and cannot be safely biopsied like other organs, Dr. Lewis continues. “In addition, the use of certain other approaches to study the function of an organ may carry greater risks for the patient when the brain is the focus of study.

“Understanding an organ’s normal function is a vital building block in the success of translational research, so advances in basic neuroscience research were needed before we could begin to explore the causes of abnormal brain function that lead to psychiatric illness.”

### **How It Works**

Dr. Lewis’ research targets the connections among the brain cells in an area of the brain called the prefrontal cortex, specifically investigating the alterations of these connections in schizophrenia. The prefrontal cortex and its connections with other brain regions are important for the thought processes that regulate behavior. Dr. Lewis is analyzing the normal structure and function of the prefrontal cortex, determining how these are altered in schizophrenia, and conducting a variety of scientific studies to understand the causes and consequences of these abnormalities, with a goal of translating the results in clinical interventions such as new, more effective medications.

Through translational research, Dr. Lewis and his colleagues are focused on understanding the neurobiological foundation for complex human thoughts and feelings, and determining what changes in the brain alter these functions to cause certain mental disorders. Through clinical observations, Dr. Lewis and his team of neuroscience researchers generate hypotheses about the factors that cause brain disturbances in major psychiatric illnesses; test these hypotheses in the controlled condition of the laboratory; and use this information to identify new strategies for treatment development. The goals are to find novel ways to reverse the processes that cause the signs and symptoms of mental illness and ultimately to prevent mental disorders.

### **Goals and Outcomes**

Dr. Lewis’ translational research on brain abnormalities has been the catalyst for a number of promising leads to develop new medications. Recently, this research identified a possible pathophysiological process in those with schizophrenia that

## **Defining Translational Research**

“Translational research includes two areas of translation,” according to the National Institutes of Health (NIH). “One [area of translation] is the process of applying discoveries generated during research in the laboratory, and in preclinical studies, to the development of trials and studies in humans. The second area of translation concerns research aimed at enhancing the adoption of best practices in the community.”

In simpler terms, translational research is the process of “transform(ing) scientific discoveries into tangible improvements in mental healthcare and in the lives of people living with and affected by mental illness,” according to the NIMH Strategic Plan.

suggested a novel drug target for enhancing working memory function. The research process to create that drug is currently underway.

“There are a number of goals related to this research,” Dr. Lewis explains. “We are seeking to find medications and other interventions that will normalize brain function to empower recovery efforts, but we also want to be able to identify people who are at high risk for serious mental illness and intervene with safe treatment options to either prevent symptoms from occurring, or to curb those symptoms from becoming severe if they do occur.”

Translational research can be effective when the basic laboratory scientists work in collaboration with clinicians and public health scientists to develop programs where targeted medical needs are identified and addressed. A stronger research infrastructure that more effectively links the bedside and the bench will produce scientific discoveries that can dramatically improve health outcomes.

### **Key Partners**

Translational research is a core component of the strategic research priorities of the National Institute on Mental Health (NIMH), the largest scientific organization in the world dedicated to research of the mind, brain and behavior focused on the understanding, treatment and prevention of

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## *In the Spotlight...*

**Stephanie E. Sluka, MSCP, Behavioral Health Rehabilitative Services Director, NHS Human Services of Allegheny County**

### **What role does NHS Human Services have in the mental health community?**

NHS is one of the largest multi-service, non-profit providers of human services for children, adults and families in the nation. We provide behavioral health services and educational opportunities for children with Pervasive Development Disorders, including autism. NHS supports individuals with intellectual and developmental disabilities, and provides juvenile justice programs and comprehensive addiction treatment. We offer integrated recovery services to adults with mental health issues and promote independent living for seniors. NHS also has specialized treatment foster care programs for children. I provide administrative and clinical support to the clinicians who support the children both on and off the Autism Spectrum by conducting functional behavior assessments and coordinating therapeutic services.

### **What are your passions?**

I have always had a passion to serve children with special needs and to eradicate stigma toward people who are different. We lost my father to suicide when he was 47 years old. I believe that he struggled with depression for most of his adult life, but because of stigma, he was unable to ask for help. I was 17 when he died, and he has missed so many important events in my life. If he had felt comfortable, accepted and empowered to seek treatment, instead of alone and misunderstood, I think he would still be alive today. By defeating stigma, others won't have to suffer the kind of loss I live with every day.

### **How have you chosen to fight stigma?**

This past summer, my supervisor asked me to serve as the NHS team captain for NAMI Walks. I am a natural encourager and was confident that I could inspire our

team to raise funds and recruit new participants, but I was unprepared for how the experience would turn my world upside down. Actually, I think the better description is that it turned my world right-side up!

### **How did your life change because of the NAMI Walk?**


As a team captain, I was invited to the NAMI Walk Kick-Off Luncheon in August. The speaker, Laura Miller, shared her personal story of how mental illness has impacted her life. I became very emotional. For years, I hadn't talked about the circumstances surrounding my father's death. For years, I had struggled silently with my own diagnoses of generalized anxiety disorder and major depressive disorder. I was so afraid of encountering stigma from those I loved and trusted if I shared my secrets. But, here was this strong, courageous woman, standing in front of a room filled with people, with her head held high. I felt so empowered at that moment. I found my voice that day. I decided to talk about how mental illness has shaped my life. I'll never be quiet again.

### **Why is it so important for people to talk about mental illness?**

When people share how they are feeling, what they are going through, and how others can support them, the education and understanding that results from those conversations is very powerful. The first time I told my story – to my co-worker Phil Horrell in the car after that luncheon – I felt so supported and encouraged. Every time I tell my story, I feel more confident that my words can make a difference, and I feel strength in knowing that I can handle stigma if I encounter it. I hope when others hear my story, they will share theirs. The more we talk, the weaker the hold stigma will have. My Dad always told me to never sign on to any project that I am not proud to be a part of. I keep his words in my heart, and I believe that he would be proud of me for being honest, open and empowering.

mental disorders and the promotion of mental health. The NIMH is part of the National Institute of Mental Health, a component of the US Department of Health and Human Services.

In addition to national organizations such as the NIMH, local organizations are also championing the benefits of translational research in the field of neuroscience. UPMC and WPIC are national leaders in translational research for behavioral health and addiction. In a spirit of competitive collaboration with other neuroscience researchers across the country including Yale, the University of California at San Diego, Columbia University, the University of North Carolina and the University of Pennsylvania, scientists are applying translational research practices to identify new, better treatments for those with mental illness.

“I have seen exponential growth in the field of neuroscience research in the past 15 to 20 years,” Dr. Lewis concludes. “I am optimistic that the substantial and clear progress that has been made utilizing translational research methods will lead to successful outcomes related to more effective treatments and preventive strategies for people affected by serious mental illness.” 



**SAVE THE DATE**

**NAMI Southwestern Pennsylvania's  
12th Annual  
Education Conference**

**Saturday, April 21, 2012  
Pittsburgh Airport Marriott**

**Over 20 different types of continued  
education credits will be offered!**

### **This Edition's Advocacy Tip:**


#### **Seven Steps When Telling Your Story**

State Legislators and policy makers want facts and figures, but they also want to talk with people who have experienced a policy issue firsthand—those who can provide illustrations in real human terms. When wanting to tell your story in person, always make an appointment. If the legislator or policy maker is unavailable, meet with staffers and treat them as professionally as you would their boss.

1. Open with a thank you for the opportunity to share your views. Describe who you are and why you are speaking (or writing). Knowing your name and more importantly where you live helps to make a connection.
2. Share how you are personally affected by mental illness. This will put a face on mental illness and recovery.
3. Tell your story. To tell your story effectively, answer the following in a few sentences: What happened? What helped? How are you different today?

4. Make your issue known up front (if possible reference a specific bill).
5. Make your point. Help others by giving a brief, positive message about community based recovery focused mental health treatment and supports.
6. Make “the ask.” Share the action or position you would want taken.
7. Close with a thank you for sharing of their time. If you are comfortable with this, please offer to serve as a resource on all mental health matters. Leave behind literature such as a NAMI brochure or newsletter and include something with your name address and telephone number.

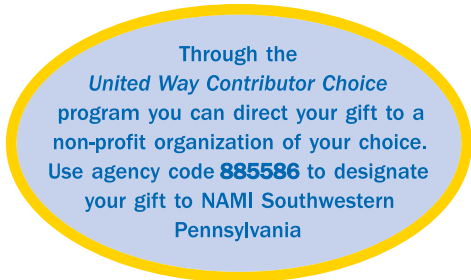
Every few months check in with your legislator either by making a brief telephone call or sending a letter or email reminding them why mental health funding matters.

Contact me at [smiller@namiswpa.org](mailto:smiller@namiswpa.org) or call the NAMI office at (412) 366-3788 for additional effective advocacy tips. Go to [www.namiswpa.org](http://www.namiswpa.org) to download the “Advocacy Toolkit.” 

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

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

- I would prefer 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) \_\_\_\_\_

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