



OUT OF THE FOG

The monthly newsletter of NAMI San Francisco
www.namif.org

September General Meeting

By Roberta K. Kaye

Most persons with a mental illness need some financial assistance and for many this need is provided by a family member. But what happens if the caregiver is deceased? Who or what is available to carry on the delivery of needed aid? How will public benefits such as Supplemental Security Income (SSI) be preserved and navigation of its convoluted rules be accomplished? Who will know how to use the available funds wisely?

Our speaker, Baron Miller, Esq.* provided us with the answer: A Special Needs Trust (SNT) SOCIAL SECURITY ACT SECTION 1917 (d)(4)(A). Mr. Miller has a 34 year old daughter with schizophrenia. Concerned with her welfare, he converted a large part of his legal practice to drafting SNTs. This is the work that gives him the most pleasure because he can share his knowledge with those in the same position.

What are the choices available to a caregiver seeking to provide for a loved one after his/her death? Here are three--all with drawbacks: 1) a person can leave money directly to a loved one with a mental illness, but this assumes that there is sufficient ability to conform to the SSI and MediCal rules. 2) One can give funds to a friend or relative to provide an informal keeper arrangement, but this is not legally enforceable. Further, the requirement to reveal the identity of an informal keeper would then end the delivery of public benefits and the

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Minds On The Edge: Facing Mental Illness

Minds On The Edge: Facing Mental Illness zeros in on wrenching situations playing out every day in hospital ERs, on city streets and school campuses, in courtrooms and in jails, as Americans struggle with serious mental illnesses like schizophrenia and bipolar disorder. The dramatic scenario of this Fred Friendly Seminars program reveals personal dilemmas facing individuals and families, medical practices that can be obstacles to treatment, and public policies that are falling short.

Moderated by Frank Sesno, the program features Supreme Court Justice Stephen Breyer, Nobel-Prize-winning neuroscientist Eric Kandel, Pulitzer-nominated journalist Pete Earley, and other panelists from law, medicine, and public policy - including several who have personally faced the challenges of mental illness and offer their riveting insights.

Visit the Minds on the Edge Web site for TV schedule information and multimedia content on serious mental illness.

See it locally at **San Francisco KQED World Sunday, Oct. 4 6:00 PM.**

If you miss the program on-air, you can watch online after 10/1.

The Monthly Meeting

STILL BEING HELD AT 1010 GOUGH

3rd Wednesday of each month
 6:30 - 8:00 pm
 1010 Gough (till Jan 2010)

October 21

Sheri L. Johnson, PhD Director, and Ann Kring of the Cal Mania (CALM) program and professors of Psychology at UC, Berkeley will talk about Psychological Treatments to Add to Medications for Severe Mental Illnesses, bipolar disorder, schizophrenia, and schizoaffective disorder.

November 18

Elizabeth J. Yetter of UCSF with Daniel Mathalon and Judy Ford of the Brain Imaging and EEG Lab at the VA Medical Center present "Out of synch and out of sorts: Schizophrenia"

December:

No meeting

Education Night

Sponsored by Depression and Bipolar Support Alliance (DBSA) SF
By Wiveka Ramel, PhD

"Psychological and Neuroscientific Perspectives on Mechanisms and Treatments for Major Depression"

Wednesday, Oct 28th at 6:45-8:15pm
Conference Room B&C (lower levels) of
St Francis Memorial Hospital
(900 Hyde St, San Francisco, CA 94109)


Dr. Wiveka Ramel is a clinical psychologist with a private practice in San Francisco and a visiting researcher at Stanford University. Born and raised in Sweden, she received her doctoral degree in Clinical Psychology at University of California San Diego in 2005, after which she completed three years of postdoctoral research at Stanford University. Her research has focused on psychological and biological risk factors and treatments for mood and anxiety disorders. For more information, see www.sevitar.com

This is a free, monthly event sponsored by DBSA SF. For more information about Education Night, please contact Margaret at dbsasf@gmail.com




Support NARSAD ArtWorks!

NARSAD ArtWorks destigmatizes mental illness by educating the public, improves self esteem and income for artists, and makes money for local affiliates and research. Visit their Web site or call and get a brochure - they offer beautiful cards and products! Buy some products! Give some as gifts! Send holiday cards from NARSAD ArtWorks! Visit www.narsadartworks.org, www.silverribbon.org or call 800-607-2599 for information or a brochure. Thank you for your support!



**The SFGH CAB
CLOTHING PROJECT**



This program is a big help to consumers who are in need of clothes while they are at SF General Hospital.

Just call and they will pick up your donation or meet you at the front door of the hospital when you bring it in.

Please call Amelia Truman, 415-206-4465

Senator Ted Kennedy: A Member of the NAMI Family

Statement of Michael J. Fitzpatrick
Executive Director, National Alliance on Mental Illness

NAMI mourns the passing of U.S. Senator Edward M. Kennedy, a true champion for individuals and families affected by serious mental illness. This is a profound loss for the NAMI family. We do not have to struggle to remember what Senator Kennedy accomplished in seeking to improve the lives of millions of Americans. The real challenge would be to try to recall what he didn't do. His idealism moved the country. His pragmatism and ability to work with liberals and conservatives alike, enacted legislation.

A year ago, along with his son Patrick, Senator Kennedy was a driving force in the enactment of the mental health insurance parity law. The parity law is one of the most significant victories of the past 10 years for people who live with mental illness. The full list is longer. It includes:

- Americans with Disabilities Act (ADA)
- Family & Medical Leave Act
- Individuals with Disabilities Education Act (IDEA)
- Children's Health Insurance Program (CHIP), supporting state programs to provide health insurance to uninsured children in low-income families.
- Family Opportunity Act, providing states the option to allow low and middle-income families with special needs children to purchase health care through Medicaid
- Recognition of the National Institute of Mental Health (NIMH) as a biomedical research institute and increased funding for research.
- Early Intervention, Treatment and Prevention Act, providing for a range of education and training and community-based prevention and diversion services.
- Civil Rights for Institutionalized Person Act (CRIPA)
- Fair Housing Act expansion to include people with disabilities
- "Ticket to work" provisions under Social Security disability programs
- Health Insurance Portability & Accountability Act (HIPAA), including restrictions on insurance limitations for pre-existing conditions
- Genetic Information Non-Discrimination Act
- "Wounded Warrior" act to improve access to mental health services for National Guard and Reserve forces

For more than three decades, Senator Kennedy has been a voice for universal health care coverage and reform. His voice, perspective and wisdom will be greatly missed in the critical health care debate that is now before the nation. Congress could do no greater honor than to pass meaningful health care reform this year-building on his legacy.

Traffic Jam in Brain Causes Schizophrenia Symptoms

Scientists create first mouse to develop disease as teenager, just like humans

Source: Northwestern University
Monday, August 10, 2009

CHICAGO --- Schizophrenia waits silently until a seemingly normal child becomes a teenager or young adult. Then it swoops down and derails a young life. Scientists have not understood what causes the severe mental disorder, which affects up to 1 percent of the population and results in hallucinations, memory loss and social withdrawal.

But new research from the Northwestern University Feinberg School of Medicine has revealed how schizophrenia works in the brain and provided a fresh opportunity for treatment. In a new, genetically engineered mouse model, scientists have discovered the disease symptoms are triggered by a low level of a brain protein necessary for neurons to talk to one another.

A Traffic Jam in Brain

In human and mouse brains, kalirin is the brain protein needed to build the dense network of highways, called dendritic spines, which allow information to flow from one neuron to another. Northwestern scientists have found that without adequate kalirin, the frontal cortex of the brain of a person with schizophrenia only has a few narrow roads. The information from neurons gets jammed up like rush hour traffic on an interstate highway squeezed to a single lane.

"Without enough pathways, the information takes much longer to travel between neurons and much of it will never arrive," said Peter Penzes, assistant professor of physiology at the Feinberg School. He is senior author of a paper reporting the findings published in a recent issue of the Proceedings of the National Academy of Science. Michael Cahill, a Feinberg doctoral student in neuroscience, is the lead author.

First Mouse Model to Develop Disease as a Teenager

Penzes discovered the kalirin effect after he created the mouse model, which was the first to have a low level of kalirin and the first to develop symptoms of schizophrenia as an adolescent (two months old in mouse time). This mimics the delayed onset of the disease in humans. In normal development, the brain ramps up the production of kalirin as it begins to mature in adolescence.

New Direction for Treatment

"This discovery opens a new direction for treating the devastating cognitive symptoms of schizophrenia," Penzes said. "There is currently no treatment for that. It suggests that if you can stimulate and amplify the activity of the protein kalirin that remains in the brain, perhaps we can help the symptoms."

Currently the only drug treatment for schizophrenia is an antipsychotic. "The drugs address the hallucinations and calm down the patient, but they don't improve their working memory (the ability of the brain to temporarily store and manage information required for complex mental tasks such as learning and reasoning) or their ability to think or their social behavior," Penzes said. "So you end up with patients who still can't integrate into society. Many attempt suicide."

Similarities Between Human and Mouse Brains

A few years ago in postmortem examinations of schizophrenic human brains, other scientists had found fewer connections between the brain cells in the frontal cortex and lower levels of kalirin. But the scientists couldn't show whether one condition led to the other.

With the new mouse model, Penzes was able to demonstrate that the low level of kalirin resulted in fewer dendritic spines in the frontal cortex of the brain, the part of the brain responsible for problem solving, planning and reasoning. Other areas of the brain had a normal number of the dendritic spines. Human brains and mouse brains share many similarities in the way they function, Penzes said.

The new schizophrenic mouse model also exhibits more schizophrenic symptoms than other models, making these mice especially good for drug testing and development, Penzes said. The mice with low amounts of kalirin had a poor working memory, were antisocial and hyperactive.

Penzes said future studies would aim at enhancing the function of kalirin in the brain in an effort to correct the cognitive symptoms of schizophrenia.

County Mental Health

The County Mental Health Access Line

for all consumers

415-255-3737

Substance Abuse Treatment Access

1380 Howard, First Floor

415-503-4730 or 1-800-750-2727

The Mobile Crisis Unit

415-355-8300

Schizophrenia, Genetics, Gene Variants, Bipolar Disorder

From UNC School Of Medicine, UNC Department Of Genetics, UNC Department Of Psychiatry

The finding suggests that schizophrenia is much more complex than previously thought and can arise not only from both rare genetic variants but also from a significant number of common ones.

Newswise - A multi-national group of investigators, including a scientist at the University of North Carolina at Chapel Hill, has discovered that nearly a third of the genetic basis of schizophrenia may be attributed to the cumulative actions of thousands of common genetic variants. The effects of each of these genetic changes, innocuous on its own, add up to a significant risk for developing both schizophrenia and bipolar disorder.

The finding, published online July 1, 2009, in the journal *Nature*, suggests that schizophrenia is much more complex than previously thought, and can arise not only from both rare genetic variants but also from a significant number of common ones.

"This is an enormous first for our field," said co-author Patrick Sullivan, M.D., Ray M. Hayworth and Family Distinguished Professor of Psychiatry in the department of genetics at the UNC School of Medicine. "You could say that we now have the outline of the puzzle, and we just need to take all of these pieces that we have identified and see how they fit them together."

Schizophrenia is a chronic and often devastating mental illness that affects one person in every 100 in the course

of their lives. Scientists have long recognized that the disease - which can run in families -- has a strong genetic component. However, only recently have they begun to pinpoint the exact spots in our genetic material that contribute to the illness. Last year, the International Schizophrenia Consortium found that rare chromosomal structural variants elevate the risk of developing schizophrenia.

In this study, Sullivan and other investigators in the Consortium used "genechip" technology to identify 30,000 genetic variants (single nucleotide polymorphisms or "SNPs") that were more common in 3,000 individuals with schizophrenia than in 3,000 comparison subjects without schizophrenia. This pattern was found in three separate samples of individuals with schizophrenia and two samples with bipolar disorder - indicating a previously unrecognized overlap between the two diseases. These risk variants were not present in patients with other non-psychiatric diseases, such as hypertension or diabetes.

"While our study finds a surprising number of genetic effects, we fully expect that future work will assemble them into meaningful pathways that will teach us about the biology of schizophrenia and bipolar disorder," says senior author Pamela Sklar, MD, PhD, associate director of the Department of Psychiatry and Center for Human Genetic Research at Massachusetts General Hospital (MGH) and a senior associate member of the Broad Institute of MIT and Harvard.

The researchers are also investigating how genes and environment interact to cause the disease. One additional finding of their study was the identification of the human leukocyte antigen (HLA) locus as a possible risk factor. Because this region plays an important role in immune response to infection, it could suggest that exposure to an infectious agent increases risk of developing psychiatric disease.

Funding for the studies led at UNC came from the National Institutes of Mental Health, the Sylvan C. Herman Foundation and the Stanley Medical Research Institute.

In addition to those from UNC, the consortium includes investigators from the University of Aberdeen, Cardiff University, University of Edinburgh, Karolinska Institutet, Massachusetts General Hospital, the Queensland Institute of Medical Research, University of Southern California, Stanley Center for Psychiatric Research at the Broad Institute of Harvard and MIT, Trinity College Dublin and University College London.

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income could be subject to the claims of the keeper's creditors. Moreover, the funds might pass on to the keeper's heirs if the keeper dies before the ill child. 3) Writing a "garden variety" trust with instructions to the trustee to "use funds for the best interests of a child" would also act to disqualify the beneficiary from public benefits.

The solution: A Special Needs Trust with specific language that protects the beneficiary from losing public benefits because he/she has no control over the funds. Their distribution is made by the designated trustee who has sole discretion over the money held in trust to provide for the ill person. The trustee must conform to the requirements of the Social Security Administration (SSA) in the same way as the original caregiver.

The SSA says that it provides SSI for disabled persons so they can pay rent, buy food and receive medical care, but the allowance provided is rarely sufficient and must be supplemented. This is possible if the supplement is not for food or rent unless the trustee determines that the reduction in the monthly SSI is a good trade-off.

The trustee is required to be trustworthy and have business savvy or work with someone who has financial knowledge along with sensitivity to the needs of those with a mental illness. The trustee is asked to be good at establishing boundaries; in other words, we must find someone like ourselves.

Often the best person to be the trustee is a family member, but it can present a tricky situation because the burden is put on that family member when he/she may not want the role. There may also be friction between the trustee and the beneficiary that should be addressed.

A solution to this possibility is to engage the Proxy Parent Foundation (PPF) a 501(c)(3) non-profit corporation which then acts as Trustee of a "Pooled" Special Needs Trust. POOLED TRUST ESTABLISHED UNDER SOCIAL SECURITY ACT SECTION 1917 (d)(4)(C)

The way it works in California is that the PPF administers PLAN (Planned Lifetime Assistance Network) allowing a beneficiary's assets to be "pooled" with other SNT beneficiaries for more economical, practical investment and management purposes. In this way governmental benefits are safeguarded while being supplemented within the rules established by the SSA.

In response to questioning, Mr Miller commented on various components of PLAN:

- 1) Case managers are hired to oversee care of the disabled person and contracts can be made with a

bank or local investment company regarding trust management. A fee is charged. The PPF Board has various committees who review the quality of care given for each beneficiary to make sure that the best is being done.

- 2) PLAN is also there to help address potential problems such as when, for example, one parent has a SNT and the other parent leaves a sum of money outside the trust. This issue and a beneficiary's request for more dollars can require a court proceeding.
- 3) A SNT can be incorporated into a living trust or can stand alone. Available funding choices are very liberal, for example, the trust can receive gifts from others. A SNT can be terminated and a specific date can be written into the contract for termination.
- 4) SNT income is taxable to the trust and not to the beneficiary. Money dispensed to the beneficiary is deemed a gift or compensation by the IRS and could be subject to a gift tax if over the allowable limit.

Resources:

Special Needs Alliance: Administering a Special Needs Trust; A Handbook For Trustees (2009 Edition) Phone or go online for a free copy: 520-546-1005, www.specialneedsalliance.org

NAMI Guidance System: Special Needs Estate Planning - Navigating the SNEP Process - a comprehensive guide to special needs planning: http://www.nami.org/template.cfm?section=Special_Needs_Estate_Planning

Proxy Parent Foundation dba Planned Lifetime Assistance Network 17602 Seventeenth Street #102-240 Tustin, CA 92780 Phone toll free 888-574-1258 www.proxyparentfoundation.org PLANofCalif@aol.com

NAMI Advocate Fall 2009 The Challenge of Finding the Best Trustee for a Special Needs Trust by Ann N. Butenhof

Social Security Online - Understanding Supplemental Security Income, SSI Spotlight on Trusts

*Baron L. Miller is an attorney in private practice in San Francisco who specializes in estate planning for California families of the mentally ill. He is a long-time NAMI family member and an advocate for the rights and interests of families of the mentally ill, and is on the board of the California Proxy Parent Foundation whose by-laws require that the board members have a mentally ill family member. He does not charge for telephone conversations on the propriety of making payments for the benefit of a SSI recipient. He can be reached at 415-522-0500.

Support Groups



Family Members' Groups

Healing Circle African American Family Support
1st Thursdays, 6 - 7:45 pm at 1099 Sunnydale Ave (The Village). Call LaVaughn at 415-832-9616

Sibling & Adult Children Network
Call Mary Gullekson at 474-7010 for information

Berkeley Sibling Support Group
Call Carolyn Defay at (510) 644-8579

Bilingual & Monolingual Support Groups

Asian Mental Health Resources
The Culture to Culture Foundation's directory of Asian-American mental health services in the Bay Area can be accessed at www.asianmentalhealth.info or call 925-938-9988

Chinese Families Mental Health Alliance. Ed Koo 352-2047

Spanish Language Support Group for family members and caregivers. 1st Tuesday 5:30-7:30 pm at Mission Mental Health, 2712 Mission Street. Call Carmen Burgos 415-401-2733 about the meetings, and for information call Anita Madrigal at 415-701-5302.

Consumer Self-Help Groups

Depression & Bipolar Support All. (formerly DMDA)
Saturday afternoons at 1:30-3:00 and
1st Mondays at 6:45-8:00 pm in the Saint Francis Hospital, 900 Hyde St., 2nd Floor Conf. Room. Call 519-0171

OASIS (Office of Self Help)
1095 Market Street at 7th, Suite 202 (415) 575-1400

RECOVERY, Inc. for nervous ailments
(415) 333-6454 Community Miracles Center,
2269 Market Street (between Noe and Sanchez)

Consumers with Schizophrenia
3rd Wednesday of each month, 5:30-6:45pm
1010 Gough. Info: Susanne at 558-5900

Hoarding & Cluttering Support
2nd Monday and 4th Wednesday of each month.
Antonio (415) 421-2926 x306

Health and Wellness Action Advocacy
1st Thursday of each month, 1-3pm. Antonio at
(415) 421-2926, x306

Alcoholics Anonymous: San Fran: (415) 621-1326
Marin: (415) 499-0400 San Mateo: (650) 573-6811

Narcotics Anonymous SF Helpline: (415) 621-8600

Harm Reduction Therapy (415)-863-4282



NAMI-SF Support Groups

For Family Members, Caregivers and Friends Only

- 1) 1010 Gough
2nd Wednesday at 6:30
Contact Vicki Evans at 661-5208
- 2) SF General Hospital
7th Floor, Room 7 M 30
Tuesdays, 5:15 – 6:45 p.m.
Call Susanne Killing at 558-5900

DBSA

Depression and Bipolar Support Alliance of San Francisco



Regular Support Group:

every Monday at 6:45-8:15pm and
every Saturday at 1:30-3:00pm.

Young Adults Support Group:

1st and 3rd Monday of each month at 6:45-8:15pm for 18 to 25+ year old people.
Contact Harry at 650-430-2909 for information.

Friends And Family Support Group:

1st and 3rd Monday of each month at 6:45-8:15pm. Contact Jane Norbeck at 415-519-0171 or Harry Walters at 650-430-2909 for information.

Location:

900 Hyde St., St. Francis Hospital
between Pine and Bush in San Francisco
At Outpatient Registration desk, take elevator down to lower level. Meeting rooms are next to the elevator.

Meetings are on a drop in basis and are open to peers, please note we do not allow observers. You do not need to be a member to attend, however memberships are \$20.00 a year and you are encouraged to join and support the organization.

NAMI-San Francisco is a self-help organization of family members, mental health consumers, friends, professionals and other interested citizens, united to provide support, education and advocacy for persons with severe mental illness. NAMI-San Francisco is a private, non-profit organization.



What is MIAW?

In 1990, the U.S. Congress established the first week of October as "Mental Illness Awareness Week" (MIAW) in recognition of NAMI's efforts to raise mental illness awareness. Since 1990, mental health advocates across the country have joined together during the first week of October to celebrate.

MIAW is NAMI's premiere public awareness and public education campaign and link NAMI's 1,100+ local affiliates across the country.

MIAW has become a tradition in NAMI. It presents an opportunity for all three levels of NAMI — national, state and local — to work together in communities across the country to achieve the NAMI mission through outreach, education and advocacy.

Building Community, Taking Action

Real recovery from mental illness requires community action, understanding and teamwork. Recovery is

possible because of improved science, better community supports and reduced stigma. But significant barriers still exist. Services are at risk, insurance can be insufficient and stigma, though less today than when MIAW was founded, is still prevalent.

Information and Resources

NAMI National offers technical assistance to all state and affiliate organizations planning activities during Mental Illness Awareness Week.

By phone: For information on teleconferencing with the NAMI Leadership Institute, look for topic and call-in information in the Friday Facts e-mail, or contact your NAMI Leadership Consultant. For contact information, e-mail info@nami.org or call the NAMI HelpLine at 1 (800) 950-NAMI (6264).

Visit www.nami.org for related resources, fact sheets, programs and more from Mental Illness Awareness Week 2009.

Out of the Fog is published 10 times a year by NAMI-San Francisco, a non-profit organization affiliated with the National Alliance on Mental Illness, which goes by the acronym NAMI, and NAMI-California, the statewide affiliate.

www.namisanfrisco.org

NAMI San Francisco

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Send newsletter additions/submissions/
change requests to roopa2nami@gmail.com



Please Join NAMI SF

NAMI-San Francisco is moving to a system where members renew in their anniversary months, but many of you are on the calendar-year system.

Please let us count you. There is power in numbers. We need the support of families, friends, consumers, professionals and others who share our goals. Your dues help us pay for the printing of the newsletter, educational materials and mailings and the Family-to-Family Education Course, an invaluable resource for people who love someone with a mental illness.

Checks may be made out to "NAMI San Francisco"

Please mail to:

NAMI-San Francisco Treasurer
77 Geary Blvd., 5th Floor
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NAME _____

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This is a: •New Membership •Renewal •Address change

What is your relationship to a person with a mental illness?

•self • parent • sibling • spouse • health care/professional
Other _____

Please Check One:

- \$10 Consumer
- \$45 Individual or Family Membership
- \$100 Organization or Benefactor Membership
- \$250 or more for Patron Membership
- \$500 or more for Sustaining Membership

• I cannot join NAMI-San Francisco at this time but I would like to receive ***Out of the Fog*** or **I am enclosing a donation of \$ _____ to help cover the cost of *Out of the Fog*.**

NAMI SAN FRANCISCO

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