



The Schizophrenia Source

A newsletter of the National Schizophrenia Foundation

Spring 2005

Conference July 6-8 highlights 20th anniversary of Schizophrenics Anonymous

To recognize the 20th anniversary of Schizophrenics Anonymous, the National Schizophrenia Foundation (NSF) will sponsor a national conference July 6-8 at the Crowne Plaza Hotel – Detroit Metro Airport. Entitled “Mental Health System Transformation: The Role of People with Schizophrenia,” the conference will be open to policymakers, advocates, providers, consumers, family members and the general public.



Joanne Verbanic, Founder, Schizophrenics Anonymous

Schizophrenics Anonymous (SA), a Six Step program, was formed in 1985 by Joanne Verbanic, a suburban Detroit resident, who sought to create a support group for herself and others diagnosed with schizophrenia. Now, 20 years later, SA is an international network of over 150 self-help groups run for/by persons

with schizophrenia and related disorders.

In addition to recognizing the SA 20th anniversary, the conference will highlight the role people with schizophrenia can play in developing and implementing a mental health system that is responsive to consumer needs.

Persons may still attend all or part of the conference, with registration rates adjusted accordingly. For more information, call (517) 485-7168, ext. 108, or go to www.NSFoundation.org.

Fred Frese, PhD, a practicing psychologist diagnosed with schizophrenia, will open the conference on Wednesday, July 6. Workshops on July 6 will target policymakers, advocates and other stakeholders. Topics include Involuntary Commitment



Fred Frese, PhD



Patrick Corrigan, PsyD

Laws, Insurance Parity, Consumers as Providers, Early Intervention Programs, Mental Health Courts, and more. Patrick Corrigan, PsyD, a leading expert on stigma, will also speak on Public Awareness & Stigma Reduction.

A mental health consumer and professional living with schizophrenia, Moe Armstrong, MBA, MA, will speak on Thursday, July 7. Workshops on July 7 will cater to a broader audience of consumers and family members. Topics include Schizophrenia 101, Ask the Doctor, Coping with Symptoms and Side Effects, Our Road to Recovery: Celebrating Our Successes, What People with Schizophrenia Wish Professionals Knew, and more. A special anniversary luncheon on July 7 will feature Joanne Verbanic, founder of Schizophrenics Anonymous.



Moe Armstrong, MBA, MA

Workshops on Friday, July 8, will be directed to a consumer audience. They will include Meditation and Relaxation Techniques, Taking Charge of Your Recovery, Art in Recovery, Self-Esteem, and more.

Treatment goals vary between physicians and patients

The number one treatment goal for patients with schizophrenia and their physicians is to improve overall happiness, according to a recent survey conducted by the National Schizophrenia Foundation and supported by funding from Janssen Medical Affairs, LLC.

This is not surprising. Anyone with an illness, and even those without one, would say that improving overall happiness is high on their list of priorities.

However, the results of the survey, entitled *Treatment Goal Expectations of Physicians and Patients with Schizophrenia*, show that the way to go about improving happiness differs between the opinions of physicians and their patients.

While “reducing the need for hospitalization” and “improving activities of daily living” ranked among the top five treatment goals for physicians, patients ranked “emotion-

See Survey page 3

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A Plea for the Forgotten People

By Margery Wakefield
SA Member, Boulder, CO

I am schizophrenic. You couldn't tell by looking at me. Even some of my acquaintances do not know this about me. It's not something you tell someone if you just know them casually. Even though it should not be so, there is a stigma attached to being mentally ill.

I was diagnosed when I was seventeen years old. I had a horrible nervous breakdown. Mental illness can be cruelly painful. This event in my life cut short a promising career as a pianist. When I think of my life, it is two parts – life before the illness began and life since.

My parents were told at this time that I would never live outside an institution. They were partly right. I have had fifty or so breakdowns since then, each requiring from a month to three months in psychiatric hospitals.

I am not a serial killer. The only person I have ever considered killing was myself, at times when the pain of the illness was unbearable. Also, I am not mentally retarded, as the two illnesses are often confused by people who do not know better.

What I am, is a survivor. Between hospitalizations I have obtained two college degrees, one a master's degree in social work. I have worked for ten years as a social worker, until the stress of the job forced me to retire early and go on Social Security.

I have written three books. I have owned a successful retail t-shirt business. I have been to Europe three times. And I have lived on my own for most of my adult life.

I have been lucky. I have been able to live fairly normally with the

help of my medications, which I take faithfully. But there are a few things I regret.

First is the stigma. This is a disease that people shy away from – even people in the healing professions who should know better. Because most of us live on limited Social Security incomes and are hindered by the earnings cap of \$500 per month, we cannot buy new clothes, drive a nice car, or live in quality housing. We do not always look “nice.”

Second is the often unmet need for insurance if you want quality care for your illness. Without insurance, if you relapse, you are relegated to state or county facilities which often still deserve the label “snake pits.”

Imagine spending a month sitting on the floor (because there are not enough chairs to go around) of a smoke filled room with thirty other patients in various stages of illness. I remember one incident when a young girl fell to the ground in a seizure. I ran to the nurse's station to get help, but no one would come. The message was clear to the rest of us. It

_____ See *Forgotten* page 6

NSF seeks nominations for new Board members

The Nominations Committee is seeking applications for the National Schizophrenia Foundation's (NSF) Board of Directors.

From the applications that are submitted, the Nominations Committee will choose a slate of candidates that it thinks will best meet the NSF's current needs. Board members serve for three-year terms.

Self-nominations are welcome. For an application, call (517) 485-7168, ext. 101.

The Schizophrenia Source

is a publication of the National Schizophrenia Foundation (NSF), a not-for-profit 501 (c)(3) agency.

Mission Statement: It is the mission of the NSF to develop and maintain support groups for individuals, and their friends and family members, affected by schizophrenia and related disorders; and to be a broad resource for all persons regarding schizophrenia and related disorders through education, information, and public awareness services.

Vision Statement: Our vision is that schizophrenia will be understood and accepted like any other treatable illness, and that persons with schizophrenia will lead optimally independent and productive lives through active participation in decision making and complete access to appropriate treatment.

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Survey (continued)

related items” (such as social activity and clarity of thought) as having most importance. See Table 1 below.

The conclusion here was that the differences in patients’ and psychiatrists’ attitudes toward the treatment of schizophrenia indicate there is room for improvement in meeting patient expectations.

“This survey is meant to help us see what steps need to be taken to improve the communication between patients and their physicians, as well as what needs to be done in order to reach a successful treatment consensus,” said Eric C. Hufnagel, President & CEO of the National Schizophrenia Foundation (NSF).

Although physicians and patients equally ranked the top two goals (overall happiness and improved mental health) and least important goals (less sexual side effects and a decreased need to visit a psychiatrist), there were large differences in the middle. Results also showed that

patients need to communicate to their physicians when treatment goals are not being met.

“Communication is a large part of treatment,” Hufnagel said. “Physicians often view success as improved symptoms, while patients may see it as establishing meaningful relationships with others. If patients can convey their views, perhaps physicians will make an effort to include them in the treatment process.”

The survey was given to 199 chronic stable patients, mostly members of Schizophrenics Anonymous (SA) self-help support groups; and to 291 psychiatrists within the United States. It had 18 and 26 questions respectively, with various formats, including yes/no, multiple choice and ratings. Questions addressed general demographics, disease characteristics, and attitudes toward schizophrenia treatment. The result was that similarities and differences in attitudes toward treatment were found.

One reason for this may lie in the fact that people with schizophrenia often view hospitalization and side effects as elements of the illness that eventually lead to improvement.

“We look at hospitalization as part of the process,” said Lisa O., SA leader in Columbus, OH. “It’s not a great thing to have to do, but when you need it, use it. Clarity of mind is more important than side effects. I’m a person that shakes; there’s nothing I can do about it. But I’ll deal with the shaking more than I will the insanity.”

Although various outcomes are valued different by patients, clinicians, family members and the general public, this study showed that the most important aspect to solving these discrepancies is communication.

“Maybe we need to come to an understanding,” Lisa O. said. “I think they need to consider the emotional parts to some degree. We’d do almost anything to be sane, but it’s something that both sides need to understand and make an effort to improve upon.”

Table 1. Rankings and Ratings of Selected Treatment Goals

| Treatment Goal | Physician Ranking | Physician Rating | Patient Ranking | Patient Rating |
|---|-------------------|------------------|-----------------|----------------|
| Similar rankings between physicians and patients | | | | |
| Improved overall happiness | 1 | 4.53 | 1 | 4.09 |
| Improved mental health | 2 | 4.46 | 2 | 4.08 |
| Other* | 3 | 4.36 | 3 | 3.88 |
| Improved ability to express yourself to others | 7 | 4.22 | 4 | 3.82 |
| Reduced depressive thoughts/feelings | 8 | 4.20 | 9 | 3.69 |
| Improved family relationship(s) | 14 | 4.13 | 15 | 3.53 |
| Feeling less agitated or irritable | 17 | 4.11 | 18 | 3.47 |
| Feeling less suspicious of others | 23 | 3.95 | 20 | 3.32 |
| Less dependency on others | 24 | 3.93 | 23 | 3.25 |
| Less sexual side effects | 27 | 3.81 | 28 | 3.01 |
| Decreased need to visit psychiatrist or other counselor | 29 | 3.58 | 28 | 3.01 |
| Considerably different rankings between physicians and patients | | | | |
| Improved ability to perform ADL | 5 | 4.30 | 19 | 3.33 |
| Reduced need for hospitalization | 4 | 4.34 | 22 | 3.30 |
| Decreased shakiness, stiffness | 6 | 4.23 | 27 | 3.09 |
| Symptom control with less frequent/complicated medication routine | 13 | 4.13 | 21 | 3.31 |
| Reduction in symptoms related to your illness such as hearing voices or hallucinating | 26 | 3.88 | 10 | 3.64 |
| Return to favorite hobbies or activities | 19 | 4.06 | 8 | 3.71 |
| Not feeling confused or disorganized, improved ability to think clearly | 18 | 4.10 | 5 | 3.75 |
| Improved physical health | 12 | 4.14 | 7 | 3.72 |

* “Other” for physicians included thoughts of harm to self and others, ability to read and learn, cost, compliance, exercise and nutrition; “Other” for patients included take charge of my mental illness, health insurance, freedom to drink. ADL indicates activities of daily living.

Schizophrenics Anonymous celebrates 20 years

It all started with a simple classified ad: “*Are you suffering from schizophrenia?*” From there, Joanne Verbanic began her mission to improve the lives of people who were experiencing what she had gone through – schizophrenia – by creating Schizophrenics Anonymous (SA) in 1985.

Now, 20 years later, SA is an international network of over 150 self-help groups run for/by persons with schizophrenia and related disorders. Thousands of people with schizophrenia have been helped through SA since that first meeting on July 7, 1985.

The National Schizophrenia Foundation will mark the SA 20th anniversary with a national conference in suburban Detroit July 6-8. Targeting consumers, family members, mental health stakeholders and providers, the conference will highlight the role people with schizophrenia can play in developing and implementing a mental health system that is responsive to consumer needs.

For more information on the SA 20th Anniversary Conference, persons may call (800) 482-9534, ext. 108, or go to [ww.NSFoundation.org](http://www.NSFoundation.org).

Other anniversary activities include the creation of an SA Commemorative Booklet featuring stories, poems and artwork by SA members; development of an SA tribute video; a Founder’s Day dinner; and local celebrations by SA groups across the country.

Schizophrenia, which affects 1 percent of the population, is a biologically based brain disease that



seriously impairs a person’s ability to think clearly and relate to others. As a result, people with schizophrenia frequently become the subject of fear, ridicule and mistreatment by the public. Those suffering from schizophrenia are often left with one option – to withdraw and isolate themselves from society. SA gives them another alternative. SA was developed as a self-help support group to prevent the

tion. The SA statement of purpose is as follows:

- To help restore dignity and sense of purpose for persons who are working for recovery from schizophrenia or related disorders.
- To offer fellowship, positive support, and companionship in order to achieve good mental health.
- To improve our own attitudes about our lives and our illness.

Schizophrenics Anonymous® Six Steps for Recovery

1. I SURRENDER... I admit I need help. I can’t do it alone.
2. I CHOOSE... I choose to be well. I take full responsibility for my choices and realize the choices I make directly influence the quality of my days.
3. I BELIEVE... I now come to believe that I have been provided with great inner resources and I will use these resources to help myself and others.
4. I FORGIVE... I forgive myself for all the mistakes I have made. I also forgive and release everyone who has injured or harmed me in any way.
5. I UNDERSTAND... I now understand that erroneous, self-defeating thinking contributes to my problems, failures, unhappiness and fears. I am ready to have my belief system altered so my life can be transformed.
6. I DECIDE... I make a decision to turn my life over to the care of GOD, AS I UNDERSTAND HIM, surrendering my will and false beliefs. I ask to be changed in depth.

isolation experienced by those suffering from schizophrenia and help them, along with medication and psychotherapy, on the road to recovery. SA is based on a Six Step program for recovery modeled after the 12 Steps used in Alcoholics Anonymous.

Schizophrenics Anonymous is organized and managed by persons experiencing schizophrenia or a related disorder. It is administered by the National Schizophrenia Founda-

- To provide members with the latest information regarding schizophrenia.
- To encourage members to take positive steps towards recovery from the illness.

“We in SA believe in recovery, medications and professional help,” says Verbanic, who has now dedicated her life to erase the stigma and help others, like herself, who are diagnosed with schizophrenia.

SA Group Listings

Schizophrenics Anonymous[®] (SA) is a Six Step, self-help support group for persons with schizophrenia and related disorders. Administered by the National Schizophrenia Foundation, SA promotes self-help as an adjunct to professional help and the use of medication. SA groups are run by their collective membership, have no dues, governing bodies, or by-laws. The following is a current listing of active SA groups. For more information, contact the NSF office at (517) 485-7168 or (800) 482-9534, ext. 103.

ALABAMA

Mobile

CALIFORNIA

Bakersfield
Chula Vista
Downey
Fairfield
Gardena
Hollister
Hollywood
Lancaster
Long Beach (2)
Palmdale
Sacramento (3)
San Diego
Santa Rosa
Tehachapi
Van Nuys (2)

COLORADO

Aurora
Delta
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Littleton
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Plymouth (5)
Port Huron
Roseville
Royal Oak
Saginaw
Westland
Wixom (3)
Yale
Ypsilanti (3)

MISSOURI

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NEBRASKA

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NEW JERSEY

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Mountain Lakes
New Brunswick
Princeton

NEW YORK

Bronx (2)
Hudson Falls
Rego Park (2)
Rochester (2)

N. CAROLINA

Carrboro
Durham
Greensboro

N. DAKOTA

Grand Forks

OHIO

Amelia
Cambridge
Cincinnati
Columbus (3)
Dayton
Elyria
Lisbon
Mansfield
Middleburg Hgts.
Newark
Port Clinton
Springfield
Toledo
Worthington
Zanesville

PENNSYLVANIA

Erie
Greensburg
Latrobe
Morrisville
Philadelphia (2)
Pittsburgh

S. CAROLINA

Camden
Columbia

TEXAS

Abilene
Austin
El Paso
Lubbock
Richardson

WASHINGTON

Medical Lake

WISCONSIN

Madison

ABROAD:

Australia
Brazil
Mexico
Venezuela

Forgotten (continued)

didn't matter to the staff if we lived or died. If you are lucky enough to have insurance, including Medicare, you can go to a plush private hospital until things are better. I would like to see equal treatment for the mentally ill whether or not they have insurance.

Third, I would like just one day without my illness. One day of just feeling really good. Waking up with the sun, putting the coffee on, and just having a normal day. Even with my meds, the most I ever get is getting through the day without an anxiety attack. I sometimes hear voices, although as I age, they are becoming more benign, mostly contributing their unique commentary on the mundane details of my life. But I never feel really, really good. I never get to feel "normal."

But I'm not giving up. I try to live as normal a life as possible. Tomorrow I am going to start work on my fourth book – in my free time. I have two part time jobs working as a nursing assistant. When I'm not doing that or writing books, I volunteer. At my church, for Hospice. I have a piano in my bedroom. I can play Beethoven's Tempest sonata by memory. I am working to memorize a mean Bach fugue.

I have a fantasy. I wish every "normal" person could get to know one person with a mental illness. Take them out to lunch, or to a park for a walk. Then maybe there wouldn't be such a stigma. Then maybe I wouldn't be afraid to tell people: "Hello, I'm Margery. I'm schizophrenic." There is always a price to pay for keeping a part of your life secret, hidden in a mental closet.

Look for me. I might live in your neighborhood. I might go to your

church. I might pass by you in the grocery store or the movie theatre or the mall.

The next time you pass someone who you think might be mentally ill, smile at them. Shake their hand or give them a hug. Know that life is hard for the person, No one deserves to have this illness. Anyone who has schizophrenia is an unlucky victim of life's lottery.

As for me, I will fight this illness until the day I die. There are more books to write, piano sonatas to learn, people to comfort. And in the end, I consider myself to be lucky. That person who told my parents that I would always live in an institution, well, they were wrong about me. I have had the last word. I am living well, and that is the best revenge.

Editor's Note: Ms. Wakefield has offered to donate a percentage of the proceeds from her book to the NSF. Thank you!

Giving Options

Thank you to everyone who's supported our cause over the last several years. Charitable donations, including cash, stocks, and professional services assist in our continuing efforts to provide support and information regarding schizophrenia.

If you would like to discuss a donation to our organization, please contact the development office at (517) 485-7168, ext. 105.

Credit card fees covered by individual donor

The NSF would like to thank the individual who generously pledged to pay the monthly service fees for our credit card processing. This ensures that 100 percent of your donation goes directly to our organization. Thank you!

Did you know?

The number of people with schizophrenia is two times more prevalent in the U.S. than Alzheimer's, five times more than Multiple Sclerosis, six times more than insulin-dependent Diabetes, and 60 times more than Muscular Dystrophy.

Yet, traditionally, schizophrenia has only received a small fraction of the amount of medical research dollars that go into other serious physical (non-brain) diseases.

- * Schizophrenia: 2.2 million people
- * Multiple Sclerosis: 400,000 people
- * Insulin-dependent Diabetes: 350,000 people
- * Muscular Dystrophy: 35,000 people

Source: Schizophrenia.com

Make a donation in honor of the SA 20th Anniversary



Join in the celebration. Everyone who donates a minimum of \$50 will be added to the SA Fellowship Wall.

Levels of Giving include:

| | |
|------------|----------|
| Diamond: | \$25,000 |
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Schizophrenics Anonymous® 20th Anniversary Conference

*“Mental Health Systems Transformation:
The Role of People with Schizophrenia”*

July 6-8, 2005

Crowne Plaza Hotel – Detroit Metro Airport

Featuring:

Moe Armstrong, MBA, MA

Patrick Corrigan, PsyD

Fred Frese, PhD

Joanne Verbanic, Founder of SA

NATIONAL SCHIZOPHRENIA FOUNDATION

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