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Understanding Schizophrenia and Recovery

What you need to know about this medical illness

NAMI
National Alliance on Mental Illness

Schizophrenia interferes with a person's ability to think clearly, manage emotions, make decisions, and relate to others.

Introduction

Schizophrenia is a serious and challenging mental illness that affects more than two million Americans today. Although it is often feared and misunderstood, schizophrenia is a treatable medical condition.

Left untreated, however, schizophrenia can have a profoundly negative effect on the lives of individuals, families, and communities. Because the illness may cause unusual, inappropriate, and sometimes unpredictable and disorganized behavior, people who are not effectively treated are often shunned and the targets of social prejudice. People living with schizophrenia may also face poverty and homelessness, and are at risk for suicide. Good information, supports, and services can often make the difference so that people living with schizophrenia can lead meaningful and satisfying lives.

Reading this brochure is an important first step to answering your questions and understanding the components of recovery for people living with schizophrenia. This brochure will explain the symptoms and causes of, and treatments for, schizophrenia and tell you where you and your family can turn for the medical care and support needed to manage this persistent illness.

What Is Schizophrenia?

Schizophrenia is a mental illness that interferes with a person's ability to think clearly, manage emotions, make decisions, and relate to others. Most people living with schizophrenia have hallucinations and delusions, meaning they hear or, less commonly, see things that aren't there and believe things that are not real or true. Organizing one's thinking, performing complex memory tasks, and keeping several ideas in mind at one time may be difficult for people who live with the illness.

> "It feels like a dream, but it's not, because you're not asleep. And because you're not asleep, you can't wake up...."

Research has linked schizophrenia to changes in brain chemistry and structure, and some of these changes may be present very early in life. Like diabetes, schizophrenia is a complex, long-term medical illness affecting different people in different ways. The course of the illness is unique for each person.

Schizophrenia is not caused by bad parenting or personal weakness. Almost all people living with schizophrenia are not dangerous when they are in treatment, although the behavior of a person living with schizophrenia can be unsettling or unusual. Violence is a noteworthy risk for people living with schizophrenia who are not taking medications and who also have alcohol or drug use problems.

How did schizophrenia get its name? In an effort to describe the mismatch he observed between the feelings and thoughts of people experiencing this medical condition, Eugen Bleuler, a Swiss psychiatrist at the turn of the twentieth century, proposed the terms *schizo* (split) and *phrene* (mind) to capture this juxtaposition. Many people have confused this term with so-called "split" or "multiple" personality (now called *dissociative identity disorder*), but there is no relation between the two conditions.

What Are the Symptoms?

No single symptom positively identifies schizophrenia. In addition, an individual's symptoms can change over time. There is no single lab test for schizophrenia, but a health care provider who sees the symptoms and watches the course of a person's illness over six months or more can almost always diagnose schizophrenia correctly.

The symptoms of schizophrenia are generally divided into three categories: *positive*, *negative*, and *cognitive* symptoms.

Positive symptoms are also known as "psychotic" symptoms, because the person has lost touch with reality in certain important ways. The term "positive" symptoms refers to mental experiences that are added to the person by the illness. The most common positive symptoms include hallucinations and delusions. Hallucinations cause a person to hear voices or, less commonly, to see things that do not exist. People living with schizophrenia also commonly experience delusions, which means they believe ideas that to others are clearly false, such as that people are reading their thoughts or that they can control other people's minds.

Medications are crucial to symptom control, and other psychological strategies are also gaining acceptance to augment their impact.

For example, a treatment called *cognitive behavior therapy* to manage these symptoms is well-established in England and is gaining acceptance in the United States as a useful strategy to help people actively manage their hallucinations.

Negative symptoms are called "negative" not because of the person's attitude, but because these are symptoms that take away from the person's usual way of being in the world. Negative symptoms often include emotional flatness or lack of expressiveness, an inability to start and follow through with activities, speech that is brief and lacks content, and a lack of pleasure or interest in life. Difficulties with social cues and relationships are common. These symptoms challenge rehabilitation efforts, as work and school goals require motivation as well as cognitive and interpersonal capacity. Negative symptoms can also be confused with *clinical depression*.

Cognitive symptoms pertain to thinking processes. People living with schizophrenia often struggle with executive functioning (prioritizing tasks), memory, and organizing their thoughts. Other cognitive problems may also occur in the illness. These are quite challenging, as cognitive function is involved in many tasks of daily living, and especially in work or school settings. A common cognitive deficit associated with this condition can be a "lack of insight," or lack of awareness of having an illness. This difficulty in understanding is based in the brain, is not a choice, and adds many challenges to working with people coping with this problem.

Who Develops Schizophrenia?

People can develop schizophrenia at any age, but about three-quarters of those living with the illness develop it between the ages of 16 and 25; women typically have a later onset than men. It is found around the globe in one percent of the population. Children can also be diagnosed with schizophrenia, though this is relatively uncommon. New cases are quite rare after age 40.

It is important to have a good medical evaluation to be sure the diagnosis is correct, especially at the onset of symptoms. Drug use can present with these symptoms, or can trigger underlying vulnerability in a person. Brain tumors and other rare medical conditions must be assessed. Other psychiatric diagnoses, such as depression, need to be screened for as well.

Although the illness runs in families, the chance of being diagnosed with schizophrenia is very small for most people. If no one in your family has ever been diagnosed with the illness, then the chances are 99 out of 100 that you won't be, either. If one of your parents, a brother, or a sister has a diagnosis of schizophrenia, there's still about a 90 percent chance you will never develop the illness. If both of your parents have a diagnosis of schizophrenia, there is more than an 80 percent chance that you will never have one. And, if you have an identical twin with a diagnosis of schizophrenia, there is a 50 percent chance you will not develop this illness. Twin research illustrates the complex relationship between environment (birth trauma, viruses, stressors) and biology. If it were all simple gene biology, the chance would be close to 100 percent, rather than 50, that if one identical twin developed schizophrenia, the other one would as well.

What Causes Schizophrenia?

Scientists still don't know exactly what causes schizophrenia, but they do know that the brains of people living with schizophrenia are different, as a group, from the brains of those who don't live with the illness. Research suggests that schizophrenia has something to do with problems with brain chemistry and brain structure.

Schizophrenia, like many other medical illnesses, such as cancer, heart disease, and diabetes, is thought to be caused by a combination of problems, some inherited and others occurring during a person's development. For example, some scientists think that schizophrenia may be triggered by a viral infection affecting the brain very early in life or by mild brain damage from complications during birth.

How Is Schizophrenia Treated?

The treatment of schizophrenia requires approaches in many dimensions. Medications are the cornerstone of symptom management but are not themselves sufficient to promote recovery. Rehabilitation strategies involving work, school, and relationship goals are also essential and need to be addressed in creating a plan of care.

Medication

Schizophrenia can usually be successfully managed. As with other kinds of illnesses, such as diabetes, a cure for schizophrenia has not yet been found, but most people's symptoms can be improved with medication. The primary medications for schizophrenia, called *antipsychotics* or *neuroleptics*, help relieve the hallucinations, delusions, and, to a lesser extent, the thinking problems people have with the illness. These drugs are thought to work by correcting an imbalance in the chemicals that help brain cells communicate with each other.

The first generation of antipsychotic medications were introduced beginning in the 1950s. These earlier medications, now called *conventional* or *typical* antipsychotics, include chlorpromazine (Thorazine), fluphenazine (Prolixin), haloperidol (Haldol), thiothixene (Navane), trifluoperazine (Stelazine), perphenazine (Trilafon), and thioridazine (Mellaril). These medications have side effects of restless motion (called *akathesia*), Parkinson-like symptoms, stiffness, dry mouth, sedation, and over the long term can cause a disabling, embarrassing, and untreatable movement disorder called *tardive dyskinesia*.

There is a second generation of antipsychotic drugs called *atypical* antipsychotics, so-called because they do not cause most of the movement problems noted above.

Individual responses to medicines vary, as do side-effect vulnerability, and NAMI supports individual and physician choice in the selection of a medication to best promote recovery.

Clozapine (Clozaril) was the first atypical antipsychotic in the United States, and it has demonstrated a clear advantage over

the other medications for difficult-to-treat symptoms. Clozapine seems to be a very effective medication, particularly for people who have not responded well to other drugs. A drawback is that it requires blood monitoring to check for and prevent a very rare but serious problem in which too few white blood cells are produced. Clozapine appears to dramatically reduce the symptoms of schizophrenia in some people, but it is hard on the body and causes a risk of diabetes, weight gain, myocarditis, and other medical concerns that need to be planned for.

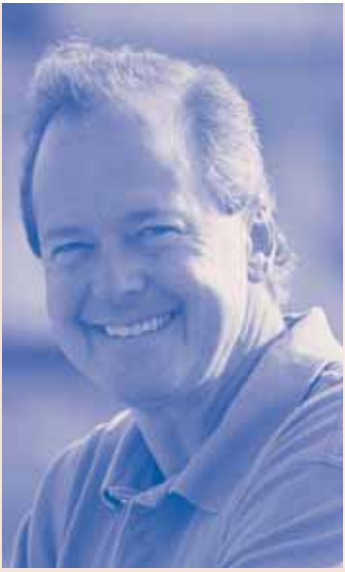
The other atypical drugs do not require blood monitoring. These drugs include risperidone (Risperdal), olanzapine (Zyprexa), quetiapine (Seroquel), ziprasidone (Geodon), paliperidone (Invega) and aripiprazole (Abilify). All the atypical antipsychotics appear to have a low risk of causing tardive dyskinesia, the movement disorder that is the most troubling problem with conventional antipsychotic drugs. However, they all can cause important yet largely preventable side effects: weight gain and diabetes, both of which increase cardiac risk. Clozapine and olanzapine have the highest risk of these two problems; ziprazidone and aripiprazole have the lowest. These side effects are important problems to anticipate and prevent.

The selection of a medication must be tailored to the person's individual needs. The Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study funded by the National Institute of Mental Health, released in 2006, looked at medication adherence in individuals with chronic schizophrenia. The study, which raises more questions than it answers, confirmed that the differences in side effects in and between these newer and older medications are substantial, which further emphasizes the need to individually tailor the treatment to the individual. Another noteworthy aspect is that among severely ill individuals who had not responded to other treatments, most subjects in the study did not continue their treatments. This is another argument for letting the individual and the doctor choose the best medicine. The study, which has many elements, is referenced below at the NAMI and NIMH Web sites.

Two compounds--risperidone (Risperdal) and aripiprazole (Abilify)--have recently been approved by the FDA for use in teenagers from ages 13-17.

Psychosocial Rehabilitation

Like everyone, individuals living with schizophrenia typically have important goals for themselves in the areas of relationships, work, and living. Developing supports and strategies to help people living with schizophrenia achieve wellness is an active area of psychosocial research today.



Psychiatric rehabilitation strategies are designed to enable people to compensate for, or eliminate, the environmental and interpersonal barriers as well as the functional deficits created by a disability related to this illness. The goal of rehabilitation is to recover meaning and value in one's life through work, education, and socializing, as well as increased autonomy.

For example, supported employment helps people develop skills at real jobs, not at practice jobs. This strategy involves job coaches and has good results, but it is in short supply across America. This shortage is an advocacy concern for NAMI.

The field of psychosocial rehabilitation is very concerned with supporting people in order to help them successfully live in independent housing and pursue education, and with training in relationships and social interaction.

Another effective psychosocial approach for people with the most severe illnesses or those with both mental illness and substance abuse is the Program for Assertive Community Treatment (PACT). PACT is an intensive, integrated, outpatient, team effort in local communities to help people stay out of the hospital and be full members of the community while maintaining a high standard of living. Available 24 hours a day, seven days a week, PACT professionals meet consumers where they live, providing at-home and in-community support at whatever level is needed. Professionals work with consumers to address problems effectively, to ensure medications are being properly taken, and to help them meet the routine challenges of daily life, such as grocery shopping and money management. PACT programs are growing, thanks in part to NAMI's advocacy, but their availability is still well short of the demand. PACT is significantly reducing hospital admissions and improving the functioning and quality of life for people living with schizophrenia.

Recovery Supports

There is increasing recognition of the benefits of learning from someone who has "been there." Mutual support, such

as NAMI's C.A.R.E. groups and other peer support groups, are often the first step in recovery. People who have lived with schizophrenia and learned to live well with it have much to teach others. NAMI's *Peer-to-Peer* recovery education program is a model of this type of learning and teaching. *In Our Own Voice* is another NAMI program that offers individuals living with the illness opportunities to teach others.

Medical Care

People living with schizophrenia are subject to many medical risks and typically receive poor medical care. High rates of smoking (which has positive impacts on memory but very bad health effects) and co-occurring alcohol and drug problems are examples. Risks of obesity and diabetes related to some of the medications are also of significant concern. Better and more integrated care is essential for people living with schizophrenia. NAMI's *Hearts and Minds* program is a guide to fostering a culture of activity, self-care, and support around this crucial area of life.

Family Resources

Family support and involvement is enormously beneficial to a person's recovery. *Family-to-Family* is an important and popular NAMI education program. It is taught by families who have first-hand experience and provides education and support to thousands of families nationwide. There are *Family-to-Family* groups in most states, available through many NAMI affiliates, and provided in multiple languages.

How Successful Are Treatments for a Person Living with Schizophrenia?

Most people living with schizophrenia can manage their condition with the interventions noted above. Long-term research demonstrates that over time individuals living with schizophrenia often do better in terms of coping with their symptoms. Recovery is possible for most, and although many effective treatments exist, more research is needed to promote greater understanding, more effective treatments, and the potential for a cure for schizophrenia and other mental illnesses.

What Help Does a Person Living with Schizophrenia Need?

People living with schizophrenia need a correct diagnosis and early treatment of their illness. They also need understanding, compassion, and respect. They also need an effectively functioning mental health system, which is a rarity in the United States today. NAMI's *Grading The States* report (2006) reviews the care systems in every state and provides advocacy points as well as outlining strengths and urgent needs for each state. The report is available at *www.nami.org/grades*.

Like anyone else living with a serious, ongoing illness, a person living with schizophrenia needs help with the fear and isolation associated with this illness as well as the negative cultural attitudes surrounding it.

Because in the beginning the illness may make it so difficult to do even everyday things they did before, some who live with this illness need help with their physical care, from staying clean and eating well to following medical treatment. Although new and better treatments allow many people to return to more active lives, many people living with schizophrenia may need help over the long term with their basic needs, such as money, housing, food, and clothing.

How Can Family and Friends Help?

If you think someone you know and love may have a diagnosis of schizophrenia, the most important thing you can do is to first demonstrate your love and respect for the person, then help that person find medical evaluation and treatment that works and then encourage him or her to stay with it. Delaying care only worsens one's prospects and provides increased risk. To find a good psychiatrist, you may want to ask your family health care provider to suggest one or contact the psychiatry department of the local university medical school. You may also call NAMI's Helpline at 1 (800) 950-NAMI (6264) to talk with others who have a family member with schizophrenia or to find out how to contact a local NAMI affiliate for help and support.

Public programs such as Medicaid and Medicare help some people pay for treatment. In addition, programs such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) can help some families with low income. Social workers or case managers may help you determine if you are eligible to receive such help and can assist you through the red tape, but you may have to contact your Social Security or social services office yourself to learn eligibility requirements for benefits and how to apply for them. Then you may need to help your loved one apply for these benefits. People who depend on SSI or SSDI as their only source of income generally can receive treatment for a reduced fee if they go to their local community mental health center.

Relapse Prevention

When you face the symptoms of schizophrenia in a loved one, you can help most if you have learned everything you can about the illness. Try your best to understand what the person is going through and why the illness causes upsetting, difficult behavior. For example, it's important to know that when people are hallucinating or having delusions, the voices they hear and images they see are very real to them. Do not argue, act frightened, or make fun of the situation. It's important to stay calm, state that you are trying to understand how the person is feeling, and do what you can to help the person feel safe or more in control. Knowing the person's preferences for what should be done in a crisis is important.

> "My emotions inwardly were at a fever pitch, and it seemed to me that I was only feeling, not thinking."

How Can Families Cope with Schizophrenia?

A diagnosis of schizophrenia can present challenges not only for the ill person, but also for that person's family. Because so many people are ashamed, afraid, and uninformed about the illness, many families try to hide it from others and deal with it on their own.

If someone in your family has a diagnosis of schizophrenia, you too need understanding, love, and support from others. You may need to learn and accept that no one causes schizophrenia, just as no one causes diabetes, cancer, or heart disease. You are not to blame—and you are not alone. The community of NAMI is here for you.

To deal with schizophrenia, one of the most important steps you can take is to join a family or consumer support group, such as *Family-to-Family* or *Peer-to-Peer*. More than 1,200 such groups under the name of NAMI are now active in local communities in all 50 states. Members of these groups share information and ideas about everything from coping with symptoms to finding financial, medical, and other resources. These groups have been described as lifesaving by many who have attended.

Families who deal most successfully with a relative who has a diagnosis of schizophrenia are those who come to accept the illness and its difficulties, are realistic about what to expect from the ill person and of themselves, and are even able to keep a sense of humor. Developing and holding onto such attitudes is an ongoing process for most people, but it can happen more easily and quickly with the understanding support of others.

Schizophrenia causes many problems, but it does not have to devastate you or your family. To deal with it best, it's very important for you to take care of yourself and to continue doing things you enjoy. Scientists believe that new discoveries and new treatment will bring new hope to more people living with schizophrenia in the future.

—Written by Ken Duckworth, M.D.

What Is NAMI?

The National Alliance on Mental Illness (NAMI) is the nation's largest grassroots mental health organization dedicated to improving the lives of individuals and families affected by mental illness. NAMI has over 1,100 affiliates in communities across the country who engage in advocacy, research, support, and education. Members of NAMI are families, friends, and people living with mental illnesses such as major depression, schizophrenia, bipolar disorder, obsessive-compulsive disorder (OCD), panic disorder, post-traumatic stress disorder (PTSD), and borderline personality disorder.

To learn more about your local affiliate:

Call your state's NAMI office

Write to: NAMI • 2107 Wilson Boulevard, Suite 300
Arlington, VA 22201-3042

Contact the NAMI Information Helpline at
1 (800) 950-NAMI (6264) or

Visit NAMI's Web site at *www.nami.org*

Many NAMI affiliates offer programs designed to assist individuals and families affected by mental illness:

NAMI Peer-to-Peer is a free 9-week education course on the topic of recovery for any person with a serious mental illness. Led by mentors who themselves have achieved recovery from mental illness, the course provides participants comprehensive information and teaches strategies for personal and interpersonal awareness, coping skills, and self-care.

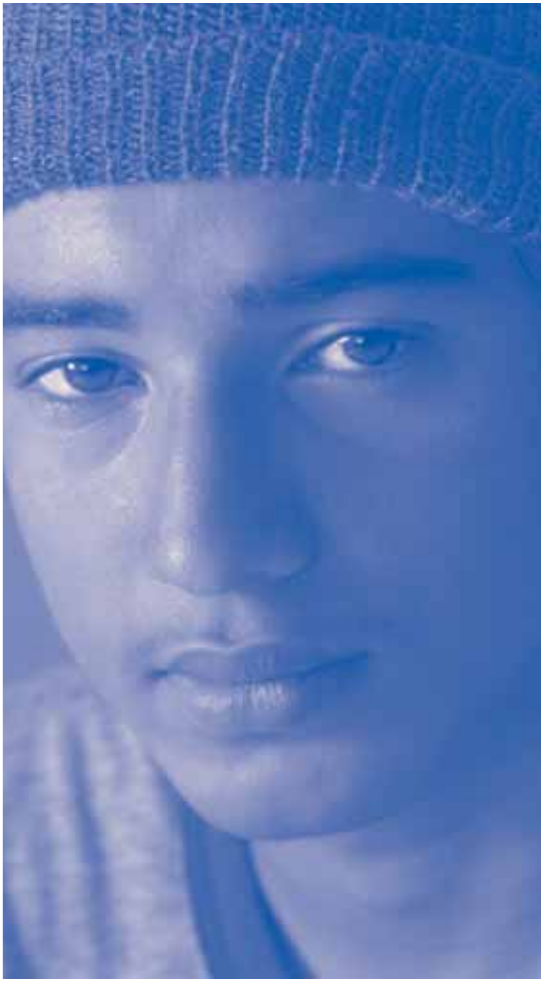
NAMI Family-to-Family is a free 12-week course for family caregivers of adults with mental illness. Taught by trained NAMI family members who have relatives with mental illness, the course provides caregivers with communication and problem-solving techniques, coping mechanisms, and the self-care skills needed to deal with their loved ones and the impact on the family.

NAMI In Our Own Voice is a public education presentation. It enriches the audiences' understanding of how the over 58 million Americans contending with mental illness cope while also reclaiming rich and meaningful lives. Presented by two trained speakers who themselves live with mental illness, the presentation includes a brief video and personal testimonials, lasts 60-90 minutes, and is offered to a variety of audiences free of charge.

NAMI Connection is a recovery support group for adults with mental illness regardless of their diagnosis. Every group is offered free of charge and meets weekly for 90 minutes. NAMI Connection offers a casual and relaxed approach to

sharing the challenges and successes of coping with mental illness. The groups are led by trained individuals who are in recovery--people who understand the challenges others with mental illness face.

NAMI Basics is a free educational program for parents and other primary caregivers of children and adolescents with mental illness. The course is presented in 6 different classes, provides learning and practical insights for families, and is taught by trained parents and caregivers who have lived similar experiences with their own children.



Information Resources:

www.nami.org Updated daily, NAMI's Web site features the latest information on mental illnesses, medication and treatment, and resources for support and advocacy. Other features include online discussion groups and **myNAMI**, which enables you to receive customized information and updates via e-mail.

1 (800) 950-NAMI, the NAMI Information HelpLine receives over 4,000 requests each month from individuals needing support, referral, and information. Over 60 fact sheets on a variety of topics are available along with referrals to NAMI's network of local affiliates in communities across the country.

Peer-to-Peer: *www.nami.org/peertopeer*

Family-to-Family: *www.nami.org/familytofamily*

In Our Own Voice: *www.nami.org/IOOV*

Connection: *www.nami.org/connection*

Basics: *www.nami.org/basics*

Star Center: *www.consumerstar.org*
The STAR Center provides Support, Technical Assistance, and Resources to assist consumer-operated and consumer-helper programs in meeting the needs of under-served populations. In pursuit of this mission, it offers leadership training, national teleconferences, listening sessions, forums, scholarships for consumers and consumer-operated organizations, as well as online resources.

National Institute of Mental Health (NIMH):
www.nimh.nih.gov

Resources about Schizophrenia

NARSAD: the Mental Health Research Association: *www.narsad.org*

Schizophrenia.com: *www.schizophrenia.com*
A non-profit source of information, support, and education.

Schizophrenia: Public Attitudes, Private Needs (2008)
www.nami.org/schizophreniasurvey

www.schizophreniadigest.com
A magazine dedicated to hope, dignity, and support by providing information about schizophrenia for individuals, families, friends and others.

Books about Schizophrenia

The following books are a good place to start learning about schizophrenia. They are available in libraries or can be ordered from booksellers, including a link to *Amazon.com* at *www.nami.org/store*. New books are also listed in the Advocate, the NAMI news magazine available to NAMI members.

100 Questions & Answers About Schizophrenia: Painful Minds (2006) by Lynn E. DeLisi, M.D.

The Center Cannot Hold: My Journey Through Madness (2007) by Elyn R. Saks

Cognitive Therapy of Schizophrenia (2004) by David G. Kingdon and Douglas Turkington

The Complete Family Guide to Schizophrenia: Helping Your Loved One Get the Most Out of Life (2006) by Kim T. Mueser, Ph.D., and Susan Gingerich, M.S.W.

Divided Minds: Twin Sisters and Their Journey Through Schizophrenia (2005) by Pamela Spiro Wagner and Carolyn S. Spiro, M.D.

I Am Not Sick, I Don't Need Help! How to Help Someone with Mental Illness Accept Treatment, revised (2006) by Xavier Amador with Anna-Lica Johanson

Surviving Schizophrenia: A Manual for Families, Consumers, and Providers, 5th ed. (2006) by E. Fuller Torrey, M.D.

Books

A Beautiful Mind: A Biography of John Forbes Nash, Jr. (1998) by Sylvia Nasar

Nothing to Hide: Mental Illness in the Family (2002) by Jean J. Beard and Peggy Gillespie

Pathways to Recovery: A Strengths Recovery Self-Help Workbook (2002) by P. Ridgeway, D. McDiarmid, et al. Published by the University of Kansas School of Social Welfare, Lawrence, Kansas

Psychiatric Rehabilitation (2002) by Carlos W. Pratt, Kenneth J. Gill, Nora M. Barrett, and Melissa M. Roberts

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www.nami.org

August 2008