



The Power of the Family Movement: Catalyst for Change

In this issue:

| | |
|---|-------|
| <i>Guatemala Declaration</i> | 3 |
| <i>India-wide family organization sets objectives</i> | 4 |
| <i>Stigma</i> | 7 |
| <i>WFSAD establishes two awards</i> | 8-9 |
| <i>Medical Journals featuring gender issues</i> | 11-12 |
| <i>Outreach Africa—Kenya</i> | 13 |
| <i>WFSAD in India</i> | 16 |

Kyoto Conference Brings Together 2,800 Delegates

On a beautiful, warm sunny day in Kyoto, Japan, WFSAD and Zenkaren (The National Federation of Families with the Mentally Ill in Japan) convened their joint conference entitled: *The Power of the Family Movement: Catalyst for Change*. Two thousand eight hundred delegates registered at the impressive Kyoto Conference Hall. This was the Fifth Biennial Conference of WFSAD. Many of you will remember the Fourth Biennial Conference held in Jerusalem in 2000. At that time the majority of the overseas visi-



tors sponsored by WFSAD were from Europe and Africa. This time the majority were

from Asia and India. We were glad that we chose to
(Continued on page 2)

Latin American Families Meet to Discuss Common Goals

“Alianza Latina WFSAD” Formed in Guatemala

WFSAD recently invited twenty-one family leaders from ten Latin American emerging family organizations, to Guatemala City, to participate in the WFSAD symposium and workshops held in conjunction with the 22nd Latin American Congress of Psychiatry.

The topic for the symposium was the benefits of family self-help and advocacy. Speakers at the symposium, were Prof. Julian Leff, Dr.

Dale Johnson and Martha Piati-gorsky.

After the symposium, family delegates took part in several workshops. At the first, delegates described their organizations and their plans for development in their own countries. Then came self-help, support and coping workshops conducted by Prof. Leff. There was a wind-up workshop to discuss common goals for the future and to establish the group as an entity. They decided that

they will meet again to discuss the progress of the network and future plans. This meeting would take place at the Regional Congress of Psychiatry to be held in Caracas, Venezuela, in October 2003. This would be dependent on funding.

We are extremely grateful to the Pfizer Foundation for their interest in supporting and helping develop family self-

(Continued on page 2)



About Zenkaren

Zenkaren, the National Federation of Families with the Mentally Ill in Japan, and host organization for the Kyoto conference, was founded in 1965. It has over fifteen hundred affiliated local groups with a total of 120,000 members from all the 47 prefectures.

Zenkaren has a number of roles: 1) as a mutual support organization of families; 2) as a promoter of community based care programs; 3) as an advocate, and 4) as a centre for practical and strategic research on issues relating to social rehabilitation.

Among its current activities are a counseling, guidance and information service; support for sheltered workshops, 897 of which are managed by local family associations; stigma-fighting activities; education through its many publications, research to promote better mental health systems; and initiatives to promote a better quality of life for consumers.

If you read Japanese, you may find out more about Zenkaren by going to their website. A page in English will shortly be available on the WFSAD website.

WFSAD Kyoto Conference —Continued

(Continued from page 1)

book all overseas guests and paying delegates at a single hotel. This gave an intimate atmosphere and one in which delegates could discuss topics of interest.

There were seventy-five overseas visitors from twenty-two countries. The majority of delegates were family leaders in their own countries. Some 25 gave presentations.

Many of the overseas visitors, especially those from developing countries, where family associations are small, were amazed at the sheer size of the conference. "I am so inspired," said Helen Dabu, a family-group leader from the Philippines. "That families have achieved so much both in Japan and around the world is truly remarkable."

The seven delegates from different parts of India expressed pleasure at being able to share information with each other and with delegates from such a broad spectrum of family organizations for the mentally ill.

On the opening day Zenkaren Executive Director, Yosi-

mori Egami, welcomed us to Japan and Kyoto. During the Members' Assembly, selected delegates were able to give us a glimpse of the activities of family groups in Thailand, India, Japan and elsewhere.

With Tatiana Solokhina from Moscow interpreting for him, Erkin Toktosunov, Chairman of Awakenings, the family association in the Kyrgyz Republic, spoke of the progress of that group, which is now well established in Bishtek.

Remembering WFSAD's Second Biennial Conference in Rotterdam in 1996, Margaret Leggatt noted how much the membership has grown. "Back then," she said, "we were few enough so that every member or associate attending was able to speak for several minutes. Now it is more important to let new members be heard."

The Members' Assembly opened with a song from Sun Yuk Song a Korean gospel singer and consumer member of the Korean National Family Association.

Ken Udagawa, a consumer member of Zenkaren, then gave us a moving welcome

with a speech urging consumers to take their lives into their own hands. "Some people think it is a virtue of the Japanese to ask the doctor nothing," he said. Ken told us that he is able to work part time but that he must balance work with time for rest. "The hospitals, the families can make us weak," he said. "The sheltered workshops are also no help in empowering us." Ken urged consumers to empower themselves.

In the afternoon we heard from someone who demonstrates what Ken was looking for in other members of the consumer movement, self confidence and ability. This was Dr. Fred Frese, who gave the luncheon address to the Members Assembly.

Dr. Frese' message was full of hope and humour. He framed his talk with references to one of the largest psychiatric hospitals in the United States to which he had been committed in 1965. He described how he had come full circle to being the director of psychology of the exact same institution many years later, after first go-

(Continued on page 10)

Alianza Latina WFSAD—Continued

(Continued from page 1)

help and advocacy associations world-wide.

During the final meeting the group selected a name for itself: **Alianza Latina WFSAD**, or the WFSAD Latin Alliance. The Alliance raised some issues and set some goals to motivate members. These were developed and later endorsed by the Board of WFSAD as the Declaration of Guatemala. Mem-

bers were passionate about this. They felt that not enough was being done about the plight of the mentally ill in their countries.

The text of the declaration is reproduced in English at right. The original text is in Spanish and will soon be available on our website.

"I feel the meeting was very successful and opened up many possibilities for the fam-

ily leaders who attended," said Martha Piatigorsky, WFSAD Vice-President and Organising Secretary for the Guatemala meeting. "We gave strength to each other. Delegates had come with the intention of learning about the world family movement. Some had nothing like a family organization in their own countries. They were able to return home better informed, and it was hardly any

(Continued on page 3)



Martha Piatigorsky,
WFSAD Vice President
and Organizing Secretary
for the Guatemala meeting.



Guatemala Declaration

We, Latin American family members of patients with schizophrenia and other mental disorders, who met in Guatemala at a symposium convened by the World Fellowship for Schizophrenia and Allied Disorders (WFSAD) from July 10 to 13, 2002, affirm the following:

Considering that stigma, discrimination, suffering and misinformation are common factors for all family members of the mentally ill in Latin America, we assume the following commitment:

1. We will look for the best care for our family member in matters of mental health.
2. We will look for psychiatric care, which is given according to the pertinent ethics and norms of mental health professionals, with access to the latest generation medicines.
3. We will call on the governments of Latin America to take responsibility for developing coordinated actions with different public and private sectors with the aim of protecting the rights of people who suffer this type of mental disorders.
4. We will call on the governments of Latin America to recognize the right of these patients to have access to the latest generation medications that offer a the possibility of reinsertion in social and community life. We urge these governments to consider the cost/benefit ratio of investments in medications in their budgets. In their mental health policies governments should conduct pertinent actions to reduce the costs of pharmacological treatments.
5. We family members recognize that the participation of the family as caregiver is essential for a positive course of the disease.
6. We commit ourselves, as family members, to foster courses, conferences, and talks with professionals so we may learn about the symptoms, management and treatment of mental disorders.
7. We will advocate strongly for the rights of our sick family member to be respected, as to his/her dignity as a person including civic, political, social and cultural rights.
8. We will encourage recovery within our own family. Acceptance and positive affection are the indispensable elements for their recovery.
9. We take as legal framework for our Guatemala Declaration the Principles adopted by the General Assembly of ACNUR in Resolution 46/119 of December 17, 1991.
10. We propose that family members of mentally ill people should continue to organize meetings in order to ensure and foster these agreements. Prepared July 13th 2002 in Guatemala and later signed by representatives of Alianza Latina and endorsed by the President and Board of Directors of WFSAD.

Members of Alianza Latina WFSAD

| |
|----------------------------------|
| APEF Argentina |
| Mood disorder group Argentina |
| Family group Chile |
| ACOFAPE Costa Rica |
| ASFAE El Salvador |
| AFAPE Mexico |
| AMAPE Mexico |
| ALAMO Peru |
| Ypsilon Surinam |
| CATESFAM Venezuela |

Alianza (Contd.)

(Continued from page 2)
time before we heard the news that a new group had already been formed in Costa Rica?.

Should you wish to make contact with the Alianza latina WFSAD, please contact Martha Piatigorsky at aproa@ciudad.com.ar or email WFSAD directly.



Family members taking a break between workshops: Margarita Saucedo Ortiz Mena de Gomez (Mexico), Teresa Gómez (México), Leopoldo Gurovich (Argentina), Magdalena De Jadur (Argentina), Dale Johnson (US and WFSAD President Elect), Elena Saban (Peru).

Thanks go to Gail Grossman of the Chilean group for translating the documentation for the Declaration and other materials.

NFMI will share information and provide educational opportunities on the nature of mental illness

National Federation for the Mentally Ill (India)

The First All India General Meeting of the Ad Hoc Management Committee of the National Federation for the Mentally Ill (India) and its supporters met in New Delhi in October 2001 to push forward the initiative begun at the First National Caregivers Conference in Chennai (formerly Madras), India, the previous May under WFSAD sponsorship.

A slate of executive officers was elected and work began on further drafts of the bylaws confirming the name of the organization, membership criteria, membership fees as well as future aims and objectives. Below we list the aims and objectives of NFMI as set out in a recent issue of the Aasha Newsletter (Vol. IV issue 2).

NFMI

- is a national level Network of Family Organisations and Institutions of Professionals rendering service to the Mentally Disabled and their Caregivers.
- is formed by bringing together grass root self-help

advocacy organisations of persons suffering from psychiatric disorder and their families as well. This also includes organizations serving the cause of the mentally ill.

- will focus and coordinate efforts to help mentally ill persons and their families, through **personal contacts, support meetings** and linking new families with experienced ones.
- will share information and provide **educational opportunities on the nature of Mental Illness, coping strategies, reading materials and enlightening the systems of care that are available.**
- will work in cooperation and coordination with other groups **dedicated to work for the cause of the mentally ill.**
- will strive hard to eradicate the **stigma attached to mental illness** and shall create awareness

among the public on such matters.

- will do the needful for exchange of information and experience in the field of **Mental Health, Treatment and Rehabilitation.**
- will conduct Seminars, Dialogues and Workshops **on subjects pertaining to Mental Health.**
- will do everything possible to move the Central and State Governments for their involvement in solving genuine problems encountered by the **Families of mentally disabled and the Disabled themselves** and will fight for implementation of the provisions under the Disability Act of 1995 ensuring **Protection of Rights** and other benefits on par with other disabilities.
- will give all guidance and support to Caregivers of the Mentally Disabled to start Self Help Family Support Groups.

I put on goggles and headphones for a virtual reality Simulation.

If you have ever had the opportunity to go to Disneyland you will know that theme parks such as this thrive on simulating experiences, whether it be traveling in a space ship or journeying through the jungle. The idea is to “get you into the skin” of the experience.

Recently Janssen Pharmaceutica and Eli Lilly have both attempted to allow people who have no experience of schizo-

phrenia to get an idea of what it is like through multimedia simulations.

For the Janssen experience I put on goggles and headphones for a virtual reality simulation. You could choose whether you would experience a doctor’s office, a trip on a city bus, or a visit to the pharmacist. I chose the visit to the doctor. As I turned my head it appeared as though I were looking around the doctor’s

office and hearing and seeing what was going on there in the distorted way a person with schizophrenia might perceive things. Everything was exaggerated and changed.

In the Eli Lilly experience you are introduced to a person with schizophrenia, Daniel, on video-tape, and follow his life as he is diagnosed but progressing

(Continued on page 14)

Another Beautiful Mind

*A recent issue of the Globe and Mail national newspaper (Canada) section on Books excerpted a section from **Beyond Crazy: Journeys Through Mental Illness**, by Julia Nunes and Scott Simmie, published by McClelland & Stewart. It featured a photograph of Margo Kidder (the film actress who suffers from mental illness herself) and part of the book in which her words are quoted.*

...She's also very gracious, agreeing to a total of three lengthy interviews. And of course, part of what everyone wants to know is a little more about what happened during that big, nasty, flip-out. "It changed my life," she says simply. For the better.

This most public of manias occurred following a highly creative and productive period of memoir-writing. A computer virus began gnawing its way through her hard drive, devouring tens of thousands of words she'd poured her very soul into. In a panic, she took her computer (with more files vanishing every time she

checked) to data recovery specialists. They told her she was out of luck.

The stress of losing all that work triggered a delusion that the virus had been deliberately planted because some very powerful people wanted the book destroyed. Before long, Kidder was convinced she was being followed — and that the lives of her sister and daughter were in jeopardy.

"I was literally all over Los Angeles for quite a few days," she recalls, "screaming at people, 'Get off my back! All these CIA agents for one middle-aged woman? How dare you, blah blah blah.' I was out there screaming, 'Just shoot me. Just get it over with. Blow me up, but don't prolong this.'"

Only those who've experienced a similar delusion could possibly relate to the feeling, but the fear was agonizing. Agents in unmarked cars lurked at every corner, relaying her whereabouts. Even bank machines had been rigged to explode if Kidder's card and pin number were en-

tered. Her only option was to try, with every ounce of strength and cunning and adrenalin she had, to abandon her identity and fell this omnipresent danger...

Later in the chapter Miss Kidder says:

"And it began to be clear to me that half of the horror of it was keeping the secret, and that half the horror of it was that none of us in society would admit that this was a very common thing, that almost every family has been through some sort of episode of somebody in the family falling apart."

... "Next time you pass someone who's homeless and crazy, give them two bucks. Don't walk on the other side of the street. They're not a bad person. They deserve respect. The lady on the street corner yelling at the phantoms deserves our respect. Because she's made it though a lot of s—t and she's still standing."...

Only those who've experienced a similar delusion could possibly relate to the feeling, but the fear was agonizing.

SANE Mental Health Report

SANE Australia has recently issued its Mental Health Report for 2002-03. The report is based on almost 200 interviews, analysis of 6,000 calls to the SANE Helpline and data supplied by the World Health Organization, Commonwealth and State governments, and Access Economics.

It is in two parts. The first examines how well the government mental health strategy has performed against the four fundamentals of the SANE Charter: access to effective

treatments; support in the community; help for family and other carers; and action to end stigma. The second part examines each state and territory individually, noting good news, bad news and specific recommendations for action.

The main findings of the report are:

- Mental health services are in disarray around the country, operating in crisis mode and with numerous official inquiries under way.

- Proven effective treatments for mental illness are not routinely available under Medicare.
- The cost of schizophrenia alone will spiral to \$10 billion a year this decade unless services are improved.
- The current mental health plan is faltering. There is an urgent need for continued action to maintain the impetus of the National Mental Health Strategy.

The report is available from www.sane.org.

Untreated mental illness is a leading contributor to Australia's suicide rate.

I felt that if I covered my eyes, no one would be able to read my thoughts.

If I need to take these medications until the day I die, I will.

Woman Defies her Demons to Excel

Excerpt from the Sacramento Bee, February 1, 2002 by Cynthia Hubert, Bee Staff Writer.

Sylvia Carleton's fifth attempt to kill herself, this time by swallowing a potpourri of pills designed to control the terrifying shadows and whispers bombarding her brain, very nearly succeeded.

A couple of days later, just before she emerged from a coma in a hospital in New Mexico, Carleton saw a blinding light, and she heard a voice very different from those of her inner demons. "It told me that I could not leave this world, that I had work to do", she said. Against the longest of odds, Carleton has prevailed.

Born to a woman suffering from paranoid schizophrenia, diagnosed with schizophrenia herself when she was a teenager, Carleton has emerged whole. Though she probably never will be cured, Carleton has beaten back her symptoms, earned a Master's degree in family therapy, and now serves others with serious mental illnesses and related problems in her job as clinical director of Turning Point's homeless intervention program in Sacramento.

Carleton, 47, may never win a Nobel Prize like John Nash, the mathematical genius and subject of the acclaimed book and movie *A Beautiful Mind*. But, like Nash, she is proof that a diagnosis of schizophrenia does not necessarily translate into hopelessness.

Carleton's first memories of her mental illness go back more than three decades, to

when she was a teenager. "I believed I had a ticker tape going in one ear and coming out the other, with all of my thoughts written on it," she recalled. "I felt that if I covered my eyes, no one would be able to read my thoughts." She kept her bizarre feelings to herself. "We never noticed anything was wrong," said her adoptive mother, Marie Carleton of Albuquerque. "She was always my 'joy child'. She was always smiling, from the moment she woke up in the morning."

But as she grew older, Sylvia Carleton's life became chaotic. She married at 17, then divorced within nine months. She lived on a beach for awhile and took hallucinogenic drugs. She suffered a major psychotic "break" and ended up in hospital.

Doctors diagnosed Carleton with schizophrenia and prescribed two medications, lithium and haloperidol. The drugs were intolerable, she said. They stiffened her joints and fogged her mind. Her tongue felt three times its size. As soon as she got out of the hospital she stopped taking them, and her paranoia and delusions and rages returned. It was a cycle that would repeat itself many times in the coming years.

Today she is in charge of a program at Turning Point that seeks to help mentally ill people find housing, jobs and medical treatment. "People with psychiatric disabilities do not often have role models," said John Buck, Turning Point's Chief Executive Officer. "They feel they are alone. Sylvia is very understanding of folks who are having a tough time, and she's unflappa-

ble." Carleton sees something of her past self in many of her clients, she said.

"The truth is that everything that has happened to me in my life led me here, to the job I am doing now. But this doesn't feel like work to me. In a way it is heartbreaking and humbling, because I know that many of these people could get better if they allowed themselves. Accepting the illness and accepting medication is the key."

Not everyone who takes the new medications will make as much progress as Carleton. Perhaps 5 percent of patients with similar histories might be able to match her achievements, estimated John Luo, an assistant professor of clinical psychiatry at UC Davis. "But many of them can have a decent quality of life now, and clearly the new medications have a lot to do with that."

But Sylvia Carleton has no illusions about her illness. She knows it will probably be with her forever. She still sees a psychiatrist and has occasional setbacks, including anxiety attacks. She is uncomfortable in crowds. She is tempted, at times, to stop taking her drugs, which among other things cause her left leg to shudder and shake. "But overall, my life is very even," she concluded. "I am living well, and I'm helping other people. If I need to take these medications until the day I die, I will. I figure that things are only going to get better and better."

Source: Treatment Advocacy Center E-News

Stigma

Sony Play Station characters explicitly labelled as mentally ill

Thanks to a Stigma Watch campaign by SANE Australia, Sony agrees to withdraw offensive Play-Station game, Twisted Metal: Black.

The game included characters that were explicitly labelled as mentally ill in promotional materials, exhibiting bizarre features and violent tendencies. SANE contacted Sony, and an intensive media campaign was

launched, with support from organizations such as NAMI in the U.S. and the National Schizophrenia Fellowship (now renamed *RETHINK* Mental Illness) in England.

As a result of the discussions between SANE and Sony Computer Entertainment CEO, Michael Ephraim, the company promptly withdrew all promotional material from

their website and postponed the launch of the game until all content is reviewed in consultation with SANE.

"We commend Sony for their responsible decision," says Barbara Hocking, Executive Director of SANE Australia. "Fighting stigma is one of the core principles of the SANE Charter, and this case demonstrates the Charter in



Surgeon General's Report on Mental Illness Revisited

In 1999, the Surgeon General of the United States published a report on mental illness. It is still available on the web. It is highly interesting reading. This short quote from the conclusion of chapter eight draws attention to one of the major problems that the schizophrenia movement faces: stigma.

Stigma must be overcome. Research that will continue to yield increasingly effective treatments for mental disorders promises to be an effective antidote. When people understand that mental disorders are

not the result of moral failings or limited will power, but are legitimate illnesses that are responsive to specific treatments, much of the negative stereotyping may dissipate. Still, fresh approaches to disseminate research information and, thus, to counter stigma need to be developed and evaluated. Social science research has much to contribute to the development and evaluation of anti-stigma programs (Corrigan & Penn, 1999). As stigma abates, a transformation in public atti-

tudes should occur. People should become eager to seek care. They should become more willing to absorb its cost. And, most importantly, they should become far more receptive to the messages that are the subtext of this report: mental health and mental illness are part of the mainstream of health, and they are a concern for all people.

<http://www.surgeongeneral.gov/library/mentalhealth/>

Quote:

I'm a teacher by profession and have taught at all levels, from infants through to tertiary. Most important, though, is the fact that somehow I've managed to bring up three lovely children alone because my husband divorced me after I became ill and in the context of a serious mental illness. They are my greatest achievement—they are all tertiary educated, have good jobs and busy social lives. They are what made me so determined to succeed and overcome the schizophrenia, because I loved them so much and wanted them to have as "normal a life as possible."

Marilyn Mitchell, speaking in the "Brain Bank" session of the Kyoto conference.

WFSAD Establishes Two Awards

Former WFSAD Presidents Honoured

The WFSAD Board of Directors has long felt it important that those who have demonstrated excellence in serving the international cause for mental illness should have an opportunity to be honoured. Thus we have established two awards.

The first is the Bill Jefferies Award for Achievement in Education. Bill Jefferies was

the founder of WFSAD and its first president.

The first recipient of this award is Margaret Leggatt, our immediate past president, primarily for her focus on psychoeducation during her presidency, but also for her long term work in educating families.

The second award is the Geraldine Marshall Award for Achievement in Outreach. It is

named after Geraldine Marshall, who was our second president. She established the WFSAD outreach program as a means to work with families in their own countries.

Geraldine herself is naturally the first recipient of this award. More about both these women on these pages.

Award Named after Geraldine Marshall

Geraldine Marshall was the second president of WFSAD. She took on her duties at a time when the initial establishment of the organization was at an end, and the way was clear to develop some new paths.

Geraldine was the first to develop a business plan for the organization, at the time simply described as the First Three-Year Plan. With our goals and objectives mapped out in terms of future activities, Geraldine set out to fulfil these dreams for a global family movement.

She began the Outreach and Mutual Exchange Program, which was to be the catalyst for WFSAD future initiatives. She saw the need to meet face to face with families, professionals, politicians and supporters in the field of mental health on their own territory and to plan with them for their own organizations. She

recognized that each and every group would have its own identity and way of doing things. By recognizing this, she established the unwritten WFSAD principle that information should be **exchanged**, not **provided**— a principle that has become a byword for WFSAD “empowerment” activities.

In the early days Geri traveled without any idea of whether she could be reimbursed for her travel or accommodation. She was utterly committed to improving the lives of families who were experiencing the difficulties of living with a person with schizophrenia. In the early nineties she made four visits to Russia and, as a result of meeting with key leaders in the field, helped establish the Russian family movement, which



today has developed into a national federation of family associations.

In 2001 she received the Meritorious Services Award from the Government of Canada in recognition of her years of work for schizophrenia.

We look forward to Geri continuing her association with WFSAD as an Honorary Member.

WFSAD Award Pins Commissioned from Young Goldsmith

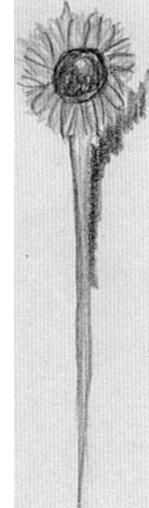
When the board gave the go ahead for two awards to be established in honour of two fine women, Margaret Leggatt and Geraldine Marshall, I was given the task having the awards designed.

It was difficult to know exactly how Marg and Geri would receive such awards. Should we have plaques designed to hang on their office wall; should we have desk ornaments, engraved paper weights or did we want something more personal?

We decided on a brooch. The Toronto Artisans Guild directed me to recently graduated goldsmiths and silversmiths, among whom Haly Mazur appeared the most original.

Haly came up with a novel idea. She designed a brooch in which the fastener was a separate pin. For Geri the head of the pin was designed like an iris and for Marg the pin was designed like a sunflower. These floral emblems have been adopted by the schizophrenia movement.

DF



Designs for the awards presented to Marshall and Leggatt

Margaret Leggatt Receives Education Award

Margaret Leggatt is the first recipient of the Bill Jefferies Award for Achievement in Education. The award is named after WFSAD's founder, who, like Margaret, founded first a regional and then a national schizophrenia organization. She has served on the board of WFSAD for twenty years, from 1982 (the very beginning) to 2002, always taking an active part in the development of the organization and its programs.

She has worked tirelessly for the cause of the families of people with schizophrenia all her adult life. As an occupational therapy graduate working in a Melbourne psychiatric hospital, she saw how little was being done for families and immediately set to work to study this topic for her PhD thesis at Monash University.

She founded the Victoria Schizophrenia Fellowship and went on to link the other Aus-



tralian state fellowships by founding Schizophrenia Australia which subsequently became **SANE** — one of the leading Australian health charities.

She was elected president of WFSAD in 1996 and served two terms during which she spearheaded our strategy to make families an integral part of comprehensive care: Families as Partners in Care.

During and after her presidency she has travelled on

visits to strengthen families through empowerment in many lands, working on the continent of Africa and in Asia and India.

Margaret is a highly respected faculty member of Monash University with which she has been associated for many years. She is currently working more than ever on early intervention initiatives, which attempt to get people with mental illness into treatment earlier, thus giving them the potential for a better recovery.

While we say goodbye to Margaret as a board member, she continues as Past President. It is our sincere wish that she maintains strong ties with WFSAD so that we may continue to benefit from her expertise and enthusiasm.

WFSAD Kyoto Conference — Continued

We offer our sincere thanks to our invited speakers who agreed to speak without benefit of a fee. It is this kind of generosity that enables charitable organizations such as WFSAD and Zenkaren to continue to offer high caliber up to date information to their members.

WFSAD and Zenkaren sincerely thank conference sponsors for their generous support.

Janssen-Cilag

Janssen Pharmaceutica
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Jeff Skoll Community
Fund

Otsuka Pharmaceutical
Co., Ltd.

Novartis Pharma K.K.

Nona ad Bill Heaslip
New Place Foundation

(Continued from page 2)

ing back to school and earning three degrees and a masters in psychology.

“In the back ward of this psychiatric ward I never had any hope of what was to come through the work of the families,” he said. He drew attention to the past year which saw the showing of the movie *A Beautiful Mind* and the making of a TV feature *A Brilliant Madness*, both of which celebrated the life of John Nash, the Nobel Prize winner (1994) for Economics. In addition, he said, the McArthur Genius Awards went to Kay Redfield Jamieson, the author of *An Unquiet Mind*, which celebrates Jamieson’s recovery from manic depressive disorder.

“We have a condition that only a few years ago we would never have acknowledged,” Fred continued. This had been brought about by organizations like NAMI, “and people like you who are listening to me now.”

10th October started with words of welcome from the City and Prefecture of Kyoto and the Japanese Ministry of Welfare & Labour. Dr. Radha

Shankar, a member of WFSAD’s Board of Directors and a long-time activist for the mentally ill and families in India, then delivered the Keynote address for the conference. She offered a comprehensive and inspiring review of the family movement around the world.

In the afternoon, concurrent workshops offered diverse topics both of local and international interest. Speaking on Human Rights, Mr. Ira Burnim, from Mental Disability Rights International based in New York, told of the achievements of MDRI in Mexico and elsewhere. He showed a compelling video.

Professor Chris Amenson from UCLA, spoke on the diversity of what is required for family education in different cultures. His colleague, Yoshihiro Matsushima, enlarged on the topic in Japanese.

Other workshops covered Brain Bank, Family Empowerment, Medication, and Family Psychoeducation issues.

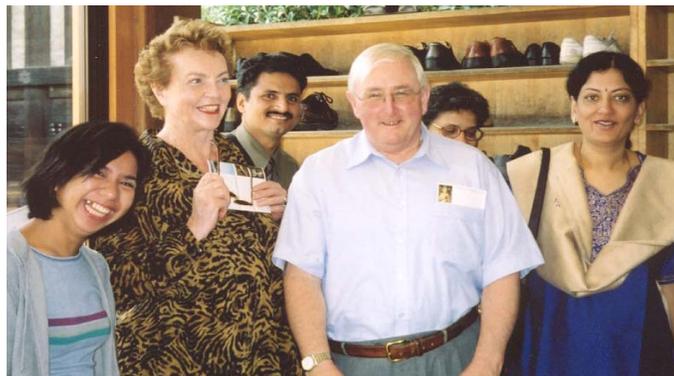
During the morning of October 11 there were two concurrent sessions. Dr. Frese and his wife Dr. Penny Frese gave a joint session delineating what

it is like to experience schizophrenia both from the consumer’s perspective and the family’s perspective. Syunsuke Turumi, a Harvard-educated philosopher and one of the most influential thinkers in Japan, spoke about his academic journey as a person with mental illness.

The two major symposia held that afternoon dealt with progress of the global family movement and the problem of stigma. At the latter, SANE’s Director, Barbara Hocking, laid out a clearly defined approach to stigma. We also heard from two consumers, Prof. Seok Hee Yun, who told her personal story, and Prof. Anil Vartak, who spoke of a holistic approach to removing the causes of stigma.

Professor. Sean Flynn, Co-Director of Research at Riverview Hospital, University of British Columbia, Canada, gave the inaugural presentation of the **Bill Jefferies Memorial Lecture**, which was this year entitled: *Recovery—Current Ideas in Clinical Practice*. Dr. Flynn gave an interactive session, asking his audience to choose from a list of topics those that were of most interest to them. The presentation that followed covered ideas on how to persuade your relative to take medications, working with the clinical team to improve care and current research on neural pathways and cell anatomy. This last topic is one of Dr. Flynn’s own research projects.

On the 12th we visited a family group-operated, sheltered workshop, as well as two historic temples in Kyoto.



Helen Dabu, Philippines, Geri Marshall, Canada, Namdev Gawas, Goa, India, Jim Crowe, New Zealand, Amita Dhanda, India, and Radha Shankar, India, outside the Sanjusangendo Temple in Kyoto.

Note:

The conference will be reported in detail in future issues of the newsletter. We anticipate preparing a conference summary for the second quarter newsletter of 2003.

Medical Journals

Predictors of Risk

Predictors of Risk of Nonadherence in Outpatients with Schizophrenia and Other Psychotic Disorders by Kim A. Weiss, T.E. Smith, J.W. Hull et al. *Schizophrenia Bulletin* 23 (2):341-349, 2002.

We quote from the Discussion section of this article:

“While a good working alliance between therapists and psychotic patients may be challenging to develop, this study suggests that developing an appreciative, trusting bond and agreement regarding what the patient’s problems are and how they should be worked on is a crucial component of outcome. Further investi-

gation is required to explore how such an alliance can be facilitated.”

“Being prescribed clozapine significantly lengthened the amount of time patients maintained medication adherence. It has been hypothesized that clozapine increases adherence because its effectiveness in reducing symptoms and improving cognition leads to increased insight into and appreciation of the necessity of medication (Marder 1998). According to the Health Belief Model (Rosenstock 1974), it is also probable that the medication’s lack of extrapyramidal side effects combined with its effec-

tiveness facilitates adherence by lowering the perceived risk-benefit ratio (Rosenheck et al. 1997). As alternative explanation is that rather than the physiological effects of the drug, it is the close monitoring that clozapine patients require that encourages adherence. The frequent clinical contact that coincides with obligatory frequent blood work may also contribute to increased adherence. Frequent visits may facilitate adherence by strengthening working alliance, but it should be noted that this study found an effect of clozapine independent of level of relationship with therapists.”

Brief notes:

A Practice Guideline for the Treatment of Patients with Bipolar Disorder was issued as a supplement to the 8/2002 issue of the *American Journal of Psychiatry*.



Novartis AG has said that the psychopharmacologic drugs advisory committee to the US Food and Drug Administration recommended that the company’s Clozaril treatment be approved for the treatment of suicidal behaviour in patients with schizophrenia or schizoaffective disorder.

Source:

www.novartis.com

Study Shows Olanzapine Linked to Diabetes

Assessment of independent effect of olanzapine and risperidone on risk of diabetes among patients with schizophrenia: population based nested case-control study by Carol E. Koro, Donald O. Fedder et al.

The study was conducted in the United Kingdom from a General Practice Research Database comprising 3.5 million patients followed between 1987 and 2000. 19,637 patients who had been diagnosed as having and treated for schizophrenia. 451 incident cases of diabetes were matched with 2696 controls.

From the discussion:

After adjustment for personal risk factors and concomitant drug use, patients taking conventional or newer antipsychotics for schizophrenia have an increased risk of diabetes. The risk was significantly increased with the newer antipsychotic olanzapine but not with the other newer antipsychotic, risperidone. Our study is the first to show these associations in a large cohort of patients with schizophrenia.

Several mechanisms are proposed for the observed association between diabetes and antipsychotic use, including weight gain and disruption of glucose metabolism. A meta-analysis showed a mean increase in

weight of 4.15 kg for patients taking olanzapine and 2.10 kg for those taking risperidone. Type 2 diabetes seems to be strongly and consistently associated with obesity and weight gain. Antagonism of histamine is also known to cause weight gain. It is possible that serotonin antagonism plays a part in the weight gain associated with the newer drugs. Weight gain can also be due to increased leptin secretion, which in turn leads to a disturbance of insulin secretion and diabetes mellitus. Lastly, dopamine has been shown to stimulate insulin secretion by a beta adrenergic mediated mechanism.

BMJ Vol. 325 3 August 2002

Quote:

Eventually, I had to face the reality that there was mental illness in my family, it was not going away and I was going to have to deal with it. That was the beginning of my recovery.

Dr. Penny Frese, speaking on “The Experience of Mental Illness” at the WFSAD Fifth Biennial Conference in Kyoto.

Medical Journals — Continued: Gender issues

Single Sex Psychiatric Services to Protect Women

Literature . . . supports same-sex facilities as options for women who feel unsafe in mixed-sex facilities.

An article by Mary V. Seeman, MD, DSc., under the above title, appears on the Medscape Women's Health eJournal [7(4), 2002 © 2002 Medscape To read the whole article go to <http://www.medscape.com/viewarticle/440095> We reproduce the abstract and introduction.

Background: Most psychiatric services (eg, inpatient units, day therapy centers, outpatient clinics, and community clinics) are not currently segregated by sex, but recent developments, such as increasing psychiatric acuity and increasing numbers

of comorbidities, have raised the level of violence and perceived threat in psychiatric facilities and have made a proportion of the more vulnerable patients feel unsafe.

Aim: The purpose of this review is to examine the concept of vulnerability as it applies to female psychiatric patients and to review the literature on the determinants of violence in psychiatric facilities and on preferences among psychiatric patients with respect to same-sex vs mixed-sex psychiatric services.

Results: Literature from Great Britain and from disability organizations supports same-sex facilities as options for women who feel unsafe in mixed-sex facilities. Outcomes with respect to violent incidents have not been evaluated.

Conclusions: Same-sex psychiatric facilities need to be implemented in a variety of communities and careful research conducted to examine potential benefits in specific populations.

What's Gender Got to Do with It?

The Experience of Schizophrenia: What's Gender Got To Do With It? *A Critical Review of the Current Status of Research on Schizophrenia by Elizabeth H. Nasser, Natalie Walders and Janis H. Jenkins.*

An interesting and thought provoking article under the above title appears in the Schizophrenia Bulletin, 28 (2):351-362, 2002. The section "Why Culture?" ends with the following paragraph:

"Unfortunately, the role of gender as a culturally informed construct has received minimal attention in the literature examining the diagnosis, management, and outcome of schizophrenia. Whereas biologically based sex differences have received attention with the literature, the sociocultural influences of gender on schizophrenia have been comparatively neglected."

We found very interesting a sub-section under "Why Gen-

der?". Family members were reported as having different outcome expectations for men as for women. According to various studies it is apparent that we need to better understand how we behave towards each gender. Expectations vary as to work and social behaviour. Demands are higher on males, a sign that families have failed to adjust their expectations, whereas they are more realistic with their female relatives. In addition independence is more highly valued for males whereas dependency on family is more gender/sex role appropriate for women. Information from a study by Haas et al. 1990 revealed that:

"family involvement in treatment was associated with improved symptomatology and global functioning for females, but males who had family-involved psychosocial treatment appeared worse off. Positive outcome for females

was related to a decrease in rejecting behaviors by family." However, families of females reported feeling a greater sense of burden than families of males. Another interesting point made was that families of males cancelled sessions more frequently than families of females. Thus, while family involvement resulted in a positive outcome for females, families experienced this involvement as a burden.

Finally under "Directions for Future Research" the authors issue a warning: "Too often in research, the *disease* becomes the focal point and the *experience* of the individual with the disease is ignored. Strauss (1989) highlights the importance of incorporating a focus on the interaction between the person and the disorder over time. A purely biological focus on research in schizophrenia may be particularly prone to neglect the "person" in "persons with

Demands are higher on males, a sign that families have failed to adjust their expectations.

Treatment Incorporates Psychosocial Rehabilitation

The University of Medicine and Dentistry of New Jersey (UMDNJ) recently launched a new program for people suffering from mental illness.

UMDNJ's University Behavioral HealthCare (UBHC) will implement and manage "Partners for Excellence in Psychiatry," a pilot program that combines psychosocial and diagnostic treatment approaches to help patients with

mental illness gain control of their lives.

The initiative, fully funded by Eli Lilly and Company, will train mental health professionals from more than 60 mostly community-based organizations from all parts of the U.S. over the next 12 months, at no cost to the agencies.

A toll-free number and a website are available to provide infor-

mation to groups who may be interested in participating in the Partners for Excellence Program. Interested groups are encouraged to call 888-888-8221 and/or visit www.partners4excellence.org.

Ed. Note: We hope that the research findings that WFSAD has been promoting on this subject will be used as a basis for the program described above.

Outreach Africa

A visit to three countries in Africa, under the WFSAD program Strengthening Families through Empowerment, was conducted in March of 2001 by Marg Leggatt (past president) and Jim Crowe (president). Later, we will bring you news from Uganda and the Republic of South Africa, but we start first with a brief glimpse of the visit to Kenya. We hope to have a fuller report on our website within the next few weeks.

The Schizophrenia Foundation of Kenya (SFK) conducted a two-day Family Education Workshop in Nairobi in March of 2001. Jim Crowe, WFSAD president and Margaret Leggatt, WFSAD past president, were two keynote speakers along with others involved with mental health services in this country. The conference theme was: 'Compassionate Mental Health Care - A Challenge for All.' The goal of the meeting was to strengthen the Family Education Program that provides awareness and promotes family participation. Sixty-four participants (from all over Kenya) attended the

workshop. Enormous progress has been made since Geraldine Marshall's intensive visit to Nairobi in 1998. This has been achieved through the hard work, leadership and perseverance of Lilian Kanaiya.

The support of the World Health Organization was also appreciated. SFK was pleased that so many government Health Department personnel attended.

Marg and Jim were also able to make a visit to the Nyahururu branch in the north, where they were well received by families and mental health professionals alike. It was exciting to see the enthusiastic participation of families and consumers – obviously an 'unusual' thing to be happening. Jim Crowe commented, "I believe a real turning point has been reached for working with patients and their families in this country."



Psychiatrist member of the Nyabururu branch of SFK thanks Marg Leggatt for her participation in the workshop.



SFK Patron Wairimu presents certificates to participants at the March 2002 workshop.

Calendar of Upcoming Meetings

The WFSAD Newsletter is the quarterly publication of the World Fellowship for Schizophrenia and Allied Disorders.

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**KILKENNY, IRELAND
November 29/30, 2002**

Schizophrenia Ireland 13th Biennial Conference:
Stigma—Break Down the Barriers
To register: Fax: 28.9038 1257
Web: www.happen.irl.com

**CHENNAI
(formerly MADRAS), INDIA
February, 2003**

Second National Conference of Caregivers of Major Mental Illness
Sponsored by WFSAD
Contact the Organizing Secretary, Dr. Radha Shankar:
radsha@md3.vsnl.net.in or
info@world-schizophrenia.org

**MELBOURNE,
AUSTRALIA
23-28 February 2003**
World Congress of the World

Federation for Mental Health

Contact: Megan McQueenie,
Mental Health Foundation of
Australia Tel: 6139427 0407
Fax: 61 3 9427 1294
Email: mentalh@mira.net

**STRATFORD-UPON
AVON, UNITED KING-
DOM 17-18 March 2003**
Meriden, the West Midlands
Family Programme (UK)
*Working with Families-
Giving People Their Lives
Back*

Contact: Conference Line,
5 Leopold Road, Wimbledon,
London SW19 7BB
Tel (020) 8944 5050
Fax (020) 8944 0866
Email:
families@conferenceline.co.uk

NEW YORK 3-5 August '03
World Association for Psycho-
social Rehabilitation: *A Better
Future for Those with Mental Illness:
Rehabilitation for Those Without
Access.* Co-sponsor: World Psy-
chiatric Association.
Contact: 212 426 7645
Email: office@wapr.net

CHENNAI, INDIA 2004
*Sixth Biennial Conference of
the World Fellowship for
Schizophrenia and Allied Dis-
orders*

To receive information as it be-
comes available, contact
WFSAD at 124 Merton Street,
Suite 507, Toronto, Ontario
M4S 2Z2, Canada or email us:
info@world-schizophrenia.org

Trying to Capture the Experience —continued

through passageways and activating various of the activities.

I found this experience more interesting and thought provoking than the “virtual delusions” in the Janssen simulation. One scene portrays the family at dinner. Daniel is hearing an entirely different conversation to the one in which the family is occupied. You are privy to this conversation (hearing voices) and quite understand when he blurts out a response to what he is hearing. This startles the family members who find no relation to what they are talking about in his outburst. They react in vari-

ous ways. The last “tableau” is of the doctor’s office where the participant gets “the pitch” for taking medication and in particular, the medication made by the pharmaceutical company. What I noticed was that the loving family present in the previous scene is nowhere to be seen in the discussion with the doctor, a fact I found a bit strange given their previous involvement and the need for the family’s support.

It was great to see the enormous amount of interest generated by both these simulations. People were queuing up on

many occasions when I passed by the exhibits. I commend the pharmaceutical companies on taking this initiative to help people understand mental illness, and in particular, schizophrenia, and to provoke interest where there might be none, but for the fact that a simulation draws people to participate.

You may get a chance to experience these simulations if you take part in a psychiatric or related conference and visit the exhibit hall. DF

Please note our new address:

World Fellowship for Schizophrenia and Allied Disorders
124 Merton Street, Suite 507,
Toronto, ON M4S 2Z2, Canada

Phone: 416 961-2855
Fax: 416 961-1948
E-mail: info@world-schizophrenia.org

JOIN ON LINE!

WWW.WORLD-SCHIZOPHRENIA.ORG

The WFSAD Newsletter is an international bulletin providing information to the world self-help movement for schizophrenia and allied disorders, which includes national and local organizations, individuals coping with the illness and friends and professionals.



Sunflower Petal Circle

Join our circle of donors by making a regular gift to WFSAD through your MasterCard or Visa. You may make quarterly donations of \$25, \$50 or an amount of your choice, or a one-time gift for the year. Write to the above address or email us: info@world-schizophrenia.org

Planned Giving

WFSAD invites you, its members and supporters, to remember us in your will, so that we may continue to advance the work to which we are all dedicated. You may stipulate the activity or program you wish to support or you may make an unrestricted gift. Here is suggested wording for an unrestricted bequest:

I give, devise and bequeath to WFSAD, located at 124 Merton Street, Toronto, On M4S 2Z2, Canada the sum of \$ _____ or _____% of (real or personal property herein described), to be used for the general purpose of the organization, at the discretion of its board of directors.

Join our Membership or Become a Donor

Annual dues for memberships are as follows:

- National family association
voting member: \$100USD (\$158Canadian)
- Regional/local family association
associate member: \$50 USD (\$79 Canadian)
- Individual (personal)
associate member: \$25 USD (\$39 Canadian)

Your membership includes a quarterly letter and regular mailings of current information throughout the year. The WFSAD Support Team is also ready to respond to your questions on any topic relating to mental illness.

Fill in your Payment Instructions below

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Postal Code: _ _ _ _ _

Telephone with codes: + _ _ _ _ _

Fax: _ _ _ _ _

Your email (please print clearly!):

Please fill in all of the above to ensure that we are able to reach you.

WFSAD in India

Meetings planned for 2003 and 2004

Second National Conference of Caregivers of Major Mental Illness Chennai (formerly Madras), February 2003

The Second National Carers' Conference, to be held in February, 2003, will be hosted by AASHA (Mr. K.K. Srinivasan, Chairman). The meeting will bring together family leaders from many parts of India to consolidate the progress made at the First Conference of Caregivers in May 2001 and build on further work done in

New Delhi at the First All India General Meeting. The aims of these meetings are to establish a National Federation for the Mentally Ill, the seeds of which have been sown.

At the meeting in New Delhi, an ad hoc executive committee was struck under the presidency of S.D. Raheja of Rashmi, Delhi, and the vice

presidency of Mukulchand Goswamy of Ashadeep, Guwahatti. (See article P.4.)

Family leaders and their supporters from India and neighbouring countries are welcome to register. Contact the Organizing Secretary: Dr. Radha Shankar at

radsha@mdl3.vsnl.net.in or
info@world-schizophrenia.org



Radha Shankar from Chennai



Mukul Goswami from Ashadeep, Guwahati



Anil Vartak from the Schizophrenia Awareness Association, Pune, Maharashtra, India



Namdev Gawas from family support group "Adbar", Goa, India.

WFSAD Sixth Biennial Conference: Join Hands and Minds Chennai (formerly Madras), November 2004

**Register your interest
now!**

Contact WFSAD

**Put your name on the
mailing list for
conference information.**

Don't delay!

**Start planning your trip
today!**

At the Closing Ceremonies of the recent WFSAD 5th Biennial Conference, *The Power of the Family Movement: Catalyst for Change*, a group of delegates, led by Dr. Radha Shankar, announced the location of the WFSAD 6th Biennial Conference to be hosted by Aasha and the Ad Hoc Committee of the National Federation of the Mentally Ill (India). The conference will take place in Chennai (formerly Madras), in November, 2004.

As the representatives from the current host, Zenkaren, looked on, Jim Crowe, WFSAD president, passed the WFSAD banner from Japan to India. The banner was received by representatives of the Indian family movement, including Radha Shankar, Mukul Goswami, Amita Dhanda, Ishita Sanyal, Anil Vartak and Namdev Gawas.

The banner is a symbol of the world family movement's commitment to meet every two years to show-case family issues and to promote and advocate for the goals of family organizations around the world.

It's never too late to begin planning!