NAMI Missouri’s 2017 Annual Conference


May 5 & 6, 2017 are the dates for NAMI Missouri’s 31st annual meeting and educational conference at the Holiday Inn Executive Center in Columbia, MO.

This year’s format represents a fresh new approach. Early Friday evening is reserved for essential nonprofit business; electing new board members, annual reports, etc. But this year, the business meeting will be followed by unprecedented treat, a night of comedic entertainment! Come celebrate more than 30 years of service and commitment to “improving the quality of life and recovery” and be entertained. Laughter is good for us and conducive to positive mental health! You won’t want to miss this.

As is our custom, a hot “farm” breakfast will be served on Saturday morning May 6 followed by interesting speakers and the great topics you have come to expect. Lecturer and author Deena Baxter will deliver the keynote and copies of her book, “Surviving Suicide, Searching for “Normal” With Heartache and Humor” will be available. Austin Campbell, Pharm D. will updates us on new medical treatments and Missouri’s own guru on dialectical behavioral therapy (DBT) Ronda Reitz, Ph.D. is on the program.

Go to NamiMissouri.org for registration information.

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In the Know

Your NAMI MO Board Working for You

The NAMI Missouri Board of Directors held its Summer meeting on August 27 at the NAMI Missouri office in Jefferson City. Board members from St. Louis, Branson, Columbia, Jefferson City, Springfield, Arnold and Fort Leonard Wood were in attendance.

Special guest Rick Gowdy, Ph.D., Director of the Missouri Department of Mental Health’s Behavioral Health Division updated the board on our state’s application for an 1115 Medicaid Waiver to provide services to young adults who are experiencing early symptoms. Also known as the Mental Health Crisis Prevention Project, we are at this writing waiting for federal approval. Dr. Gowdy also spoke to state revenue (tax) collections, recent Gubernatorial overrides and their potential impact on funding for mental health treatments and services in 2017.

NAMI Missouri’s fiscal 2016 budget is on target and the annual audit started in September, 2016. While not flush with money, NAMI MO has weathered recession with no cutting of programs or services. State and Federal charitable giving increased a bit. Membership numbers are rising, though mainly in the $3 “Open Door” category.

Scott Perkins, NAMI MO’s Director of Public Policy and Suicide Prevention, gave preliminary results from an advocacy priority survey completed by more than 80 members and allies. NAMI Missouri’s Public Policy Platform was reviewed and will be perfected at the December 10 meeting at the NAMI MO office. Executive director Cindi Keele reported on education, stigma reduction and support programs. A first FTF course is planned for the Poplar Bluff area and an increase in attendance at our Mental Health and Provider Workshops was noted.

Michael Jones, Ph.D. reported on the NAMI Homefront Course for family members of veterans. To date, courses have been taught at Fort Leonard Wood and in Branson and Joplin. Dr. Jones, Rich Bennett, Lemuel Kimes and director Keele met with officials at the Kansas City VA Medical Center to plan for a course to be taught on site. A memo of understanding with the MO National Guard is being perfected. The fundraising campaign for NAMI Homefront course teacher training was launched with a board members’ generous contribution.

Affiliate progress reports highlighted the NAMI St. Louis Gala (November), NAMI Joplin’s multiple NAMI Homefront Courses, a Mental Health First Aid Course taught in Boonville and an in-depth report on NAMI Kansas City’s efforts to expand services and reopen an office.
Marching for Mental Health

Fundraising for NAMI Greater Kansas City

NAMI GKC closed its office doors in May due to inadequate funding. The office had been a vital part of the Greater Kansas City nonprofit community. It was the coordination hub for dozens of NAMI volunteers who taught family classes, facilitated the peer and family groups and served on their speaker’s bureau. That office served thousands annually for more than 30 years. Its closing leaves a gap in the area’s mental health safety net.

Today, mission-driven volunteers are doing all they can to keep many of the NAMI services in place. The family courses, family support meetings, NAMI Connection Recovery Support meetings and stigma-reduction efforts continue; same people, same locations, same schedules. This walk was also an all-volunteer effort. It raised seed money to start a fund for the new NAMI Greater Kansas City home.

According to NAMI Greater Kansas City’s Walk co-chair Tyler Sharpe, “The stigma of mental illness is making us sicker. Our voices will push to end discrimination and stigma associated with mental illness”. Runners and walkers from as far away as Columbia, MO and Indiana came out on a chilly, damp Sunday morning to raise awareness and much needed funds. This walk was the first in what will be an annual event.

Adam Custin (son of walk co-chair Heidi Custin and NAMI GKC president Joe Custin) was involved early and got things rolling. Tragically, Adam died a few months before the walk was held.

The energetic and well-managed committee included Charles French, Lisa Ann Bailey, Abbey Holtz, Sarah Caldwell, Isabelle Abar, Kate Springer, Jennifer Wolfe, Cathy Simonds and Annette Hugill. Motley Cakes (of Kansas City) generously provided breakfast for walkers and volunteers.

Some walked for fun and fitness, racking up the miles on their Fitbits. Some walked to support a great cause, and some walked with an even deeper purpose; to honor a loved one lost tragically and far too soon. And they all walked to advance a very important goal, making NAMI Greater Kansas City whole again.
In Rememberance

Memorial Donations & Tributes
A memorial donation in memory of longtime NAMI St. Louis member George Ferguson, husband of Christine by Brian and Pam Sweeney

A memorial donation in the memory of Cody Stretz, son of NAMI Boonville member Marla Stretz by Tim and Linda Harlan

A memorial donation in the memory of Adam Custin, son of NAMI Kansas City’s Joe and Heidi Custin

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

Get Social!
Follow us on Twitter at twitter.com/NAMIMissouri
Join us on Facebook at fb.me/NAMIMissouri.org

NAMI Missouri Trainings

Contact Alice Kliethermes about these courses at alice@namimissouri.org or 1-800-374-2138

Citizens Advocacy & Leadership Development Training
March 13 - 14, 2017
Training to become mental health advocates and consumer leaders. Openings for 60.

Registration Deadline is February 22

In Our Own Voice: Living With Mental Illness Presenter Training
June 2 - 3, 2017
Training for teams of 2 consumers to give interactive presentations about mental illness, including video, personal testimony & discussion. Openings for 16 Consumers.

Registration Deadline is May 1

NAMI Connection Recovery Support Group Facilitator Training
August 4 - 6, 2017
Training for teams of 2 consumers to facilitate support groups for persons living with mental illness. Openings for 18 Consumers.

Registration Deadline is July 4

Trainings will be held in Jefferson City at the Best Western Plus Capital Inn.
## Family-to-Family Courses in Missouri

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

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## Family-to-Family Teacher Training Courses in Missouri

Trains individuals to teach 12-week educational course to family members/caregivers of adults living with mental illness.

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## NAMI Basics Courses in Missouri

6-week education course for parents, caregivers and foster parents of young children living with mental illness.

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In the Know

Upcoming Legislative Summits

Be a Better Advocate, Get Informed and Earn Free CEUs

One of our more popular Facebook postings depicts the ribbon cutting at Kansas City’s new assessment and triage center for people in serious psychiatric crisis. It accompanied the Kansas City Star’s insightful October 28 article about the center opening and the lived experience of having a serious mental illness.

Someone added the caption, “This is why we advocate!”

The MO Federation of Behavioral Health Advocates will host two events that are open and free to anyone interested in mental health advocacy. Legislative Summits will be held in St. Louis on January 12, 2017 from 6:00 p.m. - 8:00 p.m. and in Kansas City, January 11 from 4:00 p.m. to 7:30 p.m. (with a light meal). Mileage reimbursement is available to advocates travelling 60 miles or more.

As Federation members, NAMI Greater Kansas City, NAMI ST. Louis, NAMI Missouri and MHA of the Heartland, MHA of Eastern MO and the MO Coalition of Community Mental Health Centers are involved in planning both events. Free CEUs (health related professions) will be provided.

A number of legislative proposals will confront mental health advocates in 2017. These summits will focus on three priority topics; closing the health insurance coverage gap (Medicaid reform), keeping access to all antipsychotic medications open in Medicaid/MO Healthnet and Mental Health Insurance Parity. Tim Clement, parity track policy director for the Kennedy Forum in Philadelphia, PA will address the latter.

Please join us for a time of learning as we prepare ourselves for the 2017 legislative session! The Kansas City legislative summit will also offer brief Advocacy 101 training conducted by the talented Sue Lewis, Mental Health America of the Heartland.

Contact Jackie Hudson jhudson@namistl.org or Cindi Keele namimockj@yahoo.com for more info or registration.
Policy Brief: Access to Psychotropic Medications

Do No Harm

Why People living with Mental Illness MUST have access to psychototropic medications:

⇒ The right medication is KEY TO RECOVERY for many children and adults with mental health conditions.
⇒ People need choices because individuals react differently to different medications and because the effects of NOT getting the right mental health medication can be COSTLY AND DANGEROUS.
⇒ Preferred drug lists, prior authorization and other restrictions pose substantial risks for people with serious mental health conditions. Medication failures can lead to emergency department visits, hospitalization, school failure, job loss—even incarceration or suicide.
  ◦ In a 2009 ten-state study of Medicaid prescription drug policies, prior authorization requirements were associated with people being 2.1 TIMES MORE LIKELY to be reported HOMELESS and 3.1 TIMES MORE LIKELY to be HOSPITALIZED (West, Joyce C., et al., 2009).
  ◦ Preferred drug lists were associated with 1.8 TIMES HIGHER RATES of EMERGENCY DEPARTMENT VISITS and 2.3 TIMES HIGHER RATES of HOSPITALIZATION (West, Joyce C., et al., 2009).

Missouri has Clinical Edits that address psychotrophic drug utilization, patient safety and saves the MO HealthNet Pharmacy Program millions of dollars.

⇒ **Atypical Antipsychotic Clinical Edit**—Ensures appropriate and prudent use of atypical antipsychotic medications within the MO HealthNet Pharmacy program. With this edit in place, the ratio of overall dollars spent on psychotropic drugs compared to total drug spending was reduced by 10 percentage points from 2007-2011, saving over $69 million.

⇒ **Psychotropic Medications Polypharmacy Clinical Edit**—Ensures appropriate and prudent use of psychotropic medications within the MO HealthNet Pharmacy program. With this edit in place, the ratio of overall dollars spent on psychotropic drugs compared to total drug spending was reduced by .4 percentage points from 2007-2009, saving over $2 million.

⇒ **15-Day Limitation Clinical Edit**—Controls the cost of expensive drug therapies by setting a days supply limitation for newly initiated drug therapies. Limiting the supply of these expensive medications at the point the initial prescription claim is presented reduces the program cost for therapies that are discontinued or changed within the first few weeks of therapy.

Recommendation:
The Missouri General Assembly should keep RSMo 208.227 as is—protecting access to psychotropic medications—and doing NO HARM to the people that need them.
We will improve the lives of millions of Americans, their families and communities if we treat addiction to alcohol and other drugs as a public health crisis. To overcome this crisis, we must accord dignity to people with addiction and recognize that there is no one path to recovery. Individuals who are striving to be responsible citizens can recover on their own or with the help of others. Effective aid can be rendered by mutual support groups or health care professionals. Recovery can begin in a doctor’s office, treatment center, church, prison, peer support meeting or in one’s own home. The journey can be guided by religious faith, spiritual experience or secular teachings. Recovery happens every day across our country and there are effective solutions for people still struggling. Whatever the pathway, the journey will be far easier to travel if people seeking recovery are afforded respect for their basic rights.

1. We have the right to be viewed as capable of changing, growing and becoming positively connected to our community, no matter what we did in the past because of our addiction.

2. We have the right—as do our families and friends—to know about the many pathways to recovery, the nature of addiction and the barriers to long-term recovery, all conveyed in ways that we can understand.

3. We have the right, whether seeking recovery in the community, a physician’s office, treatment center or while incarcerated, to set our own recovery goals, working with a personalized recovery plan that we have designed based on accurate and understandable information about our health status, including a comprehensive, holistic assessment.

4. We have the right to select services that build on our strengths, armed with full information about the experience, and credentials of the people providing services and the effectiveness of the services and programs from which we are seeking help.

5. We have the right to be served by organizations or health care and social service providers that view recovery positively, meet the highest public health and safety standards, provide rapid access to services, treat us respectfully, understand that our motivation is related to successfully accessing our strengths and will work with us and our families to find a pathway to recovery.

6. We have the right to be considered as more than a statistic, stereotype, risk score, diagnosis, label or pathology unit—free from the social stigma that characterizes us as weak or morally flawed. If we relapse and begin treatment again, we should be treated with dignity and respect that welcomes our continued efforts to achieve long-term recovery.

7. We have the right to a health care and social services system that recognizes the strengths and needs of people with addiction and coordinates its efforts to provide recovery-based care that honors and respects our cultural beliefs. This support may include introduction to religious, spiritual and secular communities of recovery, and the involvement of our families, kinship networks and indigenous healers as part of our treatment experience.

8. We have the right to be represented by informed policymakers who remove barriers to educational, housing and employment opportunities once we are no longer misusing alcohol or other drugs and are on the road to recovery.

9. We have the right to respectful, nondiscriminatory care from doctors and other health care providers and to receive services on the same basis as people do for any other chronic illness, with the same provisions, copayments, lifetime benefits and catastrophic coverage in insurance, self-funded/self-insured health plans, Medicare and HMO plans. The criteria of “proper” care should be exclusively between our health care providers and ourselves; it should reflect the severity, complexity and duration of our illness and provide a reasonable opportunity for recovery maintenance.

10. We have the right to treatment and recovery support in the criminal justice system and to regain our place and rights in society once we have served out sentences.

11. We have the right to speak out publicly about our recovery to let others know that long-term recovery from addiction is a reality.

ENDORSED BY:
American Association for the Treatment of Opioid Dependence, Inc.  •  American Society of Addiction Medicine  •  Community Anti-Drug Coalitions of America  •  Ensuring Solutions to Alcohol Problems  •  Entertainment Industry Council  •  Johnson Institute  •  Join Together  •  Legal Action Center  •  NADAC  •  NAADAC  •  National Association for Alcohol and Drug Abuse Counselors  •  National Alliance of Advocates for Superintensive Treatment  •  National Alliance of Treatment Providers  •  National Association of Alcohol and Drug Abuse Counselors  •  National Association of Addiction Treatment Providers  •  National Council on Alcoholism and Drug Dependence  •  National Council for Community Behavioral HealthCare  •  ReEntry Project for Human Rights  •  State Association of Addiction Services  •  SDC, Inc  •  Therapeutic Communities of America  •  Witness To Recovery
In the Know

What Precision Medicine Holds for Mental Illness

Eric Dishman was diagnosed with a rare form of kidney cancer when he was in college. He was given two to three years to live. That was 23 years ago.

Today, Dishman is very much alive and cancer-free, thanks to early access to precision medicine practices that helped identify the most effective cancer treatment for him. He is currently directing “All of Us,” known as the Precision Medicine Initiative Cohort Program until October. A $215 million White House initiative, All of Us is intended to create a database of at least 1 million US health records to “revolutionize how we improve health and treat disease,” including psychiatric disease.

Because One Size Doesn’t Fit All

Dishman recently described the initiative and what it holds for mental illness in a briefing for the Alliance for Research Progress, a panel of advocacy organizations the National Institute of Mental Health convenes regularly.

“In medicine, we are always looking for that one-size-fits-all drug, but we are all individual,” Dishman told Alliance members. Treatments may be effective for some patients but not for others. “Currently, our studies and data are too limited for us to understand what it takes to effectively individualize treatment for health and mental health conditions.”

By assembling the world’s largest biomedical database of health conditions and analyzing them quantitatively, the hope is to lay a data-based foundation for such individualized therapies. “What does the power of 1 million people’s data give you?” Dishman posed. “What can you learn about mental health issues from it?”

The National Institutes of Health (NIH) says All of Us “will not be focused on a specific disease, but instead will be a broad resource for researchers working on a variety of important health questions.” Precision medicine already has been successfully used to treat some cancers, such as Dishman’s. “This cohort will seek to extend that success to many other diseases, including common diseases such as diabetes, heart disease, Alzheimer’s, obesity and mental illnesses, as well as rare diseases,” according to the agency.

What Does “All of Us” Hold for Serious Mental Illness?

Dishman told Alliance members that data from the initiative could create a “platform” to inform trials of targeted therapies for diseases, including schizophrenia, bipolar disorder and depression. The premise is that the data will provide an “unprecedented resource for researchers” to identify factors that influence health and disease, with the end goal of more effectively preventing and treating illness.

(continued on next page)
Last week’s Research Weekly described research that illustrates the approach. A team from six US universities used statistical modeling to integrate behavioral markers of psychosis, like the ones contained in the widely used Diagnostic and Statistical Manual of Mental Disorders (DSM), with biological markers that can be identified and measured. From the analysis, the researchers identified three distinct “biotypes” they said were superior to the DSM for classifying psychotic disorders. With more precise diagnosis, more precise and effective treatment is projected.

Once All of Us enrollment (projected by the end of 2016) begins, anyone in the United States will be able to volunteer online or through a participating healthcare provider organization. Providers in Arizona, California, Illinois, Massachusetts, Michigan, Minnesota, New York, Pennsylvania and Texas already have received funding to begin recruiting volunteers.

Participants will be asked to contribute a range of data about themselves by completing questionnaires, granting access to their electronic health records, providing blood and urine samples, undergoing a physical evaluation and sharing real-time information via smartphones or wearable devices. “Participants will have access to their study results, along with summarized data from across the cohort. All of this will be accomplished with essential privacy and security safeguards in place,” according to the NIH website.

Widespread participation by individuals with psychiatric disease and their biological relatives will improve the likelihood that All of Us can produce meaningful findings for individuals living with serious mental illness. Federal follow-through with data-driven psychiatric treatment trials and other research will be needed to translate the initiative into better outcomes for people with serious mental illness.

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**Meeting the Challenges in a Changing Mental Health System**

**NAMI MO Mental Health & Allied Provider Workshop**

**A FREE workshop for**

Mental Health Workers and the Social Service/Helping Community

Friday, April 21, 2017
8:30 a.m. – 4:00 p.m.
Joplin History & Mineral Museum
504 Shifferdecker Ave., Joplin, MO

FREE CEUs

Seating is limited. Pre-registration required. Free lunch provided.

This program is a service of NAMI Missouri and is supported in part by a contract with the Missouri Department of Mental Health.

**To Register**

Call NAMI Missouri 1-800-374-2138
or email:kim@namimissouri.org
Children

20 Percent of Army Kids Will Need Mental Health Treatment

One in five Army kids will need mental health treatment within the first 15 to 16 years of their lives, said the Army’s director of psychological health.

But there continues to be a nationwide shortage of child psychologists and child psychiatrists, affecting not just the military community, but the civilian community at large. “We have a mismatch in what we need and what the nation can provide,” said Dr. Christopher Ivany, a doctor who is also chief of the Behavioral Health Division/Service Line Office of the Army Surgeon General. Comparing the needs of military children to children in the civilian community, the “broad averages are pretty close,” Ivany said, but experts are working on more exact comparisons.

Ivany spoke at a family forum of the annual meeting of the Association of the U.S. Army, exploring various aspects of research on the effects of deployments on military children, and some programs that help mitigate those effects.

The Army can’t just hire enough people to provide mental health care – officials have to work with the community, he said. Through the Child and Family Behavioral Health System, they bring together best practices. Part of that is school behavioral health clinics within Army schools on post at 14 installations. Officials have found children have much easier access to the mental health care they need, he said.

Researchers at RAND Corporation have found in their various studies during the last decade that there are some common elements that can help service providers craft programs that help military children. For example, children who interacted with other military children during deployments tended to fare better, so there are opportunities to facilitate activities for these children, said Terri Tanielian, senior social research analyst for RAND.

Parents who had deployed reported an increased need for mental health services for their children, and there were increased rates of depression and emotional difficulty in their children, Tanelian said. Teens may have a particularly difficult time with family relationships after the deployment; and the longer the parent was deployed, the greater the difficulty the teen faced. And findings show that a child may be more at risk when the parent is exposed to combat trauma, so programs could be targeted to those children.

But there are still gaps in the research and knowledge about the effects on military children of these deployments, Tanielian said. For example, more longer-term research is needed to consider the effects on children as they age into young adults, she said. And to the best of her knowledge, there have been no studies on college-age military children.

Officials highlighted some programs that are aimed at shoring up the resilience of military children, such as a resilience program for teens, adapted from the program for adults, said Cherri Verschraegen, chief of Child, Youth and School Services for the Army Installation Management Command. It’s being piloted at 18 Army installations.
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

Enclosed are my dues for (check one): Credit Card:

- Individual/Family ($35) □ Visa
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- Additional Contribution $___________ □ Discover
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Jefferson City, MO 65109