



The Schizophrenia Source

A newsletter of the National Schizophrenia Foundation

Fall 2006

First Gala raises funds, awareness for the NSF



NSF Board members (l-r) Joanne Verbanic, Ruth Hughes and James Harold, MD, attend the "Jazz on My Mind" Gala. Held in Landsdowne, VA, on Oct. 29, the Gala was a fundraiser, awareness event for the NSF. Besides dinner and dancing, there were live and silent auctions. Due to the success of this inaugural event, plans are already underway for next year.

SA founder, leader receive 2006 Lilly Award

Schizophrenics Anonymous (SA) founder Joanne Verbanic and SA group leader Sister Lucindia Claghorn were the recipients of 2006 Lilly Reintegration Awards. The annual awards honor mental health professionals and individuals with severe mental illness for their outstanding contributions and achievements in the mental-health community.

"We are delighted that these two women were honored, not just for their work with SA, but also for their dedication to the cause," said Eric Hufnagel, President & CEO of the National Schizophrenia Foundation, which administers SA. "They are a true inspiration to so many others."

Sister Lucindia, who is from Mobile, AL, was recognized in the Mentorship category. She is described as "a beacon of light for people with schizophrenia in the state of Alabama. She is a secular Franciscan nun and, while she has faced much rejection from society and even at times within her own church, her archbishop

See Award page 2

Save the Date Early Intervention Conference

March 30-31, 2007

Crowne Plaza Hotel
Detroit Metro Airport

For information on attending or exhibiting, call (517) 485-7168, ext. 101.

Prodromal symptoms of schizophrenia:

Is there hope for early identification and prevention?

By RP Rajarethinam MD, Harkirat Singh MD, Mary Roberts MD, MS Keshavan MD, STEP Program, Wayne State University, Detroit, MI

Schizophrenia is typically diagnosed during young adulthood or late adolescence when the characteristic symptoms of psychosis appear. However, many patients experience a variety of non-specific symptoms known as "prodrome" prior to the onset of psychosis, usually about a year or so before the diagnosis.

The prodromal phase may include behavioral changes such as being aloof and withdrawn, mood symptoms such as anxiety and depression, vague beliefs and experiences similar to psychotic symptoms of delusions and hallucinations, but milder in nature, as well as a functional decline such as poor grades in school or poor self care.

Because these symptoms are nonspecific, those who experience this and their family members may not completely understand what is going on, and even when they seek help,

most of the times it is difficult to diagnose this with any specific condition, let alone schizophrenia. The diagnosis of "schizophrenia prodrome" itself is technically retrospective, as it can only be definitely identified *after* the individual develops schizophrenia.

While the definition of the prodrome itself is challenging, it presents very interesting clinical and research opportunities.

A) If the prodrome can be identified appropriately and treated adequately, it might help the patient to obtain treatment early and hopefully prevent or at least delay the "psychotic breakdown" and so the diagnosis of schizophrenia. Although it sounds too good to be true, there are multiple research efforts around the world, and there are some encouraging preliminary research studies supporting this idea.

B) The prodrome itself is undesirable and unpleasant, even if it does not lead to schizophrenia, and may warrant appropriate treatment.

C) In addition to early identification, the prodrome offers great opportunity for researchers to understand the brain mechanisms involved in schizophrenia.

Although identification of the prodrome itself is challenging, there have been multiple efforts around the world and across the United States to identify and treat individuals during the prodrome.

These include: **EDIE** Trial (Early Identification and Intervention Evaluation), Manchester, UK; **PAS** (Psychological Assistance Service), Newcastle, Australia; **TOPP** (Treat-

See Prodromal page 2

Inside The Source

Prodromal Symptoms	Page 1
Donor List	Page 3
SA Forum/GLC	Page 4
SA Group Listing	Page 5
Schizophrenia Update	Page 12

For your added reading, this issue of *The Schizophrenia Source* also includes our Schizophrenics Anonymous (SA) publications – the *SA Forum* and *Group Leaders' Circular*.



SA member Sister Lucindia Claghorn (l) and SA founder Joanne Verbanic (r) receive 2006 Lilly Reintegration Awards for their work and dedication to the mental health community.

Prodromal (continued)

ment of Pre-psychosis Project), Stavanger, Norway; **PIER** (Portland Identification and Early Referral), Portland, Maine; **PACE** (Personal Assessment and Crisis Evaluation Service), Melbourne, Australia; **STEP** (Services for the Treatment of Early Psychosis), Detroit, MI; **RAP** (The Recognition and Prevention Program), New York; **CARE** (Cognitive Assessment and Risk Evaluation), San Diego, CA; **PRIME** (Prevention through Risk Identification, Management and Education), New Haven, CT.

These clinics use a number of criteria to define and identify prodromal individuals. One of the pioneers in this field, PACE clinic in Melbourne, Australia has utilized criteria known as "At risk mental state" (ARMS) that is fairly widely accepted in the field, also identified by this group of ultra-high-risk (UHR) individuals.

Three such UHR groups are described by them: a) Attenuated Psychotic Symptoms – odd behavior and speech, magical thinking, perceptual disturbances, paranoid ideas. b) Brief Limited Intermittent Psychotic Symptoms (BLIPS) – transient psychotic symptoms, which resolve spontaneously within a week. c) Trait and state risk factors – strong family history and a decline in functioning within the past year.

About 30-40 percent of these individuals identified as prodromal or UHR develop schizophrenia on follow up. While this may help in early diagnosis at least for some, the other aspect of this observation, that about 60 percent will not develop schizophrenia, is also reassuring. However, if the early identification and treatment (and

Award (continued)

designated her ministry to be work with the mentally ill," said Sharon Pedersen, Director of Program for the NSF, in nominating Sister Lucindia.

Verbanic, who is from Farmington, MI, was recognized for Lifetime Achievement. In 1985, Verbanic started a self-help support group for those who – like herself – were suffering with schizophrenia. Today, this group is known globally as Schizophrenics Anonymous (SA) and has 175 groups around the country and satellite groups around the world.

so prevention or delay of the dreaded illness) are the goals of studying prodrome, this poses more challenges.

Instituting antipsychotic treatment to all these individuals will endure unnecessary hardship due to the medication (for the 60 percent) but not treating them will deprive a golden opportunity for early intervention (for the 30-40 percent), if not a delay, or even a prevention of schizophrenia, among those who will develop schizophrenia. This poses ethical, clinical and therapeutic dilemmas in patients, families and care providers.

However, the prodrome itself is not pleasant and may be a call for help. The nature of help and intervention is better decided on a case-by-case basis, considering all available information, including patient history and presentation, as well as objective research evidence involving the patient, family, and treatment team as a collaborative effort. In general, the benefits and risk need to be weighed in making the decision to treat or not to treat.

First, individuals at prodrome need to be identified sooner, for which education of the community and care providers (both primary care providers such as family doctors and school nurses, as well as mental health professionals) is necessary. Once identified, they can be referred to the specialized clinics as described above.

Whether treated or not, individuals identified to be experiencing prodrome need to be monitored closely by the family as well as the care providers for any worsening symptoms. Psycho-education and supportive therapy for

See *Prodromal* back cover

The Schizophrenia Source

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

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Marjorie Cogswell
In Memory of **John D. Moore, Jr.**
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Jeannette Stokes
In Memory of **All Patients**
Helen E. Ford
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Honorariums

Sue Peterson in honor of **Daniel Peterson**
Anonymous in honor of **James Cronin**
Allan T. McCall in honor of the **SA meetings at MHCD**
Gary & Sandra Drew in honor of **Tom Sovine**
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2006 Schizophrenia Awareness Week

Thanks to all our supporters that helped to make SAW 2006 a huge success:

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Regional Events

SAW Chicago Conference
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— Welcome to the Board —

Sergio Loya

Sergio Loya is a Senior Associate with Grant Thornton LLP Global Public Sector, based in Alexandria, Virginia. He has established a career in Public Administration working in local government at the outset and now serves as a senior advisor to federal government agencies.



Grant Thornton LLP is the US member firm of Grant Thornton International, one of the seven global accounting, tax and business advisory organizations. The Global Public Sector advises federal, state and local governments.

Mr. Loya's professional experience includes the proactive and persistent pursuit of government efficiency efforts; client, union and team member relations; and organizational process/cost analysis. A consummate professional, he exhibits strong, effective communication and relationship skills, excelling in a team environment and planning projects, activities and functions.

Mr. Loya was born and raised in the barrios of South Texas along the US-Mexico Border. He is married and is the father of two children.

Schizophrenia Awareness Week is May 20-26, 2007



The Forum

Newsletter by and for members of Schizophrenics Anonymous®

Join your peers for the 2007 SA Leadership Development Conference

“Making Wellness a Way of Life”

The National Schizophrenia Foundation announces its upcoming Schizophrenics Anonymous (SA) Leadership Development Conference, entitled “Making Wellness a Way of Life.”

The conference, scheduled for March 31-April 2, 2007, will take place at the Crowne Plaza Hotel near the Detroit Metro Airport. Early Bird registration rates are available through Feb. 15 for conference registrants. Approximately 25 scholarships are also available on a 1-for-1 match basis, allowing a second group leader or professional staff person to attend this vital training.

The Leadership Development Conference brings together established, new and prospective SA leaders to foster program growth and personal development. This year’s theme echoes a national trend toward seeking recovery that includes physical as well as mental wellness, according to each person’s ability.

“This is the ideal conference to attend if you or your organization wants to start a Schizophrenics Anonymous group,” said Sharon Pedersen, NSF Director of Program.

Founder’s Column

By Joanne Verbanic

Dear SA Family:

Over the years, there have been several myths about schizophrenia. The most widespread myth has been that schizophrenia is a condition of split personality, like that of Jekyll & Hyde. Other myths, such as schizophrenia being considered untreatable or a lost cause, have added to the hopelessness that people experience when they are diagnosed.

One myth that has been propelled by the media is the idea that people with schizophrenia are violent. This couldn’t be further from the truth. We know now that they are more likely to be victims than perpetrators. Also, years ago, people were afraid that they would “catch” the illness, because they didn’t know that it tends to be hereditary.

All of these myths have spread through society, but belief in them is continuously shrinking. As long as there is education and awareness, schizophrenia will be known as a treatable condition, rather than a mysterious disease.

Love, Joanne

“The Orientation/Training sessions are what’s needed in order to establish an effective group. Continuing group leaders will also benefit from hearing from experts in the field as well as sharing ideas and networking.”

To keep costs down for mental health consumers and agencies, this year’s early-bird rate of \$375 (based on double occupancy) is the same as last year’s rate for three days of training, two nights of lodging, and meals. For those who are not involved in Schizophrenics Anonymous

yet, a one-day option will be available to attend educational and personal development workshops on Monday, April 2.

To receive a registration brochure for the Schizophrenics Anonymous Leadership Development Conference, contact Michelle Mayfield at (517) 485-7168, ext. 101.

For scholarship or other information, call Sharon Pedersen at (517) 485-7168, ext. 109, or send an e-mail to info@nsfoundation.org.

SA Groups across the U.S. and abroad

Schizophrenics Anonymous[®] (SA) is a six-step, self-help support group for persons with schizophrenia and related disorders. Administered through 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. If there is no group in your area, please contact us about starting a group. Call (800) 482-9534, ext. 109.

ALABAMA

Mobile

CALIFORNIA

Bakersfield
Chula Vista
Conoga Park
Downey
Fairfield
Hollister
Hollywood
Lancaster
Long Beach (2)
Los Angeles
Lynwood
Palmdale
Palo Alto
Sacramento (2)
San Diego
San Francisco (2)
Santa Monica
Santa Rosa
Tehachapi
Van Nuys

COLORADO

Aurora
Delta
Denver
Lakewood
Littleton
Pueblo

CONNECTICUT

Ansonia
Bridgeport (2)
Danbury
East Hartford
Enfield
Hartford (2)
Manchester
Middletown
New Haven

Newington
Norwalk
Norwich (2)
Torrington
West Haven

FLORIDA

Delray Beach
Hollywood
Jacksonville (2)
Lakeland
Lauderhill
Oakland Park
Port Charlotte
St. Petersburg
West Palm Beach

GEORGIA

Columbus

HAWAII

Honolulu

ILLINOIS

Wheaton

INDIANA

Bloomington

KANSAS

Wichita (2)

MAINE

Portland

MASSACHUSETTS

Quincy

MICHIGAN

Adrian
Ann Arbor
Bay City
Benton Harbor

Big Rapids
Charlotte
Detroit (4)
Eastpointe
Flint
Fowlerville
Fremont
Grand Haven
Grand Rapids
Holland
Holly
Ionia (2)
Kalamazoo
Lansing (2)
Lapeer
Lincoln Park
Livonia
Marquette
Midland
Mt. Pleasant
Muskegon
New Haven
Oak Park (2)
Paw Paw
Petoskey
Plymouth (5)
Port Huron
Roseville
Royal Oak
Saginaw
Southgate
Westland
Wixom (3)
Yale
Ypsilanti (5)

MISSOURI

Kansas City
St. Louis

NEW JERSEY

Jersey City
Mountain Lakes
New Brunswick
Woodbury

NEW MEXICO

Albuquerque

NEW YORK

Bronx
Hudson Falls
Rego Park
Rochester (2)
Utica

N. CAROLINA
Carrboro

N. DAKOTA

Grand Forks

OHIO

Cambridge
Cincinnati
Columbus (6)
Dayton
Lisbon
Mansfield
Marysville
Medina
Middleburg Hgts.
Newark
Port Clinton
Springfield
Toledo
Westerville
Worthington
Zanesville

PENNSYLVANIA

Erie
Morrisville
Philadelphia (3)
Pittsburgh

RHODE ISLAND

Providence

S. CAROLINA

Camden
Columbia

TEXAS

Abilene (2)
Austin
El Paso
Lubbock

WASHINGTON

Medical Lake

WISCONSIN

Madison

ABROAD:

Australia
Brazil
Canada
Mexico
Venezuela

Joining the SA Movement

By Joel B.

After I became a member of the Inner City Clubhouse, the Director asked me if I would be interested in becoming the leader of the Schizophrenics Anonymous (SA) support group that had been meeting every Tuesday from 1:30-2:00 p.m. there.

The group seemed to have run out of steam, and I had been looking for something to do and to become active and useful at the clubhouse. Even though I had no idea just what SA was all about, I knew that I had the skills to facilitate the group.

Also, I had been attending another support group for two years. The facilitator of this group, who has since become my therapist and a good friend as well, is a master of the techniques of group facilitation.

As I was recovering from my marijuana addiction, I paid close attention to the methods that he used as a facilitator at these meetings. I couldn't have learned anymore from any text book or class from anyone about refining my skills.

Being well-versed in the 12 Steps of AA and the 12 Steps of Dual Recovery, it was easy for me to introduce and discuss the Six Steps to recovery of schizophrenia to the group at the meetings. These Six Steps are the very foundation of the SA movement.

After the very first meeting that I facilitated, I noticed that a wonderful feeling had come over me. I felt

much better about myself, about my life. Every meeting seemed to get better and better, and my feelings of wellness were growing in leaps and bounds.

As a group, we were bonding and becoming trustful of one another. This is what recovery is all about. I began to help all of the group, including myself, to get in touch with our innermost feelings about our lives, about our pains and tragedies, about our joys and accomplishments, about our goals. This is what recovery is all about.

I was able to get these inner feelings about our lives out of us and onto the table so we could do some caring and sharing with each other. This is what recovery is all about.

We all learned that despite our different illnesses, we shared similar symptoms, feelings, and emotions as well. We know that we are all in the same lifeboat, that we have all walked in each others' shoes.

We talk about wellness, about our Higher Power, about forgiving ourselves for the harm we may have done to others, and then forgiving the ones that may have done harm to us. We talk about the importance of understanding our illnesses, and about making good decisions about our lives.

We talk about the need to truly love ourselves before others can love us. This is recovery.

And... This is what Schizophrenics Anonymous is all about for me. My recovery.

SA in Action...

SA members are often active in their own communities – whether it's SA-related or other personal/leadership development opportunities. Call (800) 482-9534, ext. 109, to report any SA member accomplishments.

Kudos to the following:

* Jon D. of Providence, RI, received The Advocacy Award, the highest advocacy award for consumers from The Rhode Island Council of Community Mental Health Organizations.

* Christopher C. of Silver Spring, MD, was voted best dressed employee and was named "Team Hero" by his employer for the month of October.

* Tammy N. of Sacramento, CA, attended a workshop at UC Davis and made an announcement inviting folks to come to her SA meeting. She also received an evaluation of 5.9 out of 6.0 for a presentation at the CASARA conference.

* Phil C. of Utica, NY, had his SA meeting mentioned in the listing of the local public access television station.

* Sister Lucindia C. of Mobile, AL, had her picture taken for Catholic Week of the Archdiocese for her "Respect" Award.

* Joel B. of Detroit, MI, received the Peer Supporter of the Year Award.

* David Z. of Eastpointe, MI, was elected to the local NAMI board.

* Richard S. of Aurora, CO, sent flyers about his SA group to therapists at the local mental health center. Now they are referring clients to SA.

Hope is Today's Reality!

By Ronald S.

"Hope is Today's Reality" was the theme for Schizophrenia Awareness Week 2006. As a result, I observed that when we increase awareness, we are also spreading hope.

In Big Rapids, MI, we began preparing for Schizophrenics Anonymous (SA) in October 1999. We held our first meeting on Monday, Jan. 10, 2000. Since that time we have continued to meet weekly on Mondays at New Journey Clubhouse.

In January 2006, we changed our meeting time from afternoons to mornings. Attendance has increased from five regulars to eight regulars. The new people are already seeing change and growth in their lives. They are grateful, and the group is functioning cohesively.

What we tell new people with schizophrenia and related brain disorders is that there is HOPE. Medicine, SA meetings, counseling with case managers and psychiatrists are all beneficial and helpful for recovery one small step at a time.

One member of our SA group graduated from Montcalm Community College and now attends Ferris State University full-time.

Two of our members were recently chosen to represent New Journey Clubhouse at the National Training Center for Clubhouses in Greenville,

SC. A fifth member of our SA group was hired at CMHCM as a Peer Support Specialist.

For myself, I am now functioning at a higher level than I was three years ago. My personal journaling may some day produce a book that will glorify my Creator.

View from the prison

By Mike K.

My name is Mike K. I am diagnosed with schizophrenia, paranoid type, and recently I've had schizoaffective highlights and symptoms without the depression. I have been in therapy since childhood and first heard about my schizophrenia at age 16.

I never came in contact with SA until around February 2000 at a psychiatric hospital for convicted felons. I have been a prisoner since May 1986. The State Prison system is not conducive to good mental health, but there are mental health programs governed by the Dept. of Corrections

available for those who need them, or are ordered by the court.

SA helps me by giving me the environment which restores the dignity that is otherwise taken by the system that labels us as "space cases" and "bugs." Cruelty toward the mentally ill in prison is common and mostly unavoidable. Almost two-thirds of the prisoners have schizophrenia or a schizophrenia-related illness at this facility, and for a lot of them just going through SA's first step, to admit that one needs help, isn't always easy.

It's good to know we are not alone, and SA support is important until someone can find a cure...

Schizophrenics Anonymous Materials Order Form

Please note how many of which item(s) you are requesting. Make checks payable to **National Schizophrenia Foundation**.

- _____ SA Materials Order Form. A complete list of materials available for purchase (FREE).
- _____ Yes. I would like to receive a **free brochure** which briefly describes the **Schizophrenics Anonymous** program (FREE).
- _____ Yes. I would like to receive the **SA Blue Book** (\$2.25 each).
- _____ Yes. I would like to receive the **SA 20th Anniversary Commemorative Booklet** (\$2.50 each).
- _____ Yes. I would like to receive an **NSF Apparel Order Form** (FREE).
- _____ Yes. I would like to receive the video tape "**Joanne Verbanic: On SA and Schizophrenia**" (\$15.00 each).
- _____ Yes. I would like to support the National Schizophrenia Foundation with a **financial contribution**.
- _____ Enclosed is my check for (please circle): \$10.00 \$25.00 \$50.00 \$100.00 \$ _____ Other
- _____ Yes. I am interested in forming an SA group and would like to learn more about the "Start-Up Package."

Name _____ Phone () _____ E-mail _____

Address _____ City _____ State _____ Zip _____

Total Enclosed: \$ _____ Method of Payment: _____ Check _____ Credit _____ Debit

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Complete this order form and send it, along with a check, money order or credit card information to:

National Schizophrenia Foundation, 403 Seymour Street, Suite 202, Lansing, MI 48933. Phone: (517) 485-7168. Fax: (517) 485-7180.



THE GROUP LEADERS' CIRCULAR

*Ideas, Issues, and Information for
Leaders of Schizophrenics Anonymous*[®]

Dear SA Group Leaders,

In this Issue:

- **The Necessary Value of Respect**
- **Confronting Unacceptable Behavior**
- **Sharing talk about meds and side effects: pros and cons**
- **“Good Grief” and the “Acceptance of things we cannot change”**
- **A Call for Topics: Do You Have a Question for Larry A?**

The Necessary Value of Respect

The issue I would like to address is an important one. It involves our cherished value of Respect. Respect is what we hope to find when we first come to SA, because most of the world has almost no understanding and little Respect for our status as persons with legitimate needs and a real, physical brain disorder. If we don't have our needs for Respect met at SA meetings, where are we to go?

“What am I talking about,” you ask? “Don't we express Respect in every SA meeting?” Well, when we push our ideas about what others' political, gender/interpersonal and religious views should or shouldn't be, or when we reduce the SA group to a “dating game,” we are expressing Disrespect toward our members' personhood. When we gossip or express doubt about the intensity of other's symptoms, or the seeming reality of their delusions and dreams and waking nightmares, or their “level of functioning” or how well or poorly they appear in public, or even whether or not they will ever recover, this is simple Disrespect; it hurts our members and it hurts SA.

How can we best express Respect? If a member is having a grand or strange delusion, or if they come to SA in a state of confusion about the safety of the meeting or the level of group confidentiality for the sharing they are about to take part in, how are we to respond? If a member is afraid to reveal their true feelings for fear of rejection, it is our responsibility to assure them that we will listen non-judgmentally. We assure them best by our actions, our behavior as it expresses our attitudes in response to all the members who come to SA for support.

For instance, we make sure that we support the desires of our members to not be made fun of or stigmatized in the mass media. We can support each other in facing the fear of taunts about being “different,” or expressing our uniqueness, without suggesting we argue in SA about the different views we hold. We can be empathetic to the fear of consequences or political conspiracies against us because such fears are often a part of the illness we share. We all work **STEPFIVE** eventually, if we stay in SA long enough: **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.**

But it is Disrespect to advise or cajole our members, within the context of an SA meeting, how they should behave in the political, interpersonal or religious arenas, or whom they should support or how active they should be in these parts of life. It is Disrespectful and discriminatory to tell them in the course of an SA meeting that their political, religious, interpersonal or cultural, etc. views are mistaken, evil or wrong; it's like telling them, for instance, that the only correct way to open a soft-boiled egg is from the large end (to use an example from **Gulliver's Travels**).

The same is true for expression of religious doctrines in SA. The statement, "My family belongs to Brand X Church so we believe Position Y," is a declaration that can divide the SA group, leading new or potential members to feel that their own religious sentiments will not be tolerated or respected here. You might feel very strongly that "Position Y" is morally reprehensible, but put yourself in the other members' shoes: if you felt you were going to be forced to discuss the **merits** of "Position Y" to earn the freedom to share your mental health struggles in SA, would you come to SA at all?

A Zen Buddhist might feel very comfortable ending a meeting with the "Bodhisattva Vow" and a Shiite Muslim might feel very comfortable with a reading from the Koran, but would a Southern Baptist or an Irish Catholic? I think we can agree that, no matter how much we may treasure the texts, prayers and practices of our traditions, they are out of place at a meeting about schizophrenia for people of any and all faiths, who come to the meeting to learn to better deal with the difficulties caused by schizophrenia.

If you have people at your meeting who are uncomfortable even with the Serenity Prayer, they should feel free to abstain from reciting it, or even leave the room before it is spoken, or your group may opt to end with the shared reciting of the Six Steps.

Furthermore, while male members of SA might like to talk once in awhile about the side effects of medications on their sexuality, female members might feel very uncomfortable or embarrassed (that is, Disrespected(!)) about such talk. And this is not limited to one gender, either. Therefore, discussions about "plumbing" and "intimacy" could be disrespectful. If these come up, it is up to the leader to ask the group, out of courtesy, if it's ok to continue the discussion.

If a majority of the members wish to continue the discussion, the leader should give any "minority" the opportunity to take a break. If it's a "minority vote" that wants to continue the discussion, ask them to get together after the meeting to address their issue. Each person's comfort level is important. I know that not every SA member is equally at ease with talk about intimacy. Even scientifically-based talk about relationships can be problematic for members of certain religious and cultural groups, or those with histories of childhood abuse. So as SA leaders we must place Respect as our first priority.

It is also important to remind everyone that leaders should never initiate "dating" relationships with newcomers to a group. The sense of security that belongs to us and is our right as members of SA is not yet fully felt by a newcomer; they're still getting used to SA. It is taking advantage of their vulnerability to try to date them. Sometimes it may seem that interest in dating is mutual – we are, after all, people with much in common. But if this is the case, it is better for the leader to step out of the role of leader for a time, so that the friendship can grow between equals.

SA's rock-bottom support provides the foundation for self-confidence, self-reliance and good mental health so we can be free to grow in our spiritual, interpersonal and cultural selves, to make the decisions and take the positions that seem best to us. So it's simply necessary that we drop all discussion of divisive "Positions X, Y, and Z" entirely for the sake of the higher value of self-help group support for all SA meetings.

I hope you will discuss this issue of Respect with your SA group members from time to time, because sensitivity and compassion are essential aspects of expressing Respect in your leadership.

Confronting Unacceptable Behavior

Sometimes member fears and feelings get expressed in ways that make the rest of the group uncomfortable. But if we can ride out the storm of symptoms, stay focused and consciously relaxed (letting the tension wash over us and off our backs like water off a duck), the group will be strengthened and a member might find their way out of the quagmire of despair, fear and helplessness. I have been in SA where this happened and I know it can be true. The process can go most smoothly if the group shares a “group consciousness meeting” to discuss their own fears and feelings about the suffering member’s struggle and to seek ways to be helpful.

But if a member’s behavior crosses the line to include threatening, abusive or illegal behaviors, the individual should be told that these behaviors will not be tolerated by the group, that only when the behaviors change might the member be accepted back into the SA group. This expression of concern should be as clear as possible and emphasize that what is being rejected is not the **person**, but the **behavior**.

This ejection of a member from the meeting is best handled by the SA Group as a whole; **it should not be** a burden for the leader to bear. The group simply must show unity in confronting unacceptable behavior. It is more than just a conflict between the leader and any individual member. The emphasis on behavior keeps the focus on our common responsibility to practice Step Two: “Choosing to be well” and Step Five: “Understanding that erroneous, self-defeating thinking contributes to [one’s] problems, failures, unhappiness and fears.” This focus gives the alienated and misbehaving individual member the chance to practice Step One: “I Surrender. I admit I need help. I can’t do it alone.”

Remember that among the general population of people with schizophrenia, violence is the exception and happens rarely, but anger can happen to anyone, and can get out of hand if an individual is newly diagnosed or is not using medications properly, or is abusing alcohol and/or other drugs.

Then it is the group’s responsibility to, **whenever possible**, practice SA’s Step Four, “I Forgive.” After an appropriate time period, if the damage has not been too severe, maybe there can be reconciliation with the ‘errant’ member. No one should be expected to **forget** the behavior if it has been abusive or illegal, but **“forgiveness is a choice”** that enables emotional wounds to heal.

BOTTOM LINE: It is every member’s right to feel safe in SA; it is every member’s right to BE safe in SA.

If safety is the issue, then hold a group consciousness meeting (if necessary, without the offending member present); then discuss the incident(s) involved and stand by the group decision. The leader will need the support of the entire group in confronting offensive behavior; no leader should ever be expected to confront such behavior alone. That is a recipe for more trouble. Contact your co-sponsor and the NSF for suggestions. Don’t be afraid to call “911” if you need immediate help in a crisis.

Sharing talk about medications and side effects – pros and cons

One of the joys of being in SA is the chance to compare notes on doctors, counselors, experiences of stigma and misunderstanding from those around us, and of course, the schizophrenia experience itself. Since the universal experience of schizophrenia in the USA includes use of psychiatric medications, it is natural for us to want to share our thoughts along these lines as well. We need to exercise caution, however, to be fair to everyone in the group. Every person in the group has a unique brain chemistry and tissue makeup, and there are many different genes and chromosomes linked to the experience of our challenging predicament. There is not so much “one disease” at issue here, but rather a host of brain differences that share common symptoms. Opinions about medicine are probably as diverse as your group’s membership. So what works very well for one member might be “really awful” in the experience of another. Our doctors are usually the treatment experts – they know what medications we have taken in the past and what the results of our trial-and-error treatments were. They see scores of patients and learn from their colleagues, just as we do from ours. We would not want to scare a member away from their medication regimen or away from SA.

We also should emphasize the positive when discussing meds, adding to the discussion as much factual material as we can acquire. We who attend SA are a “panel of experts” about the disorder – with the emphasis on “panel.” We can all contribute our thoughts about our own experiences and, as a group, come up with a pretty fair accounting of the status of medication treatments to date. Just remember that **we are Not doctors! No one person in the group has “all the answers” regarding medications.**

“Good Grief” and the “Acceptance of things we cannot change”

In the course of time for every long-term SA group, changes come that we cannot anticipate nor control. This is the inevitability of change, which is to say, “Nothing lasts forever.” In spite of our best efforts, groups come and go and individuals come and go within the groups. While we miss the former groups and former members, we must turn ourselves toward the future and be true to the present or we will not last long ourselves. The future waits impatiently for our new moments to arrive. We do it an injustice if we don’t prepare for it. But we must make room for the new moments by clearing up the past. For some of us, this is grief work. Each group that survives does so in the midst of honoring its history.

Some moments bring us up, fast and hard, demanding that we take a long look at the passing of a cherished member or a pleasant group circumstance. The “normal” folks around us may not deal with our need very well – they might even be bewildered at our sentimentality, such as wanting to attend a funeral with some fellow members. But don’t let anyone tell you or your group how they “should” grieve the passing of a member or the loss of a treasured situation. Years ago, a consumer group from a Midwestern city traveled to Los Angeles for a conference. While there, one of their members died of a heart attack. To deal with their grief and loss, the group decided to plant a Memorial Tree on the grounds of their clubhouse. By my reckoning, that tree is now thirty years old – and large enough to provide shade for the clubhouse members.

In a similar vein, years ago, I started an SA group in Columbus, Ohio. Located in an impoverished part of the city, the meeting site was an ideal location for SA, and we soon had eighteen members attending each week. Our success brought our downfall, however, because the local mental health center decided our audience would be ideal for a bowling trip each week. Each Tuesday, the bus would arrive and take our members away. Week after week, the bowling bus came on time, and, week after week, it returned: too late for people to attend an SA meeting before they could catch city transit busses home for the night. Our SA meeting at that location died: a victim of its own success. This was impermanence: a change we could not control. But there were only a few of us left to mourn the passing. Thankfully, several other SA groups have flourished in the Columbus, Ohio area since then.

Impermanence can rock the group when it is the passing of a cherished member, and this author has addressed aspects of this topic in these pages before. But here is a new twist: what about the relatives of our member who don’t seem to want to share their grief observances with SA members? Is it stigma or shame that motivates the hurtful expressions of exclusion? If so, it is up to us to be “large” in our response, so I would suggest that in such an event you send a “love letter” expressing sorrow at the passing, as if all the formalities had been properly addressed. This serves the multiple purposes of diminishing stigma, honoring the passing and loss, and offering comfort to the bereaved.

A Call for Topics: Do You Have a Question for Larry A?

As interesting a place as the National Schizophrenia Foundation office is, even we can use fresh ideas and topics for our newsletters. I hope you will empower me to be the best writer I can be, just as I hope this request for your ideas inspires each of you to reach out and dig in and produce some topic requests. If you would like to address a specific topic yourself, we only request that you contact us with your idea, with plenty of “lead time” to allow for scheduling, developing and editing the topic. Thank you.

Schizophrenia Update

The Latest Information Regarding Schizophrenia. . . by John P.

Yale Studies Transcranial Magnetic Stimulation for Schizophrenia

Yale University is studying the use of an experimental treatment called Transcranial Magnetic Stimulation as a means to reduce auditory hallucinations, or “voices,” in patients with schizophrenia. Initial experimentation has had promising results. The idea is that perhaps sometime in the future this method may provide symptom relief for patients with schizophrenia who don’t respond to current medication treatments.

Transcranial Magnetic Stimulation is a painless procedure – experienced simply as knocking sensation – in which an electromagnetic coil is placed on the scalp while the patient is awake. TMS is done for 16 minutes daily over a three-week period.

“It appears that stimulating populations of neurons once per second over many minutes modestly reduces the capacity of these neurons to activate each other,” said Ralph Hoffman, MD, Yale’s leader on the TMS studies. “As a result, neural populations as a whole become less reactive or excitable. Our study findings suggest that hallucinations can be curtailed using this approach without interfering with normal brain functions.”

SOURCE: Information from Yale University press release (March 9, 2006)

More on Transcranial Magnetic Stimulation

Researchers at the University of Toronto are also studying the use of TMS as a means for reducing auditory hallucinations in schizophrenia. Their findings are that a TMS treatment can reduce “voices” in patients for over a 15-20 week period.

University of Toronto researchers hypothesize that in schizophrenia, the patients’ brains lack adequate inhibition capacity to filter out the deluge of information coming at people in everyday living. The university’s studies show that indeed the schizophrenia patients did have less of the inhibitory capacity. The Toronto researchers think that the TMS increases this inhibitory ability of the patient’s brain, enabling the person with schizophrenia to better filter out information. Through this process, the “voices” are reduced.

Future hopes are that TMS can be applied to other parts of the brain of patients with schizophrenia to see if symptom relief in other areas can also be gained. For instance, it is suggested that TMS over a section of the prefrontal cortex might reduce cognitive impairment in schizophrenia.

SOURCE: Information from the NARSAD Research Newsletter (Winter 2006), publication of The Mental Health Research Association

Schizophrenia Update

(Continued)

Glutamate and NMDA Receptors Studied with Brain Imaging

The neurotransmitter glutamate and the brain chemical NMDA are being mentioned in the scientific literature more and more as having a role with some cases of schizophrenia. Researchers at King's College of London are now using brain scan imaging to identify the abnormality in the glutamate-NMDA system in the brains of people with schizophrenia. The hopes are that this work may lead to a more reliable method of diagnosis of schizophrenia, and someday to new treatments.

King's College London scientists are using SPET scans to do the brain imaging. SPET is short for single photon emission tomography. This scanning method enables researchers to "see" active brain functioning while a person is alive. Before these kinds of scan imaging, data on the brain required postmortem analysis.

Brain scans of patients with schizophrenia are compared with a control group of healthy individuals to arrive at conclusions. Among those studied with schizophrenia, there were two groups – those who had been treated with medication and those who had never been treated with medication.

The brain chemistry deficit of the glutamate-NMDA system occurs in the temporal cortex, and is connected with the left hippocampus, a part of the brain that involves learning, perception, and memory. Problems with the glutamate and NMDA receptors result in "loose wiring" between brain cells, making it difficult for communication to occur between cells.

It is noteworthy that those patients with schizophrenia taking medication showed less difficulty in the glutamate-NMDA system than those not taking medications. Some scientists suggest that at some point medications may be developed to directly target glutamate and NMDA.

The King's College London study was published in the February 2006 edition of *Molecular Psychiatry*.

SOURCES: Information from King's College London press release (April 11, 2006), BBC News online (April 9, 2006), Medical News Today online article (April 12, 2006)

EGR Genes and the Role of the Environment

Most scientists express the idea that both genes and the environment contribute to the onset of schizophrenia. Researchers at Washington University in St. Louis are studying the EGR genes, or early growth response genes. EGR genes are important because, according to NARSAD, "environmental events activate their expression at high levels of the brain." Environmental stress can activate an EGR gene. Scientists are interested in how this can impact on the development of schizophrenia.

SOURCE: Information from the NARSAD Research Newsletter (Winter 2006), publication of The Mental Health Research Association

Schizophrenia Update

(Continued)

Schizophrenia, Iceland, and Genetic Susceptibility

Time magazine recently ran a story about the important role that the small island nation of Iceland is playing in finding the genetic connection with numerous world illnesses. One of these instances is for schizophrenia. In the past we have published articles about deCODE genetics, a company in Iceland, and how they have found a gene that appears responsible for some cases of schizophrenia.

According to *Time*, Iceland is uniquely set to make these kinds of scientific contributions. This is because of the nation's "genetic isolation" and "unrivaled genealogical records." Genetically, Iceland is one of the most homogeneous nations in the world. This makes Iceland unique in its ability to isolate genes. And as this work continues, illnesses such as schizophrenia will likely have new treatments to match the new knowledge about the causes.

Iceland was settled in the 9th Century by a small number of Norsemen and Celts, and there has been relatively little immigration over the centuries. The people of Iceland are able to trace their ancestry back many centuries, in some cases to the original era of settlement. Thus, hereditary illnesses can be more easily traced over time, and the genetic links are easier to identify.

The deCODE company in Iceland has collected blood samples from 100,000 of its citizens, which is about half of the adult population of the country. From these, a person's gene spectrum can be identified. Iceland also has well-developed medical records, which is another plus in doing this genetic research.

Watch for Iceland to make more strides in finding genetic links to illnesses, such as schizophrenia.

SOURCE: Information from *Time* magazine (February 20, 2006)

Changing the Name of "Schizophrenia?"

Schizophrenia Digest published a piece discussing some of the factors that would be involved if there was an effort to officially change the illness name of "schizophrenia" to some less emotionally charged name. Many people feel that the word "schizophrenia" is frightening in itself, and that the word is stigmatizing. A couple decades ago, the name of the illness "manic-depression" was officially changed to bipolar affective disorder." Some will ask whether this same kind of deference could be granted to those with schizophrenia?

The decision on something like this would be made by a panel of experts of the American Psychiatric Association in connection with revising the DSM-IV – the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders. This next revision, DSM-V, is scheduled for 2011, but later this year, the public and professionals can begin to make suggestions for changes. Information about this can be found at www.dsm5.org.

SOURCE: Information from *Schizophrenia Digest* (Spring 2006)

Schizophrenia Update

(Continued)

Large Study Counters Link Between Antidepressants and Suicide

Many people with schizophrenia and schizoaffective disorder take antidepressants as part of their treatment. In 2004, the Food and Drug Administration issued a warning that the new antidepressants may carry a risk of suicide behavior. This warning is required to be written into the medication package inserts of the antidepressants. The 10 medications in question are Prozac, Zoloft, Paxil, Luvox, Celexa, Lexapro, Wellbutrin, Effexor, Serzone and Remeron.

In January of this year the Group Health Cooperative released the results of a large study of 65,000 patients taking antidepressants that suggests no general link between the antidepressants and suicide risk; in fact, the risk of suicide went down after patients began antidepressant treatment.

The Seattle-based Group Health Cooperative, whose researchers led the study, is a non-profit health system which serves more than 590,000 members in the states of Washington and Idaho. The National Institute of Mental Health funded the study, and a researcher from the Harvard Medical School participated in the work. The study was published in the prestigious *American Journal of Psychiatry*.

The research design of the study, according to the Group Health Cooperative press release, has these features: “This study is the first published analysis to compare the risk of suicide attempts before treatment to the risks following treatment. It is based on computerized medical and pharmacy records for more than 65,000 patients who filled prescriptions for antidepressants from 1992 to 2003. Deaths from suicide were determined from death certificates, and suicide attempts were identified from hospital discharge data.”

The results of the study are as follows:

- The number of suicide attempts went down by 60 percent in adults during the month after antidepressants began, and went down even further in subsequent months.
- The completed suicide rate was not higher in the first month of antidepressant treatment than in subsequent months.
- The newer antidepressants showed a faster decline in suicidal behavior over the older antidepressants.
- The suicide risk was higher for adolescents than adults, but the risk for adolescents also went down by 60 percent in the first month of treatment.

The results show that on average suicide risk goes down after taking antidepressants, but according to Greg Simon, MD, the lead researcher of the study, care still needs to be taken. “There may be subgroups of people who become agitated or suicidal after taking these drugs, and those people should seek help from a doctor or therapist right away if that happens,” says Simon. And Simon agrees with the FDA recommendation that physicians carefully monitor patients taking antidepressants, but largely to make sure that the patient is on the right medication and the right dosage.

SOURCES: Group Health Cooperative press release (Jan. 1, 2006); *American Journal of Psychiatry* (January 2006); About.com Web article (Jan. 13, 2006)



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Prodromal (continued from pages 1-2) _____

the patient and family are essential.

Considering the clinical dilemma explained above, the treatment options vary. It is obvious that open-ended treatment similar to that for schizophrenia is not ideal in this situation, as a majority of the individuals identified to have prodromal symptoms do not develop schizophrenia. Some believe that treating the symptoms that present at the prodrome (e.g., antidepressants for depression or behavioral therapy for anxiety) may help.

Use of antipsychotics for a limited time is a compromise option that may have the benefits of medication without the potential risks of lifelong treatment. Use of medication has been studied in Australia and in the USA. The PACE clinic study conducted by McGorry, et al, enrolled 59 individuals between the ages of 14 and 30 identified as UHR.

About half of them were treated based on the need (depends upon the problem, support, case management, antidepressants and benzodiazepine), and the other half were treated with low-dose risperidone (1 to 2 mg per day), an antipsychotic medication, for six months along with Cognitive Behavioral Therapy (CBT).

The CBT helped patients gain better understanding of the symptoms, learn strategies to control the symptoms, reduce stress and avoid substance use. On follow up at six

months, 10 out of 28 (36 percent) in the treatment as usual group developed psychosis whereas only 3 out of 31 (10 percent) of those treated with risperidone developed psychosis.

After 12 months, three more in the treatment group developed psychosis. Interestingly, only one of the 7 individuals who took the medicine as prescribed (meaning fully compliant) developed psychosis.

The PRIME study conducted by McGlashan, et al, in the U.S. used olanzapine, another antipsychotic in a blind fashion (both patients and doctors did not know who was treated with the medicine or a dummy pill).

Among the 29 individuals treated with placebo (dummy pill), about 38 percent developed psychosis, and about 16 percent of the 31 individuals treated with olanzapine developed psychosis. Although encouraging, the results of this study were not statistically significant. Olanzapine was found to be efficacious for positive psychotic symptoms but caused weight gain of about 20 pounds on average, and many individuals dropped out of the study prematurely.

Morrison, et al, in England used CBT alone without medications in a similar study in which they enrolled 60 individuals aged 16 to 36 who sought treatment using the PACE criteria. The CBT was problem-oriented, time-limited and educational. Two out of the 37 who received CBT (6 percent),

but six out of the 23 of those who did not receive CBT (26 percent) developed psychosis.

These studies are very encouraging. They indicate that the brief treatment of medication or psychotherapy can at least delay the onset of psychosis if not prevent the occurrence of schizophrenia. It is a well-known fact that early treatment can help avoid or minimize the known long-term disabilities associated with schizophrenia.

However, these studies do not answer some of the following questions. Is it possible for someone to stay on treatment, say, a low dose antipsychotic and avoid the psychosis for a long period of time – even the rest of the life? Will it become a more attractive option if we have safer medications in the future? Are we reversing or changing the underlying brain biological process with early treatment? Are there other safer medications that are considered to be neuroprotective (protecting the brain) that may help?

There is a long way to go before these are answered, but these recent developments are very encouraging and instill hope for at least the future generations for whom the cruel impact of this illness can be minimized and ideally prevented.

For more information, please call (800) 650-STEP (7837), or go to www.med.wayne.edu/psychiatry/step.