

NAMI-DELAWARE

Alliance for the Mentally Ill in Delaware

2500 West 4th Street•Suite 5

Wilmington, DE 19805

706 Rehoboth Avenue

Rehoboth Beach, DE 19971

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Consumer Services Organization Activity Centers

Wilmington Center

2500 W. 4th Street • Suite 2

Hours of Operation: Tuesday, Thursday, Friday – 10:00 am - 3:00 pm

Newark Center

The New Ark United Church of Christ • 300 E. Main Street

Hours of Operation: Tue., Thur., Fri. – 12:00 am - 5:00 pm

.....

Activity Centers Also Provide Weekly Support Groups

Tuesday: Dual Diagnosis

Thursday: Depression

Friday: Self-Esteem



**Remember NAMI-DE
in your will**

**You can leave a living
legacy in your will.
For more information on
planned giving, contact:
Dick Patterson at
427-0787 ext. 13**

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NAMI-DE

Alliance for the Mentally Ill in Delaware

News

www.namide.org

SAVE THE DATE May 10, 2003

NAMI WALKS for the Mind of America

By Pat McDowell

“Every journey begins with that first step” ...and this May thou-

sands of Americans will walk together to raise money and awareness about our country's need for a world-class treatment and recovery system for people with brain disorders (mental illness).

Delaware's own 2 mile walk will take place on Saturday, May 10 at Dravo Plaza in Riverfront Wilmington. Check in time is 9 am and the official walk start time is 10 am. There is no walker fee for registration, but we ask all walkers to raise as much money as possible through pledges from family, co-workers and business associates in support of their participation in the Walk. Walkers raising \$100.00 or more will receive a NAMIWALKS for the Mind of America tee shirt!

continued on page 2

From the Desk of the President

By Dick Patterson

Several years ago, NAMI's National office established a Leadership Institute, whose charge is to provide educational opportunities to help NAMI's 52 “state” and 1200+ local affiliate organizations develop and strengthen their volunteer and professional leadership and increase the effectiveness and efficiency of these organizations.

In mid-January, the Institute convened the Second Annual Winter Leadership Conference in Orlando, Florida. Nearly 300 NAMI leaders from around the country participated in an intense weekend of learning and sharing. NAMI-Delaware was represented by five members of our Board of Directors and staff: Rita Marocco, Pat McDowell, Dick Patterson, Alice Rauer and Mark Thompson.

The Conference was structured to provide a balance between presentations, panel discussions and special interest meetings. There was plenty of time for formal and informal networking and dialogue, to renew old friendships and make new acquaintances with persons who share a common interest.



The Keynote presentation for the Conference was given by Charlie Curie, new Director of the Federal Substance Abuse and Mental Health Services Agency. He described the Agency's program for translating the learnings from research into the causes and treatment of mental illness into services directed toward rehabilitation and recovery. A friend of NAMI, Mr. Curie urged NAMI to “keep our feet to the fire”.

With the exception of the Keynote speaker, the faculty for the conference was comprised entirely of members of the NAMI Family – National Board members and staff, Regional Directors, Consumer Council members, leaders from State Organizations and local affiliates. Without exception, the presenters were well informed, well prepared and the material presented was current and useful.

Other highlights of the conference included:

- Five concurrent three-session “learning tracks” dealing with issues pertinent to the growth and vitality of NAMI at all levels;
- A lively dialogue concerning proposed changes in organizational structure and policies aimed at strengthening the NAMI organization while preserving its grassroots nature.

continued on page 2

In this issue...

- NAMI-DE New Board Membersp. 2
- Crisis Brewing in Delaware.....p. 3
- Visions for Tomorrow.....p. 3

- Campaign for the Brainp. 5
- State Policy Makers Face Tough Decisionsp. 6
- Housing Updatep. 6
- Support Groups.....p. 7

and more...



The Alliance for the Mentally Ill in Delaware

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President continued from page 1

- Recommendation of guidelines for total integration of consumers into the life and governance of NAMI organizations;

- Presentation of the project plan and timeline for implementation of “TRIAD”, an information and advocacy database being developed to enable NAMI organizations to characterize and monitor the mental health services in their states;

- An informal get-together of participants from the northeastern states during which we exchanged ideas and discussed ways in which we can collaborate.

NAMI Walks continued from page 1

Companies, organizations and families are welcome to organize teams of walkers to take part in the Walk. Participating teams will be recognized with special awards. Corporate and individual sponsorship opportunities are available — call us at (302) 427-0787.

A Kick-Off event for team captains will be held at the end of March.

Proceeds from the NAMI-Delaware walk will help fund programs in Delaware which provide support to persons living with serious brain disorders (such as schizophrenia, major depression, bipolar, obsessive-compulsive and severe anxiety disorders) and their families. These programs provide support, education, advocacy, housing and the encouragement of research to find a cure.

Take that First Step — WE NEED YOU to walk for the Mind of America with us!

WELCOME

NAMI-DE Welcomes New Staff

Dale Eurenus
CSO Director

We are delighted to have your help and support at NAMI-DE.

The NAMI-Delaware representatives were uniformly enthusiastic about the spirit and content of the conference. NAMI is fortunate to have so many dedicated and competent professionals and volunteer leaders at all levels, representing such a diversity of circumstances. We return to Delaware stimulated by the information and challenges we received, and ready to share our learnings as we carry out our mission to support, educate and advocate for persons in Delaware with mental illness and their families, “until there’s a cure”.

NAMI-Delaware Introduces New Board Members

By Dick Patterson

Late last year, the Board of Directors of NAMI-Delaware added two new members, Alice Rauer and Al Tapert, both of Dover.

Alice and Al have been longtime members of NAMI-DE’s Dover support group, and they have participated actively in the Task Force (now Committee) that has been working to extend and improve the delivery of NAMI services to Kent and Sussex Counties.

Alice, the mother of three, works part-time as business manager of her husband’s medical practice. An accomplished violinist, she is the concertmistress of the Dover Symphony Orchestra. Al retired from the Delaware Division of Public Health after 20 years as Radiation Control Administrator. He has served as a member of the statewide Committee on Employment Opportunities for Persons with Disabilities.

Alice and Al bring needed skills, talents and interests to the Board. We welcome them and look forward to working with them to improve the services throughout the state of Delaware to persons with mental illness and their families.



Brewing in Delaware

Mental health citizens being turned away

By Rita Marocco

People living in Delaware are encountering more and more obstacles when they seek treatment for mental health or substance abuse problems. The ever-growing wall between individuals and their treatment has been created by mental health/substance abuse third party administrators and/or managed care carve outs. These managed care companies are sub-contracted by insurers such as Coventry, Mid-Atlantic and the State's Medicaid, to name a few. The carve-out managed care company's purpose is to manage the mental health and substance abuse components of Delaware's insured population. They provide utilization reviews, approve admission into each level of treatment and pay the claims submitted by mental health and substance abuse providers. Each managed care company has its own provider panel of hospitals, residential and outpatient treatment facilities. Some of the third party administrative companies do a fairly decent job. Others have created havoc in Delaware's treatment system. The result is thousands of individuals on Medicaid carve-out and other insurances in the state are being denied treatment. This is because providers are caught in the dilemma of having provided services as a preferred provider while not getting paid.

NAMI Delaware feels that at least two managed care companies operating in Delaware, APS and Magellan, employ what we consider questionable practices. According to psychiatrists, psychologists, clinical social workers, substance abuse therapists and hospitals who provide services in Delaware, millions of dollars in claims reimbursement have not been paid within the forty-five day period mandated by insurance regulations. Indeed, many providers report outstanding claims of six months or longer. Numerous providers have made the difficult decision to remove themselves from the provider panels of APS and Magellan, or to

drop clients whose treatment is being managed by these companies. The alternative for these providers is to continue treating clients covered by these third party administrators without hope of getting paid. The majority of affected providers have found this alternative to be unrealistic because of the debt they are forced to carry. This debt has threatened the economic viability of clinics, hospitals and private practices throughout Delaware. Because of the current situation, individuals suffering from symptoms of mental illness or experiencing addiction are left with few treatment alternatives.

NAMI Delaware and a contingent of mental health/substance abuse providers met with Donna Williams, Insurance Commissioner for the State of Delaware, on January 27, 2003 to alert her of the crisis developing in Delaware. Though Ms. Williams and her staff were empathetic, they clearly stated their lack of authority over the third party administrator companies operating in Delaware. The alternative action the Insurance Commission has is to go after the insurance companies that have sub-contracted with third party administrators who are in non-compliance of insurance regulations.

NAMI Delaware opposes any systematic dismantling of Delaware's treatment community. Third party administrators proven to have violated state mandated regulations need to be held accountable. Delaware's corporations, businesses and the State pay billions of dollars to insurance companies to provide mental health and/or substance abuse treatment in good faith. The result should not be that an employee's (or citizen's) recovery is dependent on which third party administrator has been chosen to manage their care. If their choice results in poor management of an employee's/citizen's care, leaving the person twisting in the wind, it is too high a price for all to pay.

Visions for Tomorrow

By Donna Anthony

The initial planning meeting to discuss steps in implementing the *Visions for Tomorrow* program was held January 14, 2003. VFT is an education program written for primary, direct caregivers of children and adolescents with brain disorders. The focus is on symptoms, not diagnosis. The curriculum covers more than a dozen major diagnoses and the basics of day-to-day skills building. The teachers (always a team of two) are themselves primary caregivers. These trained family members have experienced first-hand the rewards and the challenges of raising children with brain disorders. The course offers caregivers the opportunity to share mutual experiences and learn valuable lessons.

An informational session for families and/or other interested parties will be held in both New Castle and Kent Counties within the next couple of months. We are still looking for primary caregivers of children and adolescents with a brain disorder who may be interested in becoming trained as a teacher of the program.

MBNA has donated \$7500 in seed money toward implementation of the program; however more funds are needed to cover the costs of materials and trainings. We are currently seeking additional grant opportunities. We would like to begin the program in both New Castle and Kent Counties and with success expand to Sussex County. The target date to begin the program is fall 2003.

Please call Donna at (302) 427-0787 NAMI-DE for additional information or if you or anyone you know might be interested in becoming a trained caregiver for the program. This program has been very successful in several states since it was originally written and developed by NAMI-TX, who retains all copyrights to the curriculum.

Family-to-Family

- What do I do if there is a crisis?
- How can I get a clear diagnosis for my relative?
- How can my relative and I communicate better?
- What local services in our community am I missing out on?
- What are all those medications for?
- What are the best treatments available now?
- How do I take care of myself in the midst of all this?
- Where can you turn with these questions?

The classes fill up quickly so call today to enroll for the next series!

Consumer Service Organization

By Dale Eurenus

As the new Director of CSO, I am pleased to be part of NAMI – DE; a powerful voice in the community, not only for those who cope with mental illness but also, for their families. In our Activity Centers in Wilmington and Newark, we offer support, education and enrichment to aid in the ROAD TO RECOVERY.

Prior to CSO, I co-Founded and co-Administered a non-profit agency that assisted and empowered people toward self-sufficiency. As a consumer, I am very aware of the critical need for first-rate support services for persons throughout the recovery process.

Our experienced CSO staff provides this support to a wide range of consumers and their families, through education, support groups and programs of enrichment. Facilitators who have been through their own recovery journey ably staff our Activity Centers.

I look forward to a productive time of learning, meeting challenges, building relationships and working with the staff of NAMI-DE. *We will continue to reach out to consumers and their families as they travel their own Road to Recovery, one friend at a time.*

NAMI-Delaware presents a Free Education and Support Series for Families and Close Friends of Individuals with Brain Disorders (Mental Illness). This course is taught by trained family members — people who really understand what the class members are experiencing. People who take this class receive information about illnesses of the brain and their treatment, learn how to communicate with mental health providers and pharmacists, and focus on care for the caregiver — coping with stress, worry and emotional overload.

NARSAD Artworks for sale!

NARSAD (the National Alliance for Research on Schizophrenia and Affective Disorders) presents museum-quality art products by and on behalf of mentally ill persons. These note cards and book marks are the perfect gift for any occasion!

You can purchase your NARSAD items in our Wilmington office. Your purchase will help improve the lives of persons with brain disorders called mental illness through programs and research. To purchase NARSAD Artworks products visit our Wilmington office or call (302) 427-0787 and ask for Tere.

NAMI-DE would like to thank all those who donated through the United Way this last campaign. Thank you letters were sent out the last week of January. If you did not receive a letter but wished to be acknowledged, this may be because you didn't check the box on the United Way form stating that you wanted to be acknowledged. The United Way no longer releases the names of those who do not wish to be acknowledged, so NAMI-DE does not get a complete listing of all donors. Again, NAMI-DE greatly appreciates the support!

In Memoriam

By Sarah Budd-Bucic



Finally meeting an artist of great accomplishment can be anti-climactic — but there was nothing of the sort when one met **Gretchen Hupfel**. Named artist of the year by Atlanta magazine, Gretchen Hupfel, at age 39 touched others in a way that was memorable and intriguing. Known to those in the art scene as bright and extremely gifted, Gretchen was adept at photography, sculpture and jewelry making. Having shown her artwork at places such as the Metropolitan Museum White Columns Gallery in New York her artwork fought and defied the mental disorder of schizophrenia that eventually took her life. Gretchen's mother, Alice Hupfel, appealed to those who wanted to celebrate Gretchen's life to make contributions to the Family-to-Family program of NAMI Delaware. The response was tremendous. NAMI Delaware received over \$5,000 from all over the nation, in memory of Gretchen's life and spirit. Gretchen's early death is a loss not only for her family and friends but also for those who only knew her through her artwork and a world that will never know what she might have done next. In an interview with Alice Hupfel, she stated, "What I learned in Family-to-Family and the support I receive makes it possible for me to get through this tragic time in my life." NAMI Delaware is deeply honored that even in the midst of her grief, Alice thought to support other families struggling with the disease of mental illness by supporting the Family-to-Family educational program. Your contribution and the contribution of those who answered your appeal will assist NAMI Delaware in continuing to reach out to families and make their journey a journey of hope, not constant despair. Thank you.

Get Ready for our Third Annual Greaseband Party!

By Wendy Burns

Be sure and set aside the date Friday March 14th for our annual "Beef & Boogie" with the Fabulous Greaseband. This event will feature a Silent Auction as well as a Live Auction of some "fabulous" items. Please reserve your tickets early as they always go quickly. If anyone has any auction items they would like to donate or know anyone who would be willing to sponsor some of the costs (i.e. food, drinks, band) please contact Wendy Burns or Rita Marocco.

SAVE THE DATE
The Fabulous Greaseband
Friday, March 14, 2003



Housing Available

The National Alliance For Mentally Ill in Delaware is accepting applications for housing in Kent, Sussex, and New Castle Counties. We have immediate openings in Kent County and a short waiting list for Sussex and New Castle Counties. NAMI-DE housing is dedicated to adults who have a chronic mental illness. Applicants must be at least 18 years old & meet HUD mandated low income guidelines. Rent is based on 30% of adjusted income. Applicant screening includes criminal background check & disability certification. For more info contact the NAMI-DE office at (302) 427-0787.

Campaign for the Brain STIGMA AND DISCRIMINATION

By Pat McDowell

Mental illness affects one in four American families, yet less than 1/3 of people living with mental illness receive quality or even adequate treatment. Former U.S. Surgeon General Dr. David Satcher stated that, "those who fail to get good care are held back by enduring stigma, a fragmented system of mental health care delivery and financial strains. Mental illness is as real as heart disease; patients can benefit from new treatments and medications and can recover". Mental illness is an equal opportunity disease, crossing all socio-economic boundaries. It is as prevalent in one ethnic or cultural group as another. "Mental health is fundamental to a person's overall health, indispensable personal well-being and instrumental to leading a balanced and productive life. I want to be absolutely certain that my message is heard by America's millions of Hispanic Americans, African Americans, American Indians, and Alaska Natives. The message is

Mental illness affects one in four American families, yet less than 1/3 of people living with mental illness receive quality or even adequate treatment.

this: If you or a loved one is experiencing what you think might be symptoms of a mental disorder, seek treatment and seek it now. Insist on the kinds of services that can and should be available to you, whatever your language, your income, your geographic location, your race or your ethnicity. You will discover that your community has a wealth of resources."

NAMI-Delaware condemns all acts of stigma directed towards people with brain disorders.

Nicknames, jokes and slurs referring to persons with brain disorders in a stigmatizing way are cruel. Stigma leads to low self-esteem, isolation and hopelessness; stigma keeps families from seeking treatment for their loved ones; stigma results in stereotyping, discrimination and abuse. **STIGMA DEPRIVES PEOPLE OF THEIR DIGNITY AND INTERFERES WITH THEIR FULL PARTICIPATION IN SOCIETY.**

NAMI-Delaware is working together with the Mental Health Association and the Division of Substance Abuse & Mental Health to help the public understand the myths and misconceptions that perpetuate prejudice and stigma. We welcome the opportunity to visit schools, churches, workplaces, medical offices and organizations to increase public awareness that mental illness is a treatable, biologically based brain disease, and that effective treatment is available.

Please join us in our campaign against the cruelty of stigma.

If you would like to have an educational presentation at your school, workplace, or organization or if you would like to participate in presentations contact us at (302) 427-0787.

State Policy Makers Face Tough Decisions in Tough Times

Calculating the Wrong Variables Can Doom Thousands

By Rita Marocco

(Open Letter to State Policy Makers)

Billions of dollars have been spent on the research of mental illness. The results are tangible. The medical community is now equipped with the knowledge and the tools to alleviate unbearable symptoms and set the course for an individual's recovery. Support systems for individuals struggling with serious, biologically based mental disorders are finally beginning to emerge. We can truly state that treatment works while awaiting a permanent cure.

If policy makers in Delaware choose to disregard the recommendations of the President's Freedom Commission's Interim Report on Mental Illness the monetary cost will be obvious.

Though the community based treatment system in Delaware is in its formative stage, it stands on the threshold of greatness or disaster. The direction of its path lays solidly in the hands and hearts of our elected officials.

When Delaware policy makers put pen to paper and begin the grueling task of calculating where the state can afford to cut costs

while sustaining critical services it is a formidable task. Often times the quick fixes that are apparent initially result in tremendous financial losses over time. More importantly, the cost in human suffering is too high a price to pay for all. If policy makers in Delaware choose to disregard the recommendations of the President's Freedom Commission's Interim Report on Mental Illness the monetary cost will be obvious. The cost of repeated hospitalizations will rise far above the cost of community-based services. For many individuals suffering from untreated psychosis, paranoia, delusions and/or hallucinations, Delaware will spend an enormous amount of money to have them languish in prison when they break the law. Alcohol and illicit drug use will rise as individuals attempt to control their symptoms by self-medicating. Medical costs will rise due to other physical complications and overdoses caused by an untreated severe mental disorder. Homelessness will become increasingly common and leave individuals with serious mental disorders

to be victims of street crime. The suicide rate in Delaware will rise as desperate individuals succumb to the unbearable pain and torment caused by untreated mental disorders.

Mental disorders are the number one cause of disability in the United States. It out paces any other disease known to man. Policy makers and society in general must come to the understanding that brain is man's biological computer. When it is operating in a healthy state a person can achieve his or her maximum contribution to the community. If budget cuts impede or eliminate the possibility of recovery, thousands of Delawareans will be condemned to isolation, neglect and a life of despair. This is the most devastating price anyone could be asked to pay.

NAMI Delaware, on behalf of the families and consumers it serves, beseeches Delaware's policy makers to open their minds and hearts to the reality that mental illness is a biologically based disease. Treatment and support are not luxury items to be offered in good times and withdrawn in tough times. Every beautiful mind is an asset to the state of Delaware.



Our latest HUD project, DIMA X, is under way. The project will consist of 3 scattered site homes in Claymont, Newport and Milford for a total of 10 units. We hope to go to closing with HUD by July and complete renovations and have tenants in by the end of the year. If anyone has furniture or furnishings they would like to donate, please call Merton Briggs and he will make arrangements to pick them up.

We also took over sole ownership of the 16-unit Woodmont Gardens Apartments in Newark as of October 1, 2002. Prior to that time we were 30% owners with Community Housing, Inc. owning 70%. We bought out their equity and have also currently taken over the management of the project.

Downstate News

By Mark Thompson

The faces of NAMI-DE are becoming more and more familiar throughout Kent and Sussex counties. The NAMI-DE advisory committee members from Kent and Sussex meet regularly to report the needs of the community and strategically plan for programs, and support expansion.

Support from the southern counties' community has been overwhelming. Several community leaders have stepped up to offer contributions to initiate and expand NAMI-DE programs. One individual donated a boat for NAMI to auction or sell. In presenting her offer, this lovely and compassionate woman stated "I want to give this boat to you because NAMI-DE helped me and my family when we had no place to turn for help". The proceeds from the sale of the boat will assist us in developing a program for consumers.

A training was held in January for eleven warm-line volunteers in the Rehoboth office. These individuals are family members of a loved one who has a mental disorder. What better people to turn to than those who have experienced the fear, frustration and pain of coping with an illness in their family. Thank you volunteers!

Support Groups

Our support groups are here to make your load lighter, your days brighter and to help you as family members and consumers strengthen each other during the trials and challenges in your life. You will find friends, caring, compassion and ideas to share. We hope you'll join us!

DOVER GROUP

3rd Thursday of each month • 7:30 pm

Kent General Bayhealth

560 South Governors Avenue, Dover

Contact: Cathy Mesick (302) 492-8885 or

Joan Conard (302) 734-2603

NEWARK GROUP

2nd Thursday of each month • 7:30 pm

St. James Episcopal Church

St. James Church Road

(off Kirkwood Highway)

Contact: Mary Zickefoose 454-1379 or

Lena Angotti 368-0591

NORTH WILMINGTON GROUP

2nd Monday of each month • 7:30 pm

Brandywine Valley Baptist Church

Room 149

Mt. Lebanon Road • Talleyville

Contact: Angie Pala 656-7433 or

Jill or Simon Shute 478-3302

REHOBOTH/LEWES GROUP

4th Thursday of each month • 7:30 pm

NAMI-DE Office

706 Rehoboth Avenue, Rehoboth Beach

Contact: Mark Thompson (302) 226-3334

Sue Brunhammer (302) 645-7617

CONSUMER SUPPORT GROUP: Dual Recovery Anonymous is a Twelve-Step self-help program for individuals who experience both chemical and an emotional psychiatric disorder. The support group meets at the Rehoboth NAMI-DE office every Tuesday night at 8 pm. Attendees of the support group find understanding from others who share similar experiences, practical information and guidance.

New Activity Center Open on March 4

By Dale Eurenus

Continuing to make a difference in the lives of consumers!

As we approach spring, the Consumer Services Organization has wonderful news. The Wilmington Activities Center is moving to a new, permanent, home - in a great location. It will be housed in the same 4th Street Plaza complex as the main office for NAMI - Delaware. We will have real storage space, a large common area and four smaller rooms. It will be handicapped accessible. We will be able to have computer stations, so our consumers can practice job-related skills or learn

how to surf the Internet. It will be so convenient to have the Center located adjacent to the NAMI Delaware offices. Mike & Wade are already making preparations - they are coordinating DART bus schedules to make the transition from one location to another as easy as possible for everyone. We hope to complete the move within the next 5 or 6 weeks. We already have volunteers lined up to share their wonderful talents and ideas for additional activities. This is truly exciting!

Our Newark & Wilmington Activity Centers have expressed interest in trips to Longwood Gardens (to witness first hand the beauty of Spring) and the Camden Aquarium. Of course we plan on our annual summer picnic.

The Consumer Services Organization is made up of friends helping other friends recover from mental illness. For more information on any of our Consumer Services Organization's activities, please call (302) 427-0787.