

Newsletter

Alliance for the Mentally Ill - NAMI St. Louis
St. Louis' Voice on Mental Illness



NAMI WALKS

★ ★ ★ ★ ★ FOR THE MIND OF AMERICA

The inaugural **NAMIWALKS For the Mind of America** is planned for Saturday, May 10, 2003 in beautiful Forest Park. Check in time is at 9 a.m. and the official walk start time will be at 10 a.m. from the Upper Munny Parking Lot, *rain or shine*.

Persons with mental illness and their families have been stigmatized far too long. Sometimes we perpetuate our own stigma. Now is the time to prepare for stepping up to the starting line on May 10 to say I support **NAMIWALKS For the Mind of America**.

Wanting to create a national event that all NAMI affiliates could participate in, our national office created a pilot walk program. NAMI St. Louis competed and won a spot among the 15 sites chosen to host a walk in the pilot year. Walks are proven awareness promoters and fund raisers for health related charities as ours. It is time we did one too! Your participation will help make this Walk a successful event.

Dar Walker, NAMI St. Louis' Board President is our Family Team Chairperson. Dar has set a goal of rounding up 25 walkers who will raise a total of \$5000. KSDK – Channel 5's Jennifer Blome has signed on as our Honorary Chairperson. Eli Lilly Company has signed on as a corporate sponsor.

w and the kick off luncheon in March, we need readers of our newsletter and other interested parties to pledge to become a team captain, a Walk Committee member, or a Day-of-the-Walk volunteer. We need persons to seek Corporate Sponsors whose donations will help defray the cost of putting on the Walk. We need persons who work in corporations to become corporate team captains and build a walking team within your workplace. Please spread the word among your family, friends and fellow workers.

To receive a Walk Information Packet, Corporate Sponsorship Packet or information to get involved, contact Elizabeth Westhoff, Director of Development, Joan Beuckman, NAMI Board member and Walk Chair, or Marge Parrish, Executive Director at the NAMI office.

Area Legislators to Gather for NAMI Breakfast

The area's Missouri House and Senate members are invited to visit with NAMI members and friends at our second annual Breakfast with Legislators. This year's event will occur on Friday, January 31, 2003 at The Heights, the Richmond Heights Community Center at 8:30 a.m. Three guest speakers will address the current issues facing this year's legislative session. NAMI will extend formal invitations to legislators but NAMI members are encouraged to extend a personal invitation to their individual

house and senate members. Remembering that all politics are local, it is important that we as individuals do our part to educate our elected officials of the needs of our family members or ourselves who have a severe mental illness. Our job as advocates is to put a face on mental illness, to demystify the public view of brain disorders, and to be honest and open with those who represent us about what it will take for Missouri to have an adequate system that provides competent treatment for our consumers supporting them in a stable and productive meaningful life.

Awards Presented at Gala 2002

Over the years, NAMI St. Louis has recognized persons in the St. Louis community, who through their chosen field of work have helped to further our mission of improving the quality of life for persons with mental illness and their families.

For the year 2002, the Gala was held at the beautiful Sheraton City Center, in downtown St. Louis, on December 8. Five prestigious awards were presented to the following awardees.

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Medication and Treatment

Recent Articles on Medications and Benefits

Two New Products Approved

On November 15, 2002, the U.S. Food and Drug Administration (FDA) approved **ABILIFY™** (aripiprazole), a new antipsychotic medication indicated for the treatment of schizophrenia. Bristol-Myers Squibb Company and the Otsuka Pharmaceutical, Inc. will jointly market the drug.

Clinical studies involving 1,238 patients with acute relapse of schizophrenia demonstrated that treatment with Abilify was statistically superior providing significant improvements in the positive and negative symptoms of the illness. Importantly treatment with Abilify was associated with minimal weight gain, minimal involuntary muscle movement disorders and a modest difference in sedation compared to placebo (11% vs. 8%).

As with other drugs having efficacy in schizophrenia, the mechanism of action of Abilify is unknown. It has been hypothesized that Abilify works differently than other antipsychotics mediated through activity at the dopamine D2 and serotonin 5HT1A and 5HT2A receptors. The drug is taken once daily in doses ranging from 10 to 30 mg.

On November 26, 2002, the FDA approved **Strattera™** (atomoxetine HCl) judging it safe and effective for the treatment of Attention Deficit/Hyperactivity Disorder (ADHD) in children, adolescents, and adults. Strattera, a selective norepinephrine reuptake inhibitor, developed by Eli Lilly and Company is the first FDA-approved treatment for ADHD that is not a stimulant under the Controlled Substances Act.

Six placebo controlled clinical studies, some for as long as 2 ½ years, involving children, adolescents and adults have demonstrated Strattera's effectiveness. The capsule can be taken once or twice a day. It has not been tested on children under 6 years old.

Other Drug Notes

In a year long study **Zyprexa™** (olanzapine) was found to be more effective than lithium in helping patients with bipolar disorder remain in remission and prevent relapse into mania. "While both drugs performed well, Zyprexa was found to be superior to lithium. This is especially impressive from the clinical standpoint given that lithium has been the gold standard for decades for the prevention of mania," said Frederick Goodwin, M.D., Director on Neuroscience, Medical Progress and Society, George Washington University Medical Center, Washington, D.C.

Results from the largest-ever ADHD clinical trial show that **ADDERALL XR®** (mixed salts of a single-entity amphetamine product), a once-daily extended-release ADHD medication, significantly improves the hallmark symptoms of ADHD and the quality of life of children living with the condition. Quality-of-life assessments show significant improvements in social relationships with friends and family, as well as scholastic, emotional, and physical functioning in the child. Nearly 3,000 children, ages 6 - 12, participated in this study known as the Long Acting Adderall Community Assessment Trial (LADD.CAT).

Results of a double-blind placebo-controlled study evaluating the efficacy and safety of antipsychotic treatment in adolescents with bipolar disorder demonstrated that adding the atypical **SEROQUEL®** (quetiapine fumarate) to mood stabilization therapy is significantly more effective than using mood stabilizers alone. The results are significant because this is the first controlled study to evaluate efficacy and safety of antipsychotic treatment in adolescents especially when nearly half of all adolescents with bipolar disorder fail to respond to initial treatment with divalproex or lithium.

Social Security Benefit Levels Rise

The Social Security Administration has announced that monthly Supplemental Security Income (SSI) benefits will rise 1.4 percent starting December 31. This bump means the maximum monthly SSI check will rise to \$552 for individuals, to \$829 for an eligible individual with a spouse. The dollar fee limit for representative payee services will be \$30. The substantial gainful activity level for blind beneficiaries will be \$800. The earning threshold establishing a month as part of a trial work period will be \$570.

Medicare Needs Parity Too

Should you find the need to contact your Congressman or Senator about a Medicare issue such as getting a drug benefit for Medicare recipients, a helpful message to convey is that Medicare needs parity for mental health care co-pays. Medicare has a 50% co-pay for mental health services while the program has only a 20% co-pay for medical services. Congressmen and Senators' health insurance plans provided by the federal government contain a parity provision for mental health care services.

NAMI St. Louis News

Welcome New Staff

Christina Dougherty & Elizabeth Westhoff have now joined NAMI St. Louis in the Kirkwood office. Their presence rounds out the staff needs of NAMI St. Louis and we are all looking forward to a full complement of roles to perform the mission of our organization.

Elizabeth, our new Director of Development, is a talented young woman who brings her experience as Major Gifts Specialist for the American Red Cross to her new position here at NAMI St. Louis. Coupled with her professional experience Elizabeth holds a Master of Arts degree in English and is nearing completion on a second Master of Arts degree in Public Administration. The combination of Elizabeth's intelligence and strong work ethic should be of great help in ensuring funding for the mission of NAMI St. Louis. Expect great news from this front in the future!

Christina Dougherty will be serving as our Director of Volunteer Services and Family Education and Support Programs. Such Adult programs as HELPLine, Family to Family Education courses, NAMI Support Groups, and our continuing education programming will fall under her supervision. In addition, she will recruit, train and otherwise facilitate the work of volunteers, vital to the mission of NAMI. Christina brings to us an education and work experience based on analytical thinking and writing along with many years of volunteer experience, both in serving and in managing work forces. We look forward to her assistance in organizing and facilitating the programs which help us support and educate our families and the greater community.

The next time you're in Kirkwood, please take a moment to stop by and welcome Elizabeth and Christina.

Thank You!

NAMI St. Louis would like to extend a very heartfelt *Thank You* to everyone who so graciously responded to the Holiday Appeal. Without your generosity, NAMI St. Louis would not be able to help so many families in the St. Louis area.

We Need You! Volunteer Today!

The good news: We're growing and serving more of our families - those trying to cope with life with a loved one with a mental illness, and those trying to access the care and attention their loved one and themselves need so badly! That means we need each and every one of you to lend your talents, skills and time to the effort. Whether you have small blocks of time, want simple tasks, lots of regular available time, have computer skills or anywhere in between. *We Need You! There are small jobs but no insignificant jobs.*

Contact Christina Dougherty at (314)966-4670 for more information regarding the following volunteer positions:

Q HELPLine Associate: Answer calls and give information on how to reach important resources; how to find emotional, financial and legal help; how to educate, inform and deal with your family, ill loved one, and the mental health services. This requires at least a single shift per month commitment and a willingness to educate yourself to be an effective information resource and support.

Q Mailing Committee: We rely on volunteers to complete the mailings of our substantial information dissemination. From 4 days once a month (newsletters) to small periods of time throughout a month (workshops and various outreach and fundraising mailings), we have a crew of volunteers who gather to get the work done, enjoy one another's company and enjoy a meal together.

Q Library Oversight: Our lending library contains everything from tapes, videos, books and information pamphlets to allow our families to learn about every aspect of mental illness. Volunteers are needed to order, organize, maintain and record inventory.

Q Office Clerical & Data Entry Support: Every day we have need of volunteers to file, perform data entry and miscellaneous other skilled office tasks. If you have the time and talent, please contact us!

Q Fundraising Committee: Throughout the year we have a variety of fundraising activities, from a Festive Gala to a Walkathon, to smaller donation drives. Volunteers are needed to assist the Director of Development, Elizabeth Westhoff, in these efforts.

Q Family to Family Education Teachers & Support Group Facilitators: Volunteers willing to train to teach classes (2½ hours per week for 12 consecutive weeks) &/or act as a Facilitator for a Support Group (hr. per month, ongoing) are needed immediately! Education and Support are the spine of our mission and we need to share both - our experiences and wisdom to help.

Schnuck's Certificates:

Unfortunately, Schnucks has discontinued the "paper" gift certificates and have switched to the "credit card" type. Their new method would be difficult to manage in regard to purchasing and keeping track of the remaining amount on the card. Therefore, we are no longer participating in this type of donation program.

Awards Presented at Gala 2002

(continued from front page)

John G. Csernansky, M.D. was honored with the prestigious **Mortimer Goodman Award presented** to a mental health professional who has been helpful to NAMI St. Louis. Dr. Csernansky is an ardent advocate for NAMI. He will give of his time, anytime, to this organization if he can possibly fit it into his schedule. He has given us gratis numerous lectures for our Continuing Education Meetings, our Legislative Breakfast, and state conferences. He negotiated special rates at conferences for NAMI members. He invites us to speak and participate in programs and projects he is involved in. Lastly he has named NAMI St. Louis to receive the royalties from the book he edited, published this year, *Schizophrenia – A New Guide for Clinicians*. Dr. Csernansky is the Gregory B. Couch Professor of Psychiatry at Washington University School of Medicine and director of its Conte Center for the Study of Schizophrenia.

The first ever **Outstanding Legislator Award** was presented to The Honorable Timothy P. (Tim) Green, State Representative from the 73rd District. As chair of the Budget Committee during the 2002 Legislative session, Representative Green had a formidable task -- to put together and pass a final budget that didn't cut services to the state's most vulnerable citizens including persons with severe mental illnesses. Our consumers depend on appropriations given to the Department of Mental Health and the Department of Social Services, especially the Medicaid programs. Governor Holden had proposed using the Rainy Day Fund to retain mental health services. Rep. Green was able to preserve the Health and Mental Health Appropriations Committee's report to not use Rainy Day funds for mental health services. The fund was used but not as originally proposed by the Governor which preserved mental health services in future years. It is our hope this annual award will become a prestigious award for area legislators symbolizing his or her dedication to improving Missouri's mental health care delivery system.

Outstanding Media Person Award was presented to Art Holliday for producing an outstanding documentary on schizophrenia. Because media has so much influence in its portrayal of persons with mental illness in our society, NAMI St. Louis spotlights outstanding accomplishments of people in the media whose work embodies the truthful, correct message we want the public to see and hear about these severe disorders. Art is well known for his superb work on KSDK's Channel 5 Today in St. Louis Program and News at Noon anchor. Chronicling the 1994 unfortunate tragedy of Jim and Nancy McBride who were stabbed to death by their son, Matthew, during a psychotic episode of schizophrenia, Art has produced *Before They Fall off the Cliff: the Ripple Effect of Schizophrenia*. Even though Art says the documentary is still a work in progress, we are proud to honor his accomplishment. Many of us

enjoyed the several showings of the film during October, 2002.

The **Outstanding Educator Award** was presented to Lynne Midyett for developing the Education Support Program through the Special School District of St. Louis County in cooperation with the Mehlville School District. Several others in St. Louis County are being replicated. This program fills a gap in the array of day treatment programs available to children and youth with mental illnesses where none existed. Children in this program spend a portion of each school day working on social skills and the behavioral problem areas that prevent their full participation in public school so that the remainder of their school day can be focused on academics. The result is success in school and in life. This award recognized Lynne's vision and leadership in establishing these programs.

This year's **Outstanding Volunteer Award** was given to someone who has given a lifetime of work to the NAMI mission. Ann Sheehan has been passionately motivated to work for NAMI because of her own family's experiences with mental disorders. Ann and her husband Jack were in Madison, Wisconsin in 1979 to witness the formation of the National Alliance for the Mentally Ill. Even though Ann has done about everything one can do at NAMI, her current area of work is focused on the HELPLine and Advocacy. Ann has served as President of the Board for this affiliate numerous times, on the State NAMI Board and the National NAMI Board. She has worked on most all of our projects from past galas to police training. She frequently has traveled to Jefferson City to walk the Capitol halls working on an issue for NAMI. Ann has always seen the big picture of what needs to be done to correct our ailing mental health system and has dedicated the last twenty-four years trying to do just that.

Congratulations to all our award winners!

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Treasurer: Jeffrey Pass
Executive Director and Editor: . . . Marge Parrish

Our mission is to improve the quality of life for persons with severe mental illness and for their families.

From the Desk of Elizabeth Westhoff, Development Director

How to include NAMI St. Louis in your will...

Many of our supporters make charitable gifts by naming NAMI St. Louis as a beneficiary in their wills. The federal government encourages these gifts, or bequests, by allowing an unlimited estate tax charitable deduction. Perhaps there is some service or program offered by NAMI St. Louis that is of special interest to you. If so, you may be able to extend your influence into the future in order to benefit many other people. We encourage you to plan carefully as you draft and execute your will in consultation with a legal advisor. It is also advisable to review it occasionally.

The following language will be helpful to your lawyer:

"I give, devise and bequeath to the Alliance for the Mentally Ill - NAMI St. Louis, 134 West Madison Avenue, St. Louis, Missouri, the sum of \$_____ or _____% (or real or personal property herein described), to be used for the general purpose of the organization, at the discretion of its Board of Directors."

Interested in having 4,500 people see your ad?

If your organization would be interested in purchasing advertising space in the NAMI St. Louis newsletter, please contact Elizabeth Westhoff @ 314-966-4670.

Washington University School of Medicine Seeks Participants for Study on Schizophrenia

Families are currently being recruited to participate in a Washington University School of Medicine study to determine the genetic and environmental factors associated with schizophrenia. If two or more sisters and/or brothers in your immediate or extended family suffer from schizophrenia, your family may be eligible to participate in this research. Participation will include:

- ' A confidential personal and family history interview.
- ' A small blood sample.
- ' Monetary compensation for time and travel.

For more information about this study, please contact Art Schaffer, Research Coordinator, at (314) 286-1506 or toll free at 1-888-925-7252

How Shopping online can

benefit NAMI St. Louis

Great news everybody! We've just signed up for a DollarBack Fundraiser that will give us a donation every time we shop online at great places like Amazon.com, LL Bean, Lands End, Office Max, Toys-R-U's and over 250 other popular stores! The donation is typically 2-3% of the purchase price and it's paid by the, so there is no added cost to the person making the purchase.

All we have to do is remember to go to www.dollarback.com/namistl and click on the link for the store we want. Then when we buy something, The Alliance for the Mentally Ill - NAMI of St. Louis will get a donation from the merchant. Tell all your co-workers, family and friends to use this site and we'll get donations for their purchases as well.

Are you thinking of trading in that old car, boat, or RV? Why not donate it instead?

NAMI St. Louis is a participating organization in the America's Car Donation Charities Center. The donation of your vehicle to our organization means that you would possibly be able to receive the full fair market value as a tax deduction, and as a charitable contribution to our organization - your car donation would make a big difference. The process of donating a vehicle is a hassle-free process for you. We will make all the arrangements for the pick-up of your car, title transfer requirements, and providing you with a tax-deductible donation receipt. To learn more about how to donate a vehicle and to get answers to frequently asked questions, please call Elizabeth @ (314)966-4670.

United Way Allocations

Many of you allocate a certain percentage of your paycheck for NAMI St. Louis through the United Way pledge system. If you would like to receive our newsletter and other mailings, please don't forget to let us know that you're helping support NAMI St. Louis through the United Way.

Don't Forget...

Many of you help support NAMI St. Louis through the matching gift programs your employer offers. Utilizing these matching gift programs is a great way to double the financial support you provide for NAMI St. Louis. We thank those of you who have been utilizing these programs to enable us to improve ours.

Memorials & Tributes

June 29, 2002 through December 13, 2002

É *In Loving Memory of*
Don Berg

The Harrison Family

É *In Loving Memory of*
Louis Blome

Beaumont Davidson

É *In Loving Memory of*
Colette Yvette Brinzel

Mary E. Carmody
Deborah J. Connors
Chuck & Patti Fisher
Kevin Kipp
June D. Kreyling
Debra Mesle
Arlene Schalk & Family
Johanna Taylor

É *In Loving Memory of*
David Camp

Patricia Rudloff

É *In Loving Memory of*
Alice R. Dyer

Mary Ann Kacin

É *In Loving Memory of*
Lucy Elseffer

Mr. & Mrs. George Meriwether
Cookie & John Meyer

É *In Loving Memory of*
Robert Finley

Mr. & Mrs. Bob Cooper
Mr. & Mrs. Walter Finley
Mr. & Mrs. Patrick Kelly
David King

É *In Loving Memory of*
Bob Frei

Mr. & Mrs. Alvin Stern

É *In Loving Memory of*
David Hayman

Roberta Hayman

É *In Loving Memory of*
Rich Hoch

Mr. & Mrs. Clyde Bollinger
Mr. & Mrs. George Ferguson

É *In Loving Memory of*
Judy Koepke's Father

"From your friends at the office"
Roz, Chris, John, Nan, Nancy, Scott,
LingWei, Shu, Kung Yu, and
Roberta

É *In Loving Memory of*
Douglas Lee Kreyling

June Kreyling

É *In Loving Memory of*
Stephanie Lopez

Ron & Suzanne Cooney

É *In Loving Memory of*
Robert Maxwell

Mr. & Mrs. Alvin Stern

É *In Loving Memory of*
Robert Rapp

Howard Blevins

É *In Loving Memory of*
Dolores Roewekamp

The Fabick Family

É *In Loving Memory of*
Dotty Sherman

Violet Steinback

É *In Loving Memory of*
Jeff Shearman

Mr. & Mrs. John Shearman

É *In Honor of Ann Sheehan*
Bettye & Leonard Siebels

É *In Loving Memory of*
Leonard Siebels

Robert Arendes
Mr. & Mrs. Clyde Bollinger
Eva Bradin
Katherine Brooks
James Casey
Mary Duffield
Dr. & Mrs. J. Ernst
Mr. & Mrs William Hester
The Johnson Family
Kim Judd
June Kreyling
Mr. & Mrs. Maguire
Mr. & Mrs. Calvin May
Chris & Marge Parrish
Ruth Renz
Ann & Jack Sheehan
Alan Siegerist
Mr. & Mrs. John Wehling

É *In Loving Memory of*
Dolores Townsend

Mary Ann Kacin

É *In Loving Memory of*
Jean Weeks

Ann Ernst

É *In Loving Memory of*
Joseph T. Wempner

John Wempner

É *In Loving Memory of*
Carol Zinnwalt's Mother

Sandy Engber

É *In Honor of Bill & Robin*
Harri's Anniversary

Linda & Jerry Meyers

É

**Memorial/Tribute envelopes
are available for those who
wish to honor a loved one
with a gift in support of the
NAMI mission.**

Mental Illness in the Elderly “A Growing Concern”

According to the American Psychiatric Association citing the report: *Consensus Statement on the Upcoming Crisis in Geriatric Mental Health: Research Agenda for the Next Two Decades*, “15 million elderly people are expected to suffer from some kind of psychiatric illness by the year 2030.” (APA Monitor Online, v3n11, December ‘99, www.apa.org/monitor/). This is triple the amount of elderly persons who are currently served by the mental health system now. As baby boomers start reaching retirement age, a new generation of geriatric mental health issues involving such problems as substance abuse, depression, late onset schizophrenia, and anxiety disorders will become more prominent.

Dr. Dilip Jeste, director of Geriatric Psychiatry at the University of California at San Diego is one of the foremost authorities on mental health and aging persons. According to his research and national data, mental illness in the elderly is under diagnosed and under treated. As the population of aging persons with mental health disorders increases, advances will have to be made in medical and community services and training among caregivers and geriatric mental health care professionals. Consequently, research, new medical technologies, education programs, and family interventions are increasing in number and quality. In fact, the National Institute of Mental Health played a significant role in the development of a professional panel, who is responsible for outlining a 15 to 25 year plan to retool medical schools and health providers to effectively deal with psychiatric problems in the elderly.

“Sleeping problems, sadness, forgetfulness, withdrawal, (irritability, and uncharacteristic behaviors and feelings we often accept in older adults. But for many people age 65 and over, these responses are not a result of the normal aging process, nor are they signs of senility. They are symptoms of common emotional illnesses. If the signs of the illness are recognized and appropriate help is sought, most elderly patients can experience improvement within weeks.” (Psychiatric Institute of Washington: Depression in the elderly, www.psychinstitute.com/).

If you are a caregiver or mental health professional seeking assistance in providing care for an elderly person coping with a mental health disorder get the facts and be supportive.

Depression

Depression is a mood disorder, involving your body, thoughts, and behavior. It affects the way you eat and sleep, how you feel about yourself and your thoughts about once pleasurable activities. A depressive illness is not a passing blue mood or a sign of personal weakness. People with depressive illness cannot “pull themselves together” and get

better. Depression is a combination of symptoms that interfere with your daily ability to function normally at work, home and socially. Without treatment, symptoms can last for weeks, months or years.

At any given time, ten million Americans suffer from this disabling illness, which can appear at any age. One in five adults can experience depression at some point in their life. About 5% of children and adolescents also suffer from this disorder. It is twice as common in females than males.

Signs of Depression:

Depression or sad mood, excessive crying

- Irritable mood in children and adolescents
- Decreased interest or pleasure in almost all activities, lack of interest in yourself.
- Change in appetite and/or weight
- Change in sleep pattern
- Restlessness, irritability, agitation, feeling “on edge and nervous”
- Decreased energy or fatigue, feeling “on edge or nervous”
- Continual feelings of worthlessness, excessive guilt, or hopelessness
- Lack of concentration
- Avoidance of family or friends
- Thoughts of death or suicide, suicide attempts

Depression, if left untreated can persist for years and may result in suicide. It is the most treatable of all mental illnesses. With modern treatment methods, people can return to full and productive lives.

If you or someone you know appears to suffer from the signs of depression, call for help.

The NAMI St. Louis HELPLine is available Monday - Friday, 9:00 a.m. to 5:00 p.m. @ 314/966-4670

