



OUT OF THE FOG

The monthly newsletter of NAMI San Francisco

April Meeting Notes

By Suzanne Brady

The speaker at our April General Meeting was Kiki Chang, MD, Director of the Pediatric Bipolar Disorders Program at Stanford University. With him was Meghan Howe, MSW, a therapist at the program who talked about psychotherapy for children with bipolar disorder (BD).

The general public first heard about pediatric bipolar disorder (PBD) in the year 2000 when the book, "The Bipolar Child," by Demetri Papolos, MD and Janice Papolos was published. The authors were seen on television talk shows and many viewers learned about PBD for the first time. The beginning of that book consists of a symptoms questionnaire for parents to fill out if they are concerned that their child might have BD. (As with BD in adults, there is no biological test for PBD.) However, the symptoms listed are quite broad: aggression, night terrors, poor handwriting, bedwetting, carbohydrates craving and reading problems.

To this day, about half the children referred to the Pediatric Bipolar Disorders Program do not get diagnosed with PBD. Many of the children are prone to angry outbursts, but a child can have poor impulse control and problems regulating their emotions without having bipolar disorder, Dr. Chang said.

Yet studies show that the onset of BD begins in childhood between 50 to 67 percent of the time. In addition, children with BD have poor psychosocial outcomes and higher rates of substance abuse and suicide attempts. With a misdiagnosis or a late diagnosis of PBD, a child may also be prescribed unnecessary

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Saturday, May 31, 2008

Speedway Meadows, Golden Gate Park

Check-In: 9:30am; Walk Starts: 11:00am

SIGN UP at
www.namiwalkSFbay.org
or at the Walk

Join this year's participating affiliates of Alameda, Contra Costa, Marin, San Francisco, San Mateo, Santa Clara and Solano counties for a 5k walk!

- Registration is FREE! All participants are encouraged to collect donations from family members, friends, co-workers and business associates in support of their participation in the Walk.
- All walkers raising \$100 or more will receive an event T-shirt.
- Companies, organizations and families are encouraged to organize teams of walkers made up of employees, organization members, relatives and friends to take part in the Walk.
- There is a wide-range of corporate sponsorship opportunities available to local companies and businesses. To find out about Walk sponsorship, please contact Laurie Williams, SF Bay Area Walk Director at 800-556-2401 or laurie@namiwalksfbay.org.

3rd Wednesday of each month
 6:30 - 8:00 pm
 1010 Gough St.
 (between Eddy & Ellis)

The Monthly Meeting

May 21

Nena St. Louis, performer and artist, and fellow performers from Jump! Theater will perform and discuss a new play.

June 18

Richard Heasley, Executive Director, Conard House, Inc., will speak on the lessons learned from self-management of chronic medical conditions and their application to serious mental illness."

'Mad Pride' Fights a Stigma

By Gabrielle Glaser, reprinted from *The New York Times*, 5/11/08

In the YouTube video, Liz Spikol is smiling and animated, the light glinting off her large hoop earrings. Deadpan, she holds up a diaper. It is not, she explains, a hygienic item for a giantess, but rather a prop to illustrate how much control people lose when they undergo electroconvulsive therapy, or ECT, as she did 12 years ago.

In other videos and blog postings, Ms. Spikol, a 39-year-old writer in Philadelphia who has bipolar disorder, describes a period of psychosis so severe she jumped out of her mother's car and ran away like a scared dog.

In lectures across the country, Elyn Saks, a law professor and associate dean at the University of Southern California, recounts the florid visions she has experienced during her lifelong battle with schizophrenia - dancing ashtrays, houses that spoke to her - and hospitalizations where she was strapped down with leather restraints and force-fed medications.

Like many Americans who have severe forms of mental illness such as schizophrenia and bipolar disorder, Ms. Saks and Ms. Spikol are speaking candidly and publicly about their demons. Their frank talk is part of a conversation about mental illness (or as some prefer to put it, "extreme mental states") that stretches from college campuses to community health centers, from YouTube to online forums.

"Until now, the acceptance of mental illness has pretty much stopped at depression," said Charles Barber, a lecturer in psychiatry at the Yale School of Medicine. "But a newer generation, fueled by the Internet and other sophisticated delivery systems, is saying, 'We deserve to be heard, too.'"

About 5.7 million Americans over 18 have bipolar disorder, which is classified as a mood disorder, according to the National Institute of Mental Health. Another 2.4 million have schizophrenia, which is considered a thought disorder. The small slice of this disparate population who have chosen to share their experiences with the public liken their efforts to those of the gay-rights and similar movements of a generation ago.

Just as gay-rights activists reclaimed the word queer

as a badge of honor rather than a slur, these advocates proudly call themselves mad; they say their conditions do not preclude them from productive lives.

Mad pride events, organized by loosely connected groups in at least seven countries including Australia, South Africa and the United States, draw thousands of participants, said David W. Oaks, the director of MindFreedom International, a nonprofit group in Eugene, Ore., that tracks the events and says it has 10,000 members.

Recent mad pride activities include a Mad Pride Cabaret in Vancouver, British Columbia; a Mad Pride March in Accra, Ghana; and a Bonkersfest in London that drew 3,000 participants. (A follow-up Bonkersfest is planned next month at the site of the original Bedlam asylum.)

Members of the mad pride movement do not always agree on their aims and intentions. For some, the objective is to continue the destigmatization of mental illness. A vocal, controversial wing rejects the need to treat mental afflictions with psychotropic drugs and seeks alternatives to the shifting, often inconsistent care offered by the medical establishment. Many members of the movement say they are publicly discussing their own struggles to help those with similar conditions and to inform the general public.

"It used to be you were labeled with your diagnosis and that was it; you were marginalized," said Molly Sprengelmeyer, an organizer for the Asheville Radical Mental Health Collective, a mad pride group in North Carolina. "If people found out, it was a death sentence, professionally and socially." She added, "We are hoping to change all that by talking."

The confessional mood encouraged by memoirs and blogs, as well as the self-help advocacy movement in mental health, have deepened the understanding of bipolar disorder and schizophrenia. Books such as Kay Redfield Jamison's autobiography, "An Unquiet Mind: A Memoir of Moods and Madness," have raised awareness of bipolar disorder, and movies like "Shine" and "A Beautiful Mind" have opened discussion on schizophrenia and related illnesses. In recent years, groups have started antistigma campaigns, and even the federal government embraces the message, with an ad campaign aimed at young adults to encourage them to support friends with mental illness.

Members of MindFreedom International, which Mr. Oaks founded in the 1980s, have protested drug companies and participated in hunger strikes to demand proof that drugs can manage chemical imbalances in the brain.

County Mental Health

The County mental health access line
for all consumers is

415-255-3737

The Mobile Crisis Unit is

415-355-8300

Remember to donate to the



Community Thrift Store

This is our *best source* of income
for the NAMI SF Chapter!!

625 Valencia Street at 17th Street
415-861-4910

Mr. Oaks, who was found to be schizophrenic and manic-depressive while an undergraduate at Harvard, says he maintains his mental health with exercise, diet, peer counseling and wilderness trips - strategies that are well outside the mainstream thinking of psychiatrists and many patients.

Other support groups include the Mad Tea Party in Chicago and the Freedom Center in Northampton, Mass., which provides education, acupuncture, yoga and peer discussions to about 100 participants.

The Icarus Project, a New York-based online forum and support network, says it attracts 5,000 unique visitors a month to its Web site, and it has inspired autonomous local chapters in Portland, Ore., St. Louis and Richmond, Va. Participants write and distribute publications, stage community talks, trade strategies for staying well and often share duties like cooking or shopping.

The Icarus Project says its participants are "navigating the space between brilliance and madness." It began six years ago, after one of its founders, Sascha Altman DuBrul, now 33, wrote about his bipolar disorder in *The San Francisco Bay Guardian*, a weekly newspaper. Mr. DuBrul, who is known as Sascha Scatter, received an overwhelming response from readers who had experienced similar ordeals, but who felt they had no one to discuss them with. "We wanted to create a new language that resonated with our actual experiences," Mr. DuBrul said in a telephone interview.

Some Icarus Project members argue that their conditions are not illnesses, but rather, "dangerous gifts" that require attention, care and vigilance to contain. "I take drugs to control my superpowers," Mr. DuBrul said.

While psychiatrists generally support the mad pride movement's desire to speak openly, some have cautioned that a "pro choice" attitude toward medicine can have dire consequences. "Would you be pro-choice with someone who has another brain disease, Alzheimer's, who wants to walk outside in the snow without their shoes and socks?" said Dr. E. Fuller Torrey, executive

director of the Stanley Medical Research Institute in Chevy Chase, Md.

Dr. Torrey, a research psychiatrist who specializes in schizophrenia and manic depression, said he understood the roots of the movement. "I suspect that not an insignificant number of people involved have had very lousy care and are still reacting to having been involuntarily treated," he said.

Many psychiatrists now recognize that patients' candid discussions of their experiences can help their recoveries. "Problems are created when people don't talk to each other," said Dr. Robert W. Buchanan, the chief of the Outpatient Research Program at the Maryland Psychiatric Research Center. "It's critical to have an open conversation."

Ms. Spikol writes about her experiences with bipolar disorder in *The Philadelphia Weekly*, and posts videos on her blog, *the Trouble With Spikol* (<http://trouble.philadelphiaweekly.com/>).

Thousands have watched her joke about her weight gain and loss of libido, and her giggle-punctuated portrayal of ECT. But another video shows her face pale and her eyes red-rimmed as she reflects on the dark period in which she couldn't care for herself, or even shower. "I knew I was crazy but also sane enough to know that I couldn't make myself sane," she says in the video.

In a telephone interview, she described one medication that made her salivate so profusely she needed towels to mop it up. "Of course it's heartbreaking if you let it be," she said. "But it's also inherently funny. I'd sit there watching TV and drool so much, it would drip on the couch."

Ms. Spikol said she has a kind doctor who treats her with respect, and she takes her pharmaceutical drugs to stabilize her mood. "I have asthma, and I use medication to maintain it, too," she said.

Ms. Saks, the U.S.C. professor, who recently published a memoir, *"The Center Cannot Hold: My Journey Through Madness,"* has come to accept her illness. She manages her symptoms with a regimen that includes psychoanalysis and medication. But stigma, she said, is never far away.

She said she waited until she had tenure at U.S.C. before going public with her experience. When she was hospitalized for cancer some years ago, she was lavished with flowers. During periods of mental illness, though, only good friends have reached out to her.

Ms. Saks said she hopes to help others in her position find tolerance, especially those with fewer resources. "I have the kind of life that anybody, mentally ill or not, would want: a good place to live, nice friends, loved ones," she said. "For an unlucky person," Ms. Saks said, "I'm very lucky."

Tallying Mental Illness' Costs

By Kathleen Kingsbury, reprinted from *Time*, 5/9/08

It's a debate with which the U.S. workplace has yet to come to grips: should employees' mental and physical health be considered equal in importance?

Corporate America's answer has traditionally been unambiguous, with few employer-backed health plans offering any coverage for workers' mental conditions. But that line has been shifting recently - a change that could save the U.S. economy billions of dollars in lost income, a new government-funded study suggests.

Serious mental illnesses (SMIs), which afflict about 6% of American adults, cost society \$193.2 billion in lost earnings per year, according to findings published in this month's *American Journal of Psychiatry*. Surveying data from nearly 5,000 participants, researchers determined that people suffering from a SMI - defined as a range of mood and anxiety disorders, including suicidal tendencies, that significantly impaired a person's ability to function for at least 30 days over the past year - earned at least 40% less than people in good mental health. "The results of this study confirm the belief that mental disorders contribute to enormous losses of human productivity," says Ronald Kessler, a Harvard professor of health care policy and lead author of the study, funded by the National Institute of Mental Health.

Researchers arrived at that figure using data from the 2002 National Comorbidity Survey Replication, a nationally representative study designed to gauge the overall mental health of Americans, and extrapolated it to the general population. Kessler and his colleagues determined that a person suffering from SMI had earned \$23,000 on average in the previous year. Those respondents without SMI averaged nearly \$40,000. The researchers attributed 75% of that difference to the person's mental illness. The other 25% was attributed to a greater likelihood that a mentally ill person would not have worked at all, thus earning nothing - Kessler says, for example, that very few participants with autism, schizophrenia or other chronic illnesses were included in the \$193 billion figure.

Though these figures may seem high, Kessler and his colleagues caution that they are likely too conservative. For one thing, the study's conclusions are based on data from 2002; today, Kessler says, the rate of mental illness is likely higher due to a variety of causes, including the Iraq war starting in 2003. But, more importantly, lost earning potential is only one of the many indirect costs of mental illness in American society. Social

Security payments, homelessness and incarceration add to that economic burden, as well as direct costs such as medications and physicians' care. "The actual costs are probably higher than what we have estimated," Kessler says.

What's more, Kessler's report considers only severe mental illness in its calculations. Yet more than one in four American adults suffers from shorter-term, but clinically diagnosable mental disorders in a given year - including depression or an eating disorder - and such disorders are the leading cause of disability among U.S. workers under age 45. In 2005, research by Kessler showed that 60% of Americans with a mental disorder got no treatment for their ailment at all.

One longtime barrier to psychiatric care has been reluctance by insurance companies to consider mental illnesses on par with physical ones and thus not pay as well to treat them. Only 6.2% of current U.S. health care spending is devoted to the treatment of mental disorders. Federal lawmakers may soon change that. Following the

lead of many states, the U.S. House of Representatives in March passed legislation that

would require equal health insurance coverage for mental and physical illnesses, when policies offer coverage for both. "Mental illness and drug addiction are every bit as real and serious as physical illness," said

Congressman Joe Courtney, a Democrat from Connecticut, of his vote in favor of the bill. "And by providing intervention and early treatment we may be able to prevent more serious and costly conditions down the road."

The Senate passed a narrower version of the bill last September, and the two houses are currently working on a compromise to send to President Bush. Both the drug industry and large insurers have been vocally opposed, saying the legislation could result in higher premiums for customers. "[The bill] would offer more generous mental health benefits to Americans," said Sonya D. Sotak, director of federal affairs for drugmaker Eli Lilly, "but it risks doing so on the backs of the sickest and poorest Americans." Rep. John Sullivan, a Republican from Oklahoma, admitted the changes could adversely affect the pharmaceutical (a clause in the House bill could force drugmakers to lower prices) and health care industries but decided to support the bill anyway. "Each year the economic cost of untreated mental illness is staggering - over \$100 billion on untreated mental health disorders and \$400 billion on addiction disorders," Sullivan said. "Our country cannot afford to continue losing \$500 billion a year to these treatable diseases."



VA Faulted in Diagnosing Suicide Candidates

Bob Egelko, Chronicle Staff Writer, 4/23/08

Former soldiers are killing themselves at three to seven times the rate of the general population and the Department of Veterans Affairs is failing to diagnose or treat them effectively, a suicide expert testified Tuesday in a lawsuit challenging the VA's mental health system.

Department personnel aren't asking enough questions to determine whether veterans are suicidal, aren't sharing information about suicide risks with the VA's network of hospitals and clinics and aren't implementing their own plans to improve the system, Ronald Maris, a University of South Carolina sociology professor, told U.S. District Judge Samuel Conti in San Francisco.

A majority of the VA's counselors, doctors, social workers and psychologists "don't have the tools and the information that they need to intervene effectively with suicidal vets," said Maris, a former president of the American Association of Suicidology who has been a consultant to the Army on suicide prevention.

He was particularly critical of the VA's top health care administrator, William Feeley, who said in a pretrial deposition April 9 that the agency has no systematic national plan for suicide prevention. Feeley also said he was unaware of any methods of tracking veterans at risk of suicide and that suicide rates "are not a metric we are measuring."

"I would say he was singularly uninformed about suicide," Maris said. He testified on the second day of a nonjury trial in a suit by veterans' advocacy groups accusing the government of wrongly denying mental health care and benefits to troops returning from Afghanistan and Iraq. The groups are asking a judge to order the VA to promptly screen and treat those at risk of suicide and set timetables for handling claims for medical benefits.

During cross-examination of Maris, Justice Department lawyer James Schwartz suggested that Feeley's comment about suicide rates referred to factors he considered in evaluating VA division chiefs, not his own ignorance about the subject. But Maris said the statement contained no such indication.

The emotional nature of the case was underscored Tuesday when an unidentified woman rose during Maris' testimony and denounced "warmongers ... eating our children for profit." The woman spoke for several minutes before being led off by a federal marshal. She was not arrested, the marshal's office said.

During opening statements Monday, a lawyer for the veterans' groups displayed an e-mail that a top VA mental health official, Ira Katz, sent in December in which he said veterans were committing suicide at the rate of 18 a day.

Maris said Tuesday that Katz had been referring primarily to veterans of the wars in Afghanistan and Iraq. In an interview, he said the suicide rate among veterans has been increasing since 2001, according to government reports he has studied.


In court, Maris said a more recent study by Katz showed a suicide rate among veterans that was 3.2 times as high as the rate among the general population. A May 2007 report by the VA's inspector general found a suicide rate 7.5 times as high as the public rate for veterans who were in the department's health care system, Maris said.

Among the reasons for the disparity, Maris said, is that veterans are mostly men, who generally have higher suicide rates than women; they suffer from depression more often, have higher rates of alcohol and drug abuse than the general population, are separated from their families for long periods and often have access to guns.

Maris also faulted the VA's standard procedure for screening returning soldiers for suicidal tendencies. He said they are asked whether they thought of harming themselves during the previous two weeks or decided life was not worth living. If they deny having any such thoughts, he said, they are classified as nonsuicidal and the questioning ends.

That's far short of the generally accepted standard of care, Maris testified. He said soldiers are often reluctant to admit psychiatric problems and should be asked numerous follow-up questions about such topics as alcohol use, medications, gun ownership, any past suicide attempts and any history of suicide in their family.

—E-mail Bob Egelko at begelko@sfchronicle.com.



**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

Support Groups



Family Members' Groups

African American Family Support

1st Thursdays, 5:30-7:30 pm at
1380 Howard St., Rm 537. Call Wanda at 255-3694

San Francisco Family Support Group

Tuesdays, 5:15-6:45 p.m. at SF General Hospital, 1001 Potrero St., Room 7M30. Info: Susanne at 415-558-5900

Sibling & Adult Children Network

Call Mary Gullekson at 474-7010 for information

Berkeley Sibling Support Group

Call Carolyn Defay at (510) 644-8579

Support Group for Family Members, Friends & Care Givers

Tuesdays, 5:30- 7:30 pm at Mission Mental Health,
2712 Mission St. Child care and refreshments provided.
Call Carmen Burgos at 415-401-2733

Bilingual & Monolingual Support Groups

Chinese Families Mental Health Alliance. Ed Koo 352-2047

NEW!

Spanish Language Support Group for family members and caregivers has started. Info: Carmen Burgos 415-401-2733.

Tuesdays 5:30-7:30 p.m. at Mission Mental Health, 2712 Mission Street in San Francisco.

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 pm
1380 Howard St., 5th floor. 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



NAMI-SF Support Groups

- 1) **For Caregivers and Friends Only**
1010 Gough
2nd Wednesday at 6:30
Contact Vickie at 661-5208
- 2) San Francisco General Hospital
7th Floor, Room 7 M 30
Tuesdays, 5:15 – 6:45 p.m.
Call Susanne Killing at 558-5900

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

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 at 415-519-0171 or Harry at 650-430-2909 for information.

Location:

2nd floor of St. Francis Hospital
900 Hyde St.
between Pine and Bush in San Francisco
Conference rooms B, C, and D

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.

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stimulants or anti-depressants and untreated early episodes may contribute to more severe later episodes.

"The heart of our work is to get to kids with bipolar disorder before they have a full expression of it," Dr. Chang said. "Or at least to do interventions that help prevent the full expression of later episodes."

The Stanford Pediatric Bipolar Disorders Program works with the families of children who have at least one parent with BD. These children are at relatively high risk for eventually developing BD and therefore can help the program identify factors that contribute to the onset of PBD.

The program offers Family Focused Therapy for families with bipolar disorder as part of its study of five different psycho-educational therapeutic models. Families must have at least one parent with BP and at least one child who has significant mood problems or ADHD. Family members receive thorough diagnostic evaluations and 12 weeks of treatment.

The goal of Family Focused Therapy is to enhance communication, develop problem-solving skills and increase healthy levels of emotional expression. Families

learn about bipolar disorder, what are triggers, and what treatments are available. The Stanford program also teaches the family cognitive behavioral skills.

"Kids with bipolar disorder will have arguments with their siblings and rages that go on for an hour," Ms. Howe said.

The Stanford program hopes to work with children with mood disorders and a parent with BD to help children learn to better manage any mood disorder and treat a child quickly if they develop PBD.

In addition, the Stanford program runs an annual three-day overnight camp for kids with mood disorders or bipolar disorder. Camp Opehay often provides the first time that kids meet other kids with mood disorders. The camp puts the children together in a non-therapeutic atmosphere with counselors with psychology backgrounds. In addition to recreation activities there are psycho-education sessions.

Anyone with questions about PBD or research at the Stanford Pediatric Bipolar Disorders Program can call 650-725-6760. Some paid research positions are available.

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.

NAMI San Francisco

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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
1010 Gough St.
San Francisco, CA 94109

NAME _____

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CITY _____ ZIP _____

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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*.**

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