



NAMI

Kansas News

July/August 2003

Revised Issue/Volume 3

As the old African proverb goes, "Sticks in a bundle don't break." NAMI Kansas' strength is its membership, and we are honored to have so many new faces who have joined our mission over the past few months. As a grassroots organization, we rely on your determination, outreach and compassion to provide peer support, public advocacy and community education around mental illness.

I am impressed at every turn by NAMI Kansas' service to those with mental illness and their families. To further your work in the coming year, the state office will provide several opportunities to develop leadership and advocacy skills amongst membership, while enhancing our affiliate outreach and peer support programs.

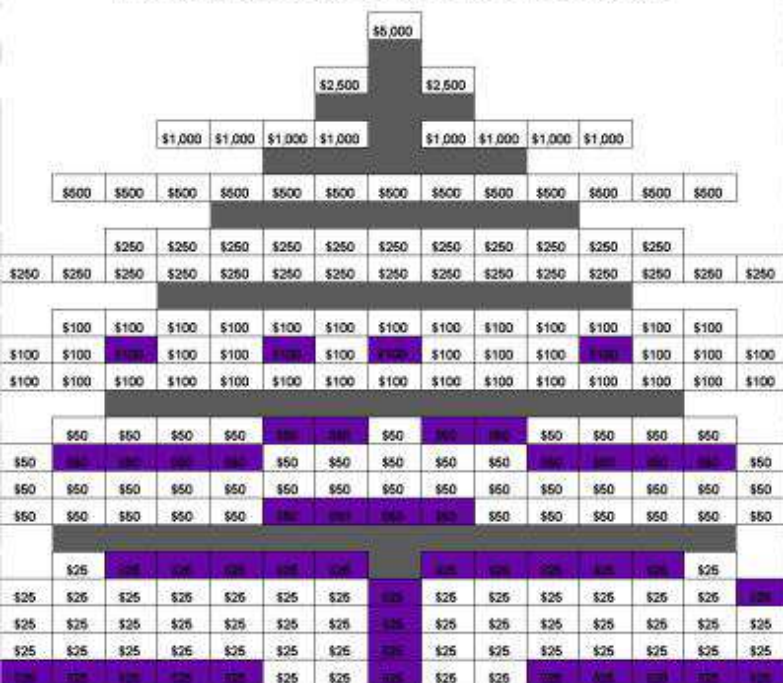
Together, we will continue to improve the quality of life for those with severe brain disorders and their families. Thank you for your hard work and sustaining energy.

*Karen Ford Manza
Executive Director*

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The NAMI Kansas Cottonwood Campaign



Looking for a terrific way to honor your loved ones?

Donate to the NAMI Kansas Cottonwood Campaign!

Need a pick-me-up?

Feel good by contributing to the Cottonwood Campaign!

Are you grateful for the NAMI education and support you have received?

Send a heart-felt gift to the Cottonwood Campaign!

Your generosity directly supports NAMI Kansas' ability to provide resources, training and education throughout Kansas. **Thank you!**

Understanding the Brain

New abilities to watch the brain at work are helping to build stronger bridges between psychotherapy and psychopharmacology, according to Dr. Glenn Veenstra, an associate professor at the University of Kansas School of Medicine – Wichita Department of Psychiatry and Behavioral Sciences.

Veenstra will be one of two presenters at a symposium that will present cutting edge information on the biology of psychiatric illnesses and how that information can be used in therapy. The other presenter will be Dr. Wayne Drevets, a Wichita native who is now a lab chief at the National Institute of Mental Health in Washington D.C.

The symposium is scheduled for August 8 at the school of medicine in Wichita and will be open to the public. Pre-registration will be \$20 if made before August 4. Regular registration is \$30. To obtain a registration form, call 316-293-2636 or 800-720-0905.

Using neuroimaging, which takes pictures of the brain at work, Drevets has shown that brains of people suffering mood disorders are different from those that are not.

"We're in a new era," Veenstra said. "The brain is so complex, but for the first time, we are able to watch the brain as it works."

Drevets will speak in the morning, and Veenstra will

(Continued on page 2)

Important Information



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Karen Ford Manza—Executive Director/newsletter editor
Audra Sabo—Office Administrator/newsletter layout
Volunteer Webmaster—Don Kohl—Derby

Calendar of Events

June 28-July 1— NAMI Annual Convention
July 19—Board of Directors, Emporia
August 9— Executive Board, Topeka
September 13— Board of Directors, Concordia
October 24-25—NAMI Kansas Annual Conference 2003
November TBA— Board Retreat, Manhattan
December 13—Executive Board, Topeka

All interested members are invited to attend Directors' meetings to "**Tell it to the Board.**" Dates and places subject to change. Call the state office for details.

give the afternoon presentation. Drevets will offer the more technical information, with Veenstra giving further practical application, he said.


The neuroimaging research "is still in the beginning stages," Veenstra said. "I don't see it giving us any miraculous cures, but it will make us wiser about treatments."

Veenstra, a clinical psychologist, became interested in the work of Drevets and others about two years ago so that he might better explain mental illness to his patients and colleagues. Patients and their families have benefited from this information because they can associate behavior and emotions with physical activity in the brain.

Given the new research, Veenstra said, new ways of doing therapy are needed. Therapists need to move beyond simple cognitive therapy, which focuses on helping patients gain control over their disorder by helping them to think differently.

"A lot of our behavior is emotionally controlled outside of our conscious choice," Veenstra explained. "We have to look more at the role emotion plays."


The symposium will further emphasize that pharmacology and talk therapy need to work together, Veenstra said.

"The meds alone won't change the thought pattern and maintain it," he explained. But he added talk therapy also was necessary and that research has shown such therapy actually changes the way the brain functions. 

By: Stan Friedman

Leave a Legacy

Consider making a gift to NAMI Kansas in your will or trust. Your estate will not only receive a charitable deduction, but it will also enable NAMI Kansas to carry on its vital work in your memory -- providing peer support and advocacy for consumers, families, and friends of individuals with severe biological brain disorders.

It's easy to leave a bequest to NAMI Kansas. Just inform your attorney as you plan your will or trust. 

Thank you!

The NAMI Kansas News is funded by donations from members and partners. It is published to inform, educate and strengthen the community of individuals and families affected by brain disorders that manifest as mental illness. The articles and opinions within are not necessarily those of the NAMI Kansas organization. Content is not intended to endorse any political candidate, viewpoint, treatment or medication.

The President's Message

For the past year, as Chair of the NAMI State Presidents' Council I have represented the interests and concerns of the state presidents at NAMI Board meetings and have served on its State Relations Committee and its Planning Committee. This has given me an opportunity to observe the work of the Board and to develop a strong personal sense of the values, talents, and aspirations of its members and the national staff that support them.

I recently attended an affiliate Executive Committee meeting where concerns were expressed about the new organizational initiatives that have been taken by the NAMI National Board of Directors. In particular, there was concern about what some of the committee believe is an intention to change NAMI from its

historic "grassroots" focus to a "top down" corporate entity. This view of the proposed changes in the structure and function of NAMI is not unique to Kansas. I would like to share with you my personal impressions of the motivations and intentions that underpin the Board's initiatives.

It is important to note that the members of the NAMI Board of Directors and the senior national staff are as "grassroots" as anyone can be. They are family members, consumers, former affiliate and state presidents, former executive directors, and Mental Health professionals. They come to the table with a history of caring for loved ones with mental illness as well as commitment and service to their local and state NAMI. They agonize over the same crises as you do and they passion-

ately defend the individuality of each of their state organizations and local affiliates. I am reminded of the famous statement by the cartoon character Pogo, who said, "We have met the enemy and they are us".


The discussions of the "Call to Action" that I heard in every Board meeting, committee meeting, and task force over the past year have been about improving NAMI's effectiveness, expanding services to local affiliates and state organizations, strengthening recruitment and retention of members, and strengthening funding capability at every level of the organization. This is all about getting better at what we do and how we do it so that we can survive and grow in today's social, political, economic, and technological environment. If the proposed changes in organization or function

feel like control issues, that was certainly not the intention.

The NAMI Board is now engaged in a dialogue with all of us about the future of our organization. The result of that dialogue will be a revised and updated strategic plan that will guide the whole organization over the coming year. I hope that you will take advantage of coming opportunities to share your hopes, concerns, and insights with the Board Planning Committee. If there are items of concern that you would like me to bring to the NAMI Board meeting this June 27-28 please contact me by telephone at 913-837-5523 or by e-mail at shfjak@micoks.net.

*Stephen H. Feinstein, Ph.D.
President, NAMI Kansas
Board of Directors*

A guiding thought from the late Senator Paul Wellstone, whose brother has schizophrenia:

"It shouldn't be this way. I wish I'd gained my understanding of this subject solely through research and ethical inquiry. But for many people, the problems of mental illness are still utterly abstract, and their urgency becomes apparent only through intense involuntary immersion in them. We need an education initiative to pave the way for a legislative one." 


Quoted in Andrew Solomon's [The Noonday Demon](#).

★ ★ ★ Consumer Corner ★ ★ ★

NAMI Kansas, the Dwight D. Eisenhower VA Medical Center in Leavenworth, and the Colmery-O'Neil VA Medical Center in Topeka have teamed up to present an exciting peer support program for veterans.

NAMI-C.A.R.E. is a peer-based, mutual support group program for individuals facing the challenges of recovering from any serious mental illness. The "CARE" in NAMI-C.A.R.E. stands for "Consumers Advocating Recovery through Empowerment." In this group, participants will share their experiences and learn from each other in a safe and confidential environment. NAMI-C.A.R.E. will meet once a month beginning this fall.

Feelings of isolation can be immobilizing. Support can give relief from isolation while giving the opportunity to not only associate within a group, but possibly form meaningful, lasting, individual friendships. Sharing experiences can lead to increased self-esteem, self-awareness and self-confidence. Groups provide great opportunities for learning new strategies and options for dealing with the day-to-day rigors of living with any mental illness. Support can keep us focused on the here and now, while moving consumers forward with their recovery.

This partnership hopes to begin Family-to-Family support groups later this fiscal year. For more information, please call the state office. 

Spotlight: Family-to-Family

Garth House is a free-lance writer and director of volunteers for the NAMI Ohio state office. Below, he describes the tremendous effectiveness of the Family-to-Family Education Program and tells us much about his own personal growth.

I feel compelled to write a testimonial to NAMI Ohio's Family-to-Family Program because it has so radically transformed my relationship to my mother and consequently my ability to cope with the bipolar disorder I have had for so many years.

Eighteen years ago, when I left law school and entered a psychiatric ward for the first of what would be many, many times, my parents had no idea of the nature or dynamics of the illness from which I suffered. They felt the need to shield my brothers from what was happening to me, and a silence fell upon my parents and me about my bizarre and incomprehensible behavior. Thus began the enormous isolation that was to plague me for many years. It was bad enough that friends and lovers fall away, but what was really excruciating was that within my own family I was left alone to bear the burden of the strange psychotic world I kept going in and out of.

My parents stuck by me, refusing to abandon me to the streets (as recommended by the doctors I had seen); nonetheless, their ignorance of the true nature of my illness created enormous tension and stress within the household. I must add that my ignorance of the

illness also contributed to the suffering, since for years I bore great guilt over what I was convinced was not an illness, but rather a weakness of character or a perverse refusal to "grow up."

Convinced that work would straighten me out, my parents urged me take jobs, even though in retrospect I realize I was suffering from clinical depression. Not surprisingly, these attempts failed, bringing yet more despair and more guilt. My parents and I became an isolated trio of silence and pain. They had nowhere to turn, and neither did I.


There was unexpressed anger and frustration on both sides. As an adult yearning for independence, I began to see my parents as adversaries. They in turn, were torn between viewing me as ill and yet wondering if there were not something willful and perverse in my inability to cope.

When my mother decided to enroll in the Family-to-Family Education Program, I had managed to achieve two years of psychiatric stability. About four weeks after they started the program (and due to medically supervised reduction in my medication), I suffered a de-compensation that landed me once again in the hospital. I shall never forget my mother's demeanor when she came to visit me. There was a clarity and strength in her presence I had never experienced before. There was a calmness in the face of this crisis that I found strengthening. And she was very clear in her understanding that we had

a common enemy in the disease itself. How liberating it was to hear her words, "You are not to blame for this."

For the first time since the onset of the illness, I felt a precious family member was allied with me in a common understanding of what I had been up against for years. The knowledge, emotional support, and insight that my mother had gained through the Family-to-Family Program had shattered years of silence and denial, opened gates of communication between us, and allowed us to speak openly about this catastrophic illness that had struck our family. Her understanding of serious brain disorders gained through the program has helped me better accept and understand my own illness and permitted me to let go of the shame and guilt that haunted me for so many years. Now she has taken it upon herself to educate my brothers about my illness.

The NAMI Ohio program has brought healing to me and to my family. I am convinced it is the single most important vehicle for driving the future growth of the family movement, providing as it does such a comprehensive approach to every aspect of dealing with a serious disorder in a loved one. My mother bore the pain of my illness so deeply for so many years.

The NAMI Ohio Family-to-Family Education Program has liberated both of us from being mute victims so we could become unrelenting fighters against these devastating illnesses, illnesses which are so cruel and which show no quarter. 

Excerpted from *NAMI Advocate* (May/June 1998)

Family-to-Family Training

The NAMI Kansas **Family-to-Family Education Program** is a free 12-week course for family caregivers of individuals with severe brain disorders (mental illnesses). The course is taught by trained family members. All instruction and course materials are free for class participants.

The Family-to-Family curriculum focuses on schizophrenia, bipolar disorder (manic depression), clinical depression, panic disorder and obsessive-compulsive disorder (OCD). The course discusses the clinical treatment of these illnesses and teaches the knowledge and skills that family members need to cope more effectively.

Joyce Hedstrom and Shirley Moynihan will lead Family-to-Family starting September 8th at the Christian Church, 6th & Cedar in Concordia from 6:30-8:30 PM. Please call Joyce for more information at (785) 374-4590 or (800) 539-2660.

Member & Affiliate Resources

NAMI Kansas Library Additions

Mad in America: Bad science, bad medicing, and the enduring mistreatment of the mentally ill by Robert Whitaker, Perseus Publishing, 2001



Mad in America raises important and very disturbing questions about the present approach to treating the mentally ill. This is a serious and well documented book about the history of the medical treatment of the mentally ill in the United States, from its roots in England to the present. Whitaker reports schizophrenics in the U.S. currently fare worse than patients in the world's poorest countries, and worse than the early nineteenth century in the U.S. He also reports how drug companies skew their studies in an effort to prove the effectiveness of their products. -*Andy Labosky, NAMI Kansas-Wichita*

Surviving Schizophrenia: A Manual for Families, Consumers, and Providers, by E. Fuller Torrey, M.D., 4th edition, Quill, 2001

The Inclusive Corporation: A Disability Handbook for Business Professionals, by Griff Hogan, Ohio University Press, 2003


CALL NOW TO ORDER!

A complete & current listing of library resources will be available soon — stay tuned!



Governor Sebelius Proclaims May 2003 Kansas Mental Health Month



From left to right: Jo Ann Howley-former NAMI Kansas Board Member, Judy Thompson-Sunshine Connection, Jan Clay-The Consortium, Amy Thompson-Family Service & Guidance Center, Karla Hedquist-Valeo, Karen Ford Manza-NAMI Kansas, Mike Hammond-Association of C.M.H.C. of Kansas, Bryce Miller-Depression Bipolar Support Alliance, Mike Horan-Break-through House and Kathleen Sebelius-Governor of Kansas (seated). 

Learn about mental illness from people who have been there!

The In Our Own Voice: Living with Mental Illness Recovery Education Presentation is a brief, yet comprehensive interactive presentation about mental illness-including video, personal testimony, and discussion-enriches the audience's understanding of how people with serious brain disorders cope with the reality of their illnesses while recovering and reclaiming productive lives. Call to schedule a presentation for your community &/or affiliate.

Congratulations to NAMI Kansas' Certified In Our Own Voice Presenters

Barbara Bohm, Jan Graham, Jane McIrvn, Jim McKay, Jo Ann Howley, Joel Stottlemire, Kathy Brost, Marc Gardner, Marie Stadler, Marlene Townsend, Michael Bales, Phil Cammack, Richard W. Gray, Robert Chester Haggard III, Roger Potter, Steve Baur, Susan Bernstein

Where to go on the web...

For Consumer Information

- * www.phrma.org (features a link to an official directory of pharmaceutical company-sponsored patient-assistance programs that can help low-income patients with their prescriptions.)
- * www.rtk.org (while this is the official website of "Citizens for the Right to Know in California," it offers general information use for residents of other states, such as what to do if they do not receive appropriate and timely access to care. Also includes information on health plans.)
- * www.smartcoalition.org (useful information about questions to ask your doctor and pharmacist; helpful medication hints & medication problems to be aware of.)

For Prescription Assistance Programs

- * www.rxassist.org (for health-care providers to access more than 100 pharmaceutical manufacturer's patient assistance programs on behalf of their low-income patients.)
- * www.rxhope.com (resources for consumers, advocates and charitable agencies to access patient assistance offered by federal, state and other agencies.)
- * www.needymeds.com (information on drug assistance programs)
- * www.themedicineprogram.com (this organization will help determine if you qualify for patient assistance programs.)

For Discount/Membership Programs

- * www.seniorinsuranceonline.com
- * www.agelesscare.com
- * www.yourplan.com
- * www.aarppharmacy.com
- * www.seniorscrips.com
- * www.savewell.com
- * www.rxdrugcard.com

Compliments of PhRMA (Pharmaceutical Researchers and Manufacturers of America)

Affiliate Information

NAMI Central Kansas Afternoon - Meetings are on the 2nd Sunday of the month and begin at 2 p.m. at the Crossroads Lounge, 800 Elmhurst, Salina. Contact Elvin Gerard (785) 823-6139.

NAMI Central Kansas Evening - Meetings for family members are on the 2nd Thursday of the month and begin at 7 p.m. at the Bridge House on 150 South 8th, across from Ashby House, Salina. Consumer meetings are held on the 4th Thursday of the month. Contact Tony and Audrey Auernheimer (785) 825-4786.

NAMI Kansas Cowley County - Contact Diane Bradbury (620) 221-0104.

NAMI Kansas Douglas County - Meetings are on the 2nd Wednesday of the month and begin at 6:45 p.m. at the Plymouth Congregational Church, 925 Vermont Street, Lawrence. Contact Peter Haxton (785) 865-2636.

NAMI Kansas Emporia - Meetings are on the last Tuesday of each month and begin at 5:15 p.m. at the MHC/East Central Kansas, 1000 Lincoln. Contact Elsie Bohm (620) 443-5859.

NAMI Kansas Families for Mental Health of Johnson County – Meetings are at the Colonial Presbyterian Church, 95th & Wornall. Contact Carol Ann Kladuson (913) 432-8240.

***NEW* NAMI Kansas Hays**—Meetings held the 2nd Monday of the month and begin at 7 p.m. at the First Presbyterian Church. Contact Tom Pitner (785) 624-6510

NAMI Kansas Heart of America - Meetings are on the 2nd Monday of each month and begin at 7 p.m. at United Methodist Church, 5010 Parallel Parkway, KC. Contact Gerald and Ila Jean Ulrich (913) 299-8490.

NAMI Kansas Hoxie - Contact Carol Stewart (785) 675-3129.

NAMI Kansas Flint Hills - Meetings are on the 3rd Wednesday of the month and begin at 7 p.m. at Pawnee Mental Health Adult Day Treatment, 1558 Hayes Drive. Contact Larry and Sue Seitz (785) 539-6794.

NAMI Kansas McPherson - Meetings are held on the 2nd Monday of the month and being at 7 p.m. at Prairie View, 1901 E. 1st Street, Newton. Contact Sharon Wedel (620) 628-4001.

NAMI Kansas Mid-Kansas - Meetings are on the 4th Thursday of each month and being at 7 p.m. at First Mennonite Church, 429 East 1st Street, Newton. Contact Florene Wiens (316) 283-5814.

NAMI Kansas North Central - Meetings are on the 2nd Sunday of the month and begin at 2:30 p.m. at St. Joseph Hospital, Rm. 106, Concordia. Contact Fred and Martha Soucek (785) 243-3329.

NAMI Kansas Northeast/Leavenworth - Meetings are on the last Wednesday of the month and begin at 7 p.m. at Clear Skies Inc., 205 N 5th St. Leavenworth. Contact (Ret.) Col. Lynn Rolf (913) 651-0376.

NAMI Kansas Northwest – Contact Mabel Carstens (785) 734-2554.

NAMI Kansas Pathway to Hope Olathe – Meetings every Thursday evening beginning at 7 p.m. at the Olathe College Church of the Nazarene, 2021 E. Sheridan Ave. Contact Dick and Sharon Lawrenz (913) 856-6106.

NAMI Kansas Phillipsburg - Meetings are held on the 3rd Thursday of the month at the First Lutheran Church 1st and Avenue D Street. Contact Margaret Brown (785) 543-2999.

NAMI Kansas Southeast - Contact Anita Cooper (620) 431-6968.

NAMI Kansas Southwest - Contact Debra Mandeville (620) 225-3754.

NAMI Kansas Sumner County - Contact Dawn May (620) 326-7170.

NAMI Kansas Topeka – Meetings are the Second Tuesday of each month at 7p.m. at Valeo, 330 Oakley for a short educational meeting and support group—families and consumers welcome. “Coffee Club” is the 4th Tues. of each month from 7-9 p.m. at World Cup Coffee, 21st and Washburn, everyone welcome. Contact Sharon Copeland (785) 267-3827.

NAMI Kansas Wichita – Meetings are held at the First Presbyterian Church, 525 N. Broadway, Wichita. Contact Joan Buenten (316) 685-7681.



Please contact the state office for membership information. We look forward to seeing you soon!

Scholarship Application

2003 NAMI Kansas Annual Conference, Salina, October 24th-25th

“Research and Recovery, Managing Side-Effects”

You must be a paid NAMI Kansas member to receive a scholarship. Questions? Dial (800) 539-2660.

Name of Sponsor, if applicable _____

Name _____

Address _____

City, State, Zip _____ Day Phone _____

E-mail Address _____

**Please submit your request
by September 1st.**

Amount Requested

_____ Registration (\$75 per person)

_____ Hotel Room (\$75 plus tax sharing may be required)

Are you a (circle): Smoker / Non Smoker Male / Female

_____ TOTAL Requested

NOTE: Scholarships are intended for persons who would otherwise be unable to attend the conference due to financial constraints. Scholarships are awarded on a “first come-first served” basis.

Registration Form

NAMI Kansas Annual Conference—2003, Salina, October 24th-25th

“Research and Recovery, Managing Side-Effects”

Name(s) _____

Address _____

City, State, Zip _____ Day Phone _____

E-mail address _____

NOTE: Registration fee does not include hotel room expenses. To reserve hotel, call the Holiday Inn Holidome at 785-823-5605. Ask for the NAMI rate of \$75 per room per night.

Amount:

\$75 per NAMI Kansas Member _____

\$100 per Non-Member _____

NAMI Kansas Conference Scholarship Contribution _____

TOTAL ENCLOSED _____

Send check or money order and registration form to: NAMI Kansas P.O. Box 675, Topeka, KS 66601



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*When nothing is sure,
 everything is possible.*
 Margaret Drabble

NAMI Kansas News Readers' Survey, 2003

The *NAMI Kansas News* is published to meet your informational needs. Help us make it even more helpful by filling out this survey and returning it to:

NAMI Kansas Newsletter Survey, PO Box 675, Topeka, KS 66601-0675.

OR go on-line to fill out the survey at <http://ks.nami.org> under "Newsletter."

For each topic area, please circle the number that best represents your opinion, with "1" being the lowest and "5" being the highest.

- Organization/Readability 1 2 3 4 5
- Appearance/Style 1 2 3 4 5
- Variety of Articles 1 2 3 4 5
- Quality of Articles 1 2 3 4 5
- Useful Information 1 2 3 4 5

Overall Quality 1 2 3 4 5

What features do you find most helpful/interesting?

Which ones are the least helpful/interesting?

What would you like to see in future newsletters?

What are your ideas for future newsletters?

Are you a member of NAMI Kansas? Yes No

If you would like more information about becoming a member of NAMI Kansas, please include your name & address below.

Your name (optional): _____

Thank you!

"The way a team plays as a whole determines its success. You may have the greatest bunch of individual stars in the world, but if the don't play together, the club won't be worth a dime."

Babe Ruth