



National Alliance on Mental Illness

NAMI Missouri

Support / Education / Advocacy / Research

SUMMER 2016

Family-to-Family

Family Education Cited in NIMH RAISE Study on Early Psychosis

The Family-to-Family Course has long been the cornerstone of NAMI's peer-taught programs. Here in Missouri dozens of trained volunteers will enroll parents, siblings, adult children and spouses in fall, early winter and spring courses.

While most courses will occur in St. Louis and Kansas City, affiliates in Joplin, Farmington, Springfield, Rolla, and Columbia also offer the course. In July, new teachers from Cape Girardeau, St. Joseph, Springfield, Poplar Bluff, Boonville, Jefferson City and Joplin completed teacher training in Jefferson City.



The efficacy of family psychoeducation, and the NAMI Family-to-Family course in particular, is validated by medical/scientific research (the latest study was published in June).

Today, NAMI affiliates and FTF teachers have a new reason to feel proud. Peer family psychoeducation is one of the eight practices cited in the National Institute of Mental Health (NIMH) RAISE study on early episode psychosis. Applied together, these practices were shown to produce significant recovery in young adults who were in the first two years of their first episode of psychosis.

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All NAMI affiliates have support groups.
 Support groups also meet in Branson,
 Hannibal, Brunswick, and Washington

WARMLine

1-800-374-2138

**NAMI Missouri is the chartered state organization
 of the National Alliance on Mental Illness**

A Life of Service

Remembering a NAMI Family Member



Nikk (Nelson) Thompson

Our NAMI family suffered a loss on August 5th. Veteran, former police officer, ardent advocate for police CIT training, NAMI teacher/speaker and so much more, Nikk (Nelson) Thompson touched thousands of lives.

As a NAMI Greater Kansas City volunteer at first, and then staff, Nikk was instrumental in bringing the first CIT courses to Missouri. He is mourned by a loving wife Cheryl, children, grandchildren and his two beloved white boxers. He will be sorely missed.

NAMI Southeast Missouri's Family-to-Family Class



From Left To Right: Ken Short, Warren Westrup, Janet Short, Tom Carroll, Teresa Carroll, Robyn Houston, Sonja Wright, And Crystal Ward.

Family education cited in study on early psychosis

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Study participants resumed nearly normal lives, returning to school and jobs. The trajectory from early episodes into permanent disability was interrupted and halted.

This good news, however, is tempered by a sad reality. Current mental health systems are ill equipped to carry out large scale early detection/prevention programs. Most require a firm diagnosis (which can take a year or more) and current systems prioritize treatment for the most ill. Helping those who are most ill while simultaneously bringing up programs to treat psychosis early won't be easy.

Recognizing this, the Center for Mental Health Services (SAMHSA) will add monies to each state's block grant for early detection and prevention initiatives. The new money isn't enough for wide-scale programming, but it will help states get started.

NAMI members across the nation are advocating for passage of Senate Bill 2680 which, if passed, will provide more funding for interrupting early psychosis, suicide prevention, crisis intervention and more. This bill passed the House in June.

Sounding Board

Noise Sensitivity & Mood

Here's a mood symptom you won't see on many lists: noise sensitivity. Science hasn't looked into this much, so it can be an Aha! moment when people realize that a sudden intolerance for sounds is connected to the onset of a mood shift.

The topic generated a passionate discussion on our bpHope Forum, and we took notice. Our Summer 2016 issue includes "When Noise Annoys," takes a deeper look into the phenomenon. Whether it's linked to depression or elevated mood, noise sensitivity usually twins with extreme irritability.

Repetitive sounds are especially triggering: barking dogs, water dripping, clocks ticking, the ticking of an appliance, a squeak in the car. Sometimes it's the noises other people make, from chewing gum to slurping soup to just plain talking. "I just want/need silence, and there is no way for me to have it," one member wrote on our Forum.

Since silence is hard to come by, what helps? Well, there's the dad who bought 25 cars in 31 years—he literally couldn't stand it when his current vehicle developed an irksome sound. Some alternate approaches: "The right meds have greatly reduced my noise sensitivity and other irritations." "For me, the best thing was meditating several times a day."

In "When Noise Annoys," Kevin H. explains how he worked with his therapist to develop a coping plan for times of depressive irritability. That way he won't lash out at his kids when they're drumming on the table, for example. For Lynn H., it's as simple as using earplugs.



In Remembrance

Memorial Donations & Tributes

A memorial donation in memory of
Cody Stretz
son of Marla Stretz of Blackwater, MO
by Tim and Linda Harlan

A memorial donation in the memory of
Charles (Chuck) Huff,
NAMI Jefferson City volunteer family
support group member
and NAMI Homefront teacher
by Cindi Keele

A memorial donation in the memory of
George A. Fergusson,
husband of long time NAMI St. Louis
member and former NAMI MO Board
Member Christine Ferguson
by George A. Reeves

A memorial donation in the memory of
Nikk Thompson
NAMI Greater Kansas City CIT Coordinator
by Cindi Keele

A memorial donation in the memory of
Ed Mehollin
by Nancy Ellis-Ordway and Family

memorial donation in the memory of
Adam Custin
son of Heidi and Joe Custin of Kansas City
an anonymous donor

NAMI Missouri Family-to-Family Teacher Training



State educators Les Joslyn and Barb Sivertes present Rolanda Wheeler of St. Peters, Missouri with her Family-to-Family teaching certificate. NAMI Missouri certified twelve new teachers in Jefferson City in July.

Check Your Label *NAMI Membership Expired?*

When did you last renew your dues? Your membership expiration date is printed above your name and address on the front of this newsletter. If that date is past, please renew today. Stay current and keep the NAMI Advocate magazine and this newsletter coming.

Renew today.

Find us on the web at namimissouri.org



Family-to-Family Courses in Missouri

Contact Sonya Baumgartner about these courses at Sonya@namimissouri.org or (800) 374-2138

Wentzville

(SSM-St. Joseph's)

08/29/2016 - 11/14/2016

Clayton

(First Congregational Church)

08/30/2016 - 11/15/2016

Poplar Bluff

(New Life Christian Church United)

08/30/2016 - 11/15/2016

St. Louis

(Webster Groves Baptist)

08/30/2016 - 11/15/2016

St. Louis

(Dayspring Baptist)

09/01/2016 - 11/17/2016

St. Charles

(St. Charles Engineering)

09/01/2016 - 11/17/2016

Kansas City

(Tri-County Mental Health)

09/06/2016 - 11/22/2016

Creve Coeur

(Mercy Behavioral Health)

09/07/2016 - 11/23/2016

Maplewood

(Fellowship Hall)

09/07/2016 - 11/23/2016

Lees Summit

(Rediscover)

09/12/2016 - 11/28/2016

Springfield

Begins September 2016

Jefferson City/Columbia

Begins September 2016

Belton/Raymore

Begins October 2016

Kansas City

(Tri-County Mental Health)

01/10/2017 - 03/28/2017

Kansas City

(Research Psychiatric)

Begins January 2017

Kansas City

(Tri-County Mental Health)

09/05/2017 - 11/21/2017



The Do's and Don'ts of Election 2016

Operating Within Permissible Boundaries

Now that the Republican and Democratic National Conventions are behind us, Election 2016 is in full swing. NAMI grassroots advocates have a crucial role to play in telling candidates for federal, state and local office - across all parties - that voters care about mental health.

Keep in mind that NAMI organizations are nonprofits. While election education and engagement activities are allowed, there are some restrictions. Here is what to do—and what not to do—to operate within permissible boundaries while you urge candidates to #Act4MentalHealth.

What to do:

- Educate candidates on mental health.

- Download NAMI's priorities and share with candidates.
- Ask candidates open-ended questions about mental health.
- Highlight on social media, websites and newsletters when candidates speak out about mental health, but only if all candidates are covered in a politically neutral way (see below for examples).

- Promote voter registration.

- Promote voter registration on your website and in your communications.
- Provide voter registration forms at community events, NAMI meetings, NAMIWalks or other venues.

- Help get out the vote.

- Help voters determine where and when to vote, and what to expect at the polling place.
- Display nonpartisan sample ballots before the election.
- Distribute information about voter rights for people with mental illness.

- #Act4MentalHealth

- Go to www.nami.org/Act4MentalHealth and find materials including:
 - Sample social media posts
 - Voting rights for people with mental illness
 - #Act4MentalHealth materials for sale (magnets, stickers, folders, signs, etc.)
 - Place to share how you #Act4MentalHealth



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The Do's and Don'ts of Election 2016

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What not to do:

- Endorse or oppose a candidate—or appear to be favoring or disfavoring one candidate or party over another.

- Example: A candidate mentions what he will do for mental health in a speech. His opponent does not mention mental health at all. In this circumstance, you should not comment on either candidate or link to a candidate's speech.
- Example: Both parties release a party platform that mentions mental health. Since both platforms mention mental health, you may provide access to or copies of the platforms to your members—but you may not comment on either platform's provisions.
- Example: Both candidates for the same elected office talked about or provided answers to questions on mental health. In this circumstance, you can provide both candidates' commentary or answers—but without NAMI's commentary or unbalanced placement.

- Make a campaign contribution to, or an expenditure for, a candidate from NAMI.

- Rate candidates on who is most favorable to NAMI's issues or publicize which candidates share the NAMI's views.

- Example: You want to create a voting record on mental health issues. There are some narrow circumstances when you may publish a voting record, but before an election is not advisable for a nonprofit.

- Host a candidate forum or event unless candidates of both parties or the majority of candidates for an office are able to attend.

- Example: You invite all candidates for your state representative seat, but only one can make it. You should either reschedule for a time that the majority of or all candidates for the office can be present or cancel the event. If there is only one candidate, you may invite him or her to an event.

- Do not ask candidates questions that have a "right" answer or answer that clearly aligns with NAMI's positions—ask open-ended questions only.

FAQs for Nonprofit Staff, Board Members and Volunteers:

- Can I express my personal political views?

- NAMI staff, Board members and volunteers are free to participate in partisan activities in their personal time. To engage in partisan activities during the work day, staff members must take non-paid personal time.
- You may not make partisan comments in NAMI organization publications and you may not publicly express your opinions on candidates while serving as a representative of NAMI at an event.
- If you are a NAMI staff member or leader who is primarily using your social media account(s) in your professional NAMI role, you should avoid tweeting or posting your personal political views, candidate comments or political commentary or information that could be viewed as partisan.
- You may share your political views in your personal social media accounts. But, we recommend that you note that the views you express are your own if you are known as a NAMI representative or staff.
- NAMI staff, Board members and volunteers should not wear pins, stickers or visibly identify with specific candidates or political parties while representing NAMI at an event, such as a NAMI booth or candidate forum.
- Do not use your NAMI's resources to help or oppose a particular candidate—such as organization vehicles, paper, copy machine, etc.

Suicide Prevention Awareness Month

Play a Role in Prevention

The most recent data from the MO Dept. of Health & Senior Services show that more than 1,000 Missourians now die by suicide each year. That is an average of nearly 20 lives that are tragically lost per week, making suicide the 10th leading cause of death in our state. Although this is an alarming increase, it is important to remember that not only is suicide preventable, but that we can each play a role in its prevention.

For several years, the Governor's Office has issued annual Proclamations, declaring September as Suicide Prevention Month in Missouri. Thanks to a new resolution sponsored by Sen. Jamilah Nasheed, D-St. Louis, which was passed during the 2016 Legislative Session and recently signed by Gov. Nixon, September will now be recognized each year as "Suicide Prevention Awareness Month." The resolution further encourages citizens of Missouri to "participate in appropriate activities such as wearing turquoise and purple ribbons to raise awareness of suicide prevention."

We encourage our members to follow NAMI Missouri on Facebook and Twitter as we share resources throughout the month of September. NAMI Missouri is also asking everyone to Take 5 to Save Lives on September 10th, which is World Suicide Prevention Day. Take5ToSaveLives is a public awareness campaign started and run by the National Council for Suicide Prevention to increase participation in World Suicide Prevention Day. By giving people the tools necessary to help save more lives, we hope to end the tragedy of suicide. What does it mean to Take 5 to Save Lives? Check out www.take5tosavelives.org to learn 5 steps you can take and in just 5 minutes! The steps include:

- 1. LEARN THE SIGNS.** An expert-consensus list of warning signs was created to help people identify someone who may be in suicidal crisis or experiencing suicidal thoughts. Learn the warning signs of suicide and other suicide prevention preparedness so you can help save more lives.
- 2. JOIN THE MOVEMENT.** Just like other important causes, suicide prevention needs your voice. Add yours by joining the Take 5 social media pages and engaging in the conversation.
- 3. SPREAD THE WORD.** One great way to end stigma is to talk about suicide prevention and share real life stories of living with depression, other mental illnesses and suicidal thoughts. We challenge you to share the Take 5 campaign with at least 5 other people!
- 4. SUPPORT A FRIEND.** Knowing what to do when you are concerned about a friend who might be thinking about suicide is vital. The most important thing you can do is ASK. Learn the best ways to approach a friend who may be experiencing suicidal thoughts.
- 5. REACH OUT FOR HELP.** There are many resources for those experiencing suicidal thoughts or a suicidal crisis. Know where to turn to if you or someone you know needs help.

There are two things we want you to know about this important issue: 1) Healing, help, and hope happens; and 2) We all have a role in preventing suicide. By sharing this message, your stories of hope and recovery, and by taking 5 minutes to learn about suicide, you will be making a difference in the world!

If you or someone you know is in need of emotional support or help, please call the National Suicide Prevention Lifeline at 1-800-273-TALK (8255).

For information about the NAMI Warmline and other resources, please visit our website at: www.namimissouri.org/crisis-info/

A Mother Reflects on her Family's Journey Turned Movie *Randi Silverman's New Film Reflects Her Family's Real-Life Struggles*

The bewildering effort to figure out what was wrong and how to make it better fired Randi's passion to help other parents. She co-founded a support group, dove into advocacy, and wrote the script that became *No Letting Go*.

How closely does the movie mirror your own family's experiences?

My son was actually diagnosed with bipolar disorder when he was 9 years old and seriously ill by age 10. In the movie, we made "Tim" a teenager because onset of mental illness during adolescence is more typical. Also, my son was treated voluntarily, but we wanted to acknowledge that it is often very difficult and painful to get teens to comply with treatment. Otherwise, every scene in the movie, every conversation, actually happened in real life in some way or another.

Why expose your family's raw pain on screen?

It's not my son's fault that his brain works the way it does, any more than it is another child's fault for having asthma or diabetes. I decided that if I didn't talk about it honestly and without shame, then I couldn't expect the conversation about mental health disorders to change. But I would never have put our story out there for the world to see if my family wasn't 100 percent supportive.

Your son got the help he needed to recover. What's he up to now?

He's doing very well. He actually graduated from high school "on time," which was a huge accomplishment given how much school he missed during the years he was ill. Like other 20-year-olds, he is trying to figure out how to be an independent grown-up. His goal is to make a living as a photographer.

What kept you going during the long years of not knowing how to help?

My children needed me. It was my job to take care of them and keep them safe. But a lot of the time I was barely holding on. I cried, screamed, and felt isolated. I became so depressed and irritable at one point that I decided that it was time for me to go on medication myself. Medication helped me feel normal for the first time in years.

What helped your family heal from all the anger and blame?

Therapy, individual and as a family, and psychoeducation. Ultimately, learning that my son's behaviors were actually manifestations of anxiety, depression and bipolar helped us work through a great deal.

How about you personally?

Peer support—being with other parents who had gone through similar experiences, who "get it"—was life-saving.



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No Letting Go Reflects Family's Journey

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Knowing what you know now, what do you wish you'd done differently?

I wish I had trusted myself more.

Pediatricians, teachers, even school psychologists, told me it was “just a stage” or that my son’s behavior was the direct result of my parenting or my personal “issues.” I felt in my gut that something was not right, but I listened to everyone around me and blamed myself. But the truth is that you can’t solve a problem if you aren’t even aware that the problem can exist.

What should other parents know?

It was eye-opening to discover my son qualified as a student with a disability, which meant the school district was legally required to provide accommodations for him. I never knew to ask. There are great books and online resources out there now about special education law, and agencies that will help parents advocate for their children.

Do you think anything has changed for the better in the decade since your son was diagnosed?

There are more conversations about mental health and mental illness in adults. Sadly, I don’t think there has been as much movement regarding children and adolescents. Given that 50 percent of all lifetime cases of mental illness emerge before the age of 14 and 75 percent before the age of 24, we need to break the cycle of stigma and normalize mental illness so that it can be treated with the same respect and compassion as physical illness.



Tourette: A Personal Account

by Samantha Gierer

It all started with a case of walking pneumonia. In fourth grade I was somehow given pneumonia and one of the side effects from it is you have a cough for the rest of your life. At least that's what happened to me. Well, not exactly. I had always had a throat clearing "habit"- which we later found was my first tic- but we never really noticed it until my cough from the pneumonia did not go away.



My mom kept saying I needed to suck on lozenges so it would stop, but I couldn't. Fast forward to seventh grade. I was sitting at the dinner table with my aunt and my dad when my head just started jerking in random motions, mostly up and down. My dad asked me if I was doing that on purpose, and I said, "No why would I do that?" He kind of just pushed it aside until my mom got back from my sisters dance competition. My mom, being, well, a mom, freaked out and started consulting the most famous doctor in the world, doctor Google. The first thing she found was a tumor. I got a CT scan and ruled that out. My mom then said it could be this thing called Tourette Syndrome. I had never heard of that so I then contacted lord Google just like my mom. I realized that that was what I had. We went to a neurologist in St. Louis, and I was officially diagnosed. This was the start of my Tourette journey.

For those of you who do not know, Tourette syndrome is a disorder where you have at least one vocal and two motor tics. My vocal tics are throat clearing, coughing, sniffing, clicking my mouth, and when it's a bad tic day I have a high pitched squeak. My motor tics are my head twitch, eye blinking, eye rolling, and lip pursing. Staring after my diagnosis I started to do Cognitive Behavioral Therapy (CBT) to combat my tics.

When I first started (around age 12), I focused on my eye blinking. I did it for less than a year and got it under control. My doctor and I decided that I didn't need to come back as I had it under "control." This year I started CBT again for my head tic. Tics come in waves, so one day I can be twitching or coughing non-stop, and then the next day I can maybe tic about five times an hour. It's amazing what the brain does on its own. As well as waves, tics are worse when you talk about them or are around others with it. I went to a TS conference in Atlanta, Georgia this June and there were so many people there with TS that my tics were the worst I have ever felt. My head tic started going wild, my mouth was clicking, and I was squeaking. It was kind of funny seeing my reaction. I had always known my case was mild, but after the conference it was put even more into perspective. People with TS are just like you.

I am a normal 16 year old girl, am active in band (love the marimba) and school, and has a passion for the culinary arts! At the conference, I met a girl my age who also plays the marimba in marching band. The only difference between us was that she has Coprolalia and Echophelia. It makes me upset to think that people would see so many more differences between us because she may say a few more words that some may not like or she may do some motions that people might not like. We are no different than the rest of the world. We just make a few more noises and may blink more than the rest of you. It is important to educate others about TS and that is what I have spent this last year doing (through social media, podcasts, this article, etc.) and I will continue to do so.



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JOIN US!

Every membership strengthens our effort. If you belong to a NAMI chapter, you are already a member of NAMI Missouri. All members receive the quarterly NAMI Missouri Newsletter and the Advocate, the quarterly magazine published by NAMI. Members also receive reduced fees to attend NAMI Missouri's Annual Conference.

All Donations are Tax Deductible

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