

World Fellowship for Schizophrenia and Allied Disorders
 First Quarter 2005

The Power of the Family Movement: Sharing the Knowledge

By Patricia Telesnicki

Chennai, India was the location of our 6th biennial conference, co-hosted by AASHA, the family organization in Chennai, which celebrated its 15th anniversary this past year. Over 350 delegates attended the conference, representing some 20 different countries.

Prior to the opening ceremonies, WFSAD held its inaugural Training College. The idea was to provide resources and knowledge for family members wishing to improve their skills related to the management and organization of family associations and for those wishing to begin support and advocacy groups for families and friends. To make the day effective, we had to limit the number of individuals who took

part in the college, although the interest surpassed our capabilities. The trainers and facilitators who were chosen to lead the workshops took up the task with great enthusiasm. They put together very comprehensive, interactive presentations that provided the attendees with practical solutions and ideas for their own family groups. Attendees have been asked to implement what they have learned and provide feedback on their experiences. We plan to follow-up with the

attendees in the near future and will share this information in an upcoming issue of the newsletter.

The conference proper began with a press conference that included members of the local media. Unfortunately, the governor of Tamil Nadu, the state in which Chennai is located, had resigned the day before and was therefore not available to officiate at our opening ceremonies as previously planned. This was a disappointment, but did not distract from the excitement and festivities

of the day. We were fortunate to have Dr. J. K. Trivedi,



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“Even though I was familiar with the phrase ‘the power of family movement’ the real meaning and the strength of [this phrase] I could understand and experience only at this conference”

Anil, SAA member

This newsletter is an international bulletin published by the World Fellowship for Schizophrenia and Allied Disorders (WFSAD). Our goal is to provide information to the world self-help movement for schizophrenia and allied disorders that includes national and local organizations, individuals coping with illness, and friends and professionals.

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THANK YOU LETTER



Dear Dr. Radha Shankar,

Here is thanking you and your dedicated and efficient team for organizing the international conference in a most fitting manner. You made us, Indians, proud by doing so well on such a challenging task.

You shrunk the world to the size of the venues of the sessions. It gave us all an enviable opportunity to interact with individuals from different parts of India and the world. In those three and half days what we could learn was more than we could have by going through numerous books for several months. Despite this, you stood charged with putting us in a dilemma because we couldn't simultaneously be present at the plenary and concurrent sessions! We realize your predicament, you had to give adequate representation to most of the participant organizations to share their knowledge and experience.

Walter Lippman had said, "When all think alike, no one is thinking". This spirit was evident at most of the sessions as neither the presenters nor the participants hesitated to express their points of views even if different. Thus, having different perspectives on any issue was itself a creative learning process. We weren't bored by overdose of consensus!

Besides being enriched with knowledge, what inspired us most was the individuals' patience, hope, innovation, healing attitudes, compassion, care and readiness for mutual support. The transition from "Why me?" to "I'm not alone" or to "Oh, I'm better off" was inevitable as a result of Chennai interaction.

The humane side of the 'busy and indifferent' professionals came to light at this conference. The views expressed in their presentations or by answers to questions or through their warm one-to-one interaction during tea or lunch breaks were a revelation to quite a few of us. Jim is well known for his saying that he is yet to come across a schizophrenic but he knows many persons with schizophrenia. Similarly, I would say that here I discovered fine persons with psychiatric expertise (not psychiatrists) ! God bless them.

Tankful of tears of gratitude at the closing ceremony summed up what the three-hundred odd participants felt about the entire event, so well organized by WFSAD & AASHA.

Visits to facilities of AASHA and THE BANYAN were no less touching and inspiring.

Who can ever forget the cool, breezy and very captivating & entertaining evening by the seashore, coupled with a royal dinner?

While thanking you for making this an unforgettable event I wish to share with you what some of SAA family members said after participation at the Chennai conference:

[SAA family member comments on page 8]

Kind regards and best wishes,

*Gurudatt
Schizophrenia Awareness Association
Pune, India*

December 26, 2004

WFSAD sincerely hopes that all of our members and their families and friends are safe after the December 26th events in Southeast Asia. To those members who have not been directly affected by this tragedy, we urge you to remember our friends at this time and offer what support you can to help them heal and rebuild their lives through any of the organizations involved.



NEW WFSAD BOARD

Since its inception, The World Fellowship for Schizophrenia and Allied Disorders (WFSAD) has been an organization made up of volunteers. We are fortunate to have the commitment of dedicated volunteer professionals who form the board of directors. WFSAD has a board of directors of no more than 15 members. Each member conducts field work in the area assigned to him/her making the board a very active, hands-on component of the organization.

John Gray, PhD

For many years, John has worked in mental health services and more recently in policy development for the Ministry of Health in British Columbia. He has written many papers on topics related to mental health; mental health legislation and the treatment of the mentally ill, as well as the book "Canadian Mental Health Law and Policy". He has served on the board of the British Columbia Schizophrenia Society and is currently President of the Schizophrenia Society of Canada.

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Treasurer: Stephen McCourt, CA

Stephen is currently a manager at Smith, Nixon & Co. LLP in Toronto.

President : Dale Johnson, PhD

A Professor of Psychology at University of Houston, Dale has written several books to assist families of the mentally ill to cope. In 1990, together with Prof. Harriet P. Lefley, he edited the book Families as Allies in Treatment of the Mentally Ill. He was an active member of the National Alliance for the Mentally Ill, Texas, for many years and is a former president of the NAMI national organization. Dale has a son with schizophrenia.

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Secretary: Diane Froggatt, BMus, BEd

Diane was Executive Director of WFSAD since 1987 and previously worked as an educator and in public relations. Diane has developed many of the WFSAD's educational materials. She has a 40-year-old son with schizophrenia.

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President Elect: Lic. Martha Piatigorsky

Founding president of the Argentine Organization for Families and Patients-APEF- and a licensed psychologist by profession, Martha recently served as the Organizing Secretary of Alianza Latina WFSAD. Alianza Latina WFSAD is a group of family members from 12 Latin American countries. She has a daughter with schizophrenia.

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**Vice President:
Radha Shankar, MB, BS**

An internationally known psychiatrist in India, Rhada has worked in executive positions in SCARF (Schizophrenia Research Foundation) and has represented WFMH (World Federation for Mental health) and WAPR (World Association for Psychosocial Rehabilitation) at the regional level. She continues to be part of the WFSAD Families as Partners in Care strategy committee, advocating for families in the developing world. She was Organizing Secretary of the First and Second National Carers' Conference in Chennai, India, held in 2001 and 2003 respectively, as well as the WFSAD 6th Biennial Conference held in Chennai this November.

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Susie Kim, RN, DNSc, FAAN

A Professor and former Dean of College of Nursing Science, Ewha Womans University, Seoul, Korea, and Director of Research Institute of Nursing Science and Chairperson of Psychiatric-Mental Health Nursing Division, Susie has published twelve books and over one hundred research articles in nursing. She has made invaluable contributions to the rehabilitation and welfare of mentally ill persons in Korea by pioneering a community-based mental health nursing care program in 1993. She is active in the Korean Family Association.

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Chairman, Asian Region: Jim Crowe

Currently Jim holds this position in conjunction with his role as WFSAD Past President and has worked diligently for the cause, most particularly in Asia and Australasia. He is the Past President of the Schizophrenia Fellowship of New Zealand and continues to serve on many mental health committees including being a board member of Royal Australian and New Zealand College Bi-National Professional and Community Relations Committee. He has been active in outreach to Asia for the past two years. He was awarded the 1990 Commemorative Medal by Her Majesty for services to people with mental illness and their families. The board voted to extend Jim's term on the board for a further two years, to enable him to develop WFSAD's Asian region.

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Thomas Walunguba, RN

Thomas began working as a registered psychiatric nursing officer in 1993 in Kampala, Uganda. That is when his interest in working with families of people with mental illness began. In 1997 he founded the Uganda Schizophrenia Fellowship (USF) and has been the National Chairman ever since. He assisted in the first Families as Partners in Care training session of family members and carers at the Butabika Hospital in 2002 and has been instrumental in developing the USF so that it now has several branches outside Kampala. He recently led a contingent from the USF to Kenya for a cross-border workshop held by WFSAD.

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COVER STORY

Chennai (continued from cover)

President of the Indian Psychiatric Society, step in to take his place. Dr. Trivedi noted that the role of the family in mental illness had changed significantly over the past 20 years. Rather than being seen as a cause of mental illness, the family was seen as an agent of change, creating a favourable environment for enabling faster recovery.

Dr. Sarada Menon, President of the Schizophrenia Research Foundation, India, and a conference patron, inaugurated the opening ceremonies by lighting a 'kuthuvilakku' (a ceremonial lamp common in South India). Dr. Menon said the family emerged as a central force. Successful treatment of mental illness was possible with family support and professional help.

Dr. Radha Shankar explained the aims of the conference - service providers and seekers would come together for collaboration and cooperation. She noted that over half the presentations would be made by families and patients who recovered. The focus was on finding solutions through collective action and not on problems.

The following day, in the Hindu newspaper, there appeared a large, colour picture of the dignitaries present at the opening ceremonies, with a headline stating 'Family, key unit in treating the mentally ill'.

We were fortunate to have Dr. Norman Sartorius deliver the keynote speech 'Social Capital and the Family Movement'. He emphasized the important role of extended family in the care of those with psychiatric illnesses. Following this, delegates were treated to two days of workshops and plenaries covering everything from stigma, family education, family and consumer support, vocational interventions, legislation and advocacy, rehabilitation and after care and groups with special needs.

At the end of the second day of the conference, we were treated to a lovely dinner at the seaside resort in Muttukadu. On arrival everyone received a fresh coconut and was encouraged to enjoy the milk from it. Dancers entertained the delegates under the starry skies before we enjoyed a sumptuous Indian buffet. The fresh sea air, good food and lively conversations put a smile on all the faces of the delegates and a wonderful evening was had by all.

Our final lecture was the Bill Jefferies Memorial Lecture. Some of you may remember this from our conference in Kyoto, where we first decided to honour the founding President of WFSAD with a lecture in his name. An absolutely wonderful lecture was given by Dr. Pratap Tharayan of the Christian Medical College in Vellore, India. In keeping with the theme of the Bill Jefferies

Memorial Lecture, Dr. Tharayan explained the latest advances in research and medications in mental illness. His lecture was informative, yet easily understood and he so graciously stayed after to answer the many questions our delegates had for this outstanding psychiatrist.

Following the closing ceremonies the delegates boarded buses to be transported to one of three mental health facility site visits. I had the opportunity to visit the residence and shop of AASHA. Peter Woodhams (UK), Marie Crofts (UK) and myself were given an in depth tour from one of the gentleman who lives at AASHA.

He told us with pride about his job and how fortunate he felt to live at AASHA. It was easy to see that this organization has done tremendous work and is having very positive results. We stopped by the store on our way back to the bus and everyone was eager to purchase something from the AASHA shop, run by the residents. We featured a picture of this in a recent issue of the newsletter, but it was quite something to see it for myself.

I also had the great privilege to visit the Banyan. I know many of those who attended the conference also visited this site and



Lilian Kanaiya (left) and Gladys Okoth (right) from the Schizophrenia Foundation of Kenya enjoy a cup of tea between sessions.

anyone who has been there will tell you that a visit to the Banyan is a spiritual experience. The two women who started this home for mentally ill, homeless women had a vision and the love, caring, understanding and determination to succeed. With very little resources they have built quite an impressive home, already busting at the seams, but they somehow manage. Most of these women were destitute, living on the streets, alone and afraid but now have a safe home where the love, caring and warmth emanates from every corner of the building. As I said, it was a

privilege to visit the Banyan and I will never forget the women I met there. It touched me deeply. For more information about the Banyan there is a website www.thebanyan.org.

There is also a very good book called *Out of Mind Out of Sight - The Banyan Story* told by Kendra. You can find more information about this book at their website.

As I said in my remarks during the closing ceremonies, it was such a pleasure and an honour to meet so many remarkable families and individuals with mental illness in India. For many years I have only had email contact with these people and I was thrilled to finally meet them in person. To witness the love and support and strength of these families is an inspiration and taught me more than they will ever know. I thank all the delegates for sharing their stories with me and for the gifts and kind wishes. My thoughts and prayers are with all of you at this time of terrible tragedy in Southeast Asia and I sincerely hope all of our members and their families and friends are safe. To those members who have not been directly affected by this tragedy, I urge you to remember our friends at this time and offer what support you can to help them heal and rebuild their lives.

Conference Report

By Peter Woodhams

Carer and Chair-Meriden Advisory Programme

I was privileged to attend this 3-day conference as a delegate

representing the Meriden Family Programme along with Marie Crofts. The conference was held in Chennai, India better known under its former name of Madras-an incredibly busy city with a population of over 4 million. There were over 350 delegates at the conference from 20 different countries representing each continent including carers and mental health professionals from some 27 localities in India. Marie and I were the only UK delegates other than a Director of Basic Needs from a Leamington based mental health charity which provides a much needed but

inevitably limited, mental health service to some of the rural communities of Southern India.

Over the 3 days we heard presentations and attended workshops given by professionals and carers from around the world and which covered topics such as:



Left: Patricia Telesnicki with a resident of the Banyan.
Right: Peter Woodhams and Marie Crofts (UK) visit the AASHA residence.

- Social Capital and the Family Movement
- Mental Health Research
- Family and User Self Help Groups
- Vocational and Employment Interventions
- Educating Carers
- Stigma
- Involving families in the care process
- The common goal for patients, families and professionals
- Handling Communication and Emotion

Marie and I gave a plenary presentation 'Engaging Carers as Partners in Care' based on the Meriden approach and including the benefits that my family gained from participating in BFT. The final presentation under the banner of the Bill Jefferies Memorial Lecture (he was the visionary founder of WFSAD) was given by Dr. Pratap Tharayan of the Christian Medical College in Tamil Nadu, India. This was a fine lecture which clearly aimed at increasing the knowledge and understanding of families of schizophrenia and its treatments and although it was delivered at great pace for around an hour it was easy to follow, very

(continued on next page)

informative and highly motivating.

At the end of the conference we visited AASHA (who were joint hosts for the conference) which is a successful supported housing unit run by families in the outskirts of Chennai, which also gives vocational experience through its own retail outlet and small workshop. Marie, Patricia Telesnicki (the Executive Director of WFSAD) and I were given a very interesting tour of the unit by a resident who assumed that I was their father!!

I left India feeling enriched by the whole range of experiences I gained both in relation to mental health issues and also in gaining a greater understanding of all the problems faced by India. Hearing from carers from around the world, I do now appreciate how fortunate we are to have such relatively well-developed mental health services even though they could be a lot better.

It is clear that in India the woeful shortage of psychiatrists and other mental health professionals working in their homeland means that the services are hugely dependent on the input of families to the care process-in general they have no other community services to call on. In understanding this I could not help but conclude that we, in the UK, have the opportunity to supplement our well-developed mental health infrastructure with the enhancement of family involvement in the care process in a similar way. What an outstanding model we would have if we were able to achieve this.

Thank you for giving me the opportunity to attend this international conference.

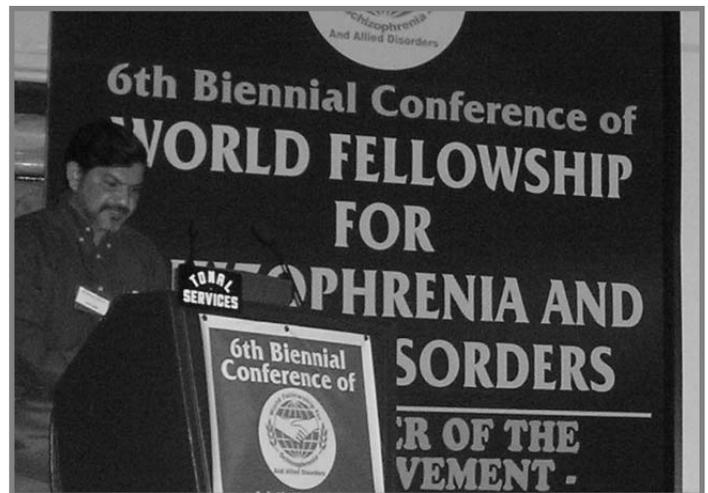
Conference comments from SAA family members

SMITA: *After learning and knowing so much I feel confident that we can function better at SAA. Everything was full of enthusiasm and efficiently worked out. It is amazing.*

SAROJ: *I was skeptical before leaving Pune but I found the conference very inspiring and motivating. I am determined to do something for the cause of consumers. I know that I will start living life again.*

ACHYUT: *There is tremendous addition to our knowledge by attending the conference. Such events should be organized more frequently.*

TERENCE: *It was a good experience and I got a chance to meet people who were experiencing the same thing that I feel.*



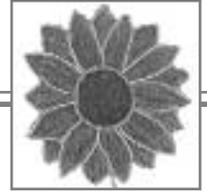
Dr. Pratap Tharayan of the Christian Medical College in Vellore, India presenting the Bill Jefferies Memorial Lecture.



Left: One of our new board members, Thomas Walunguba (Uganda Schizophrenia Fellowship) with Dr. David Basangwa (Uganda) and Lilian Kanaiya, retiring board member from Kenya.

Centre: Retiring President and new Chairman of the Asian Region, Jim Crowe, receiving his certificate of appreciation from president Dale Johnson at the Biennial General Meeting.

Right: Jim Crowe, Patricia Telesnicki and Derek Moey visit with residents of the Banyan.



A historic day for young people with emerging psychosis and their families.

Dr. Jo Smith and Dr. David Shiers

NIMHE/Rethink Joint National Directors for Early Intervention

In June 2002, at the launch of the National Institute for Mental Health in England (NIMHE) in Newcastle upon Tyne, over 40 service users, family members and expert practitioners met with representatives from the World Health Organization (WHO), Rethink and IRIS (Initiative to Reduce the Impact of Schizophrenia) to draw up a series of recommendations about the standards of care that those developing early psychosis and their families should expect. This became known as the 'Newcastle Early Psychosis Declaration'.

www.rethink.org/newcastledeclaration

In September 2002, the 'Newcastle' group developed the collaboration further with the International Early Psychosis Association (IEPA) and most recently, with the World Health Organization. On May 19th at the NIMHE/Rethink National Early Intervention Conference in Bristol, the Newcastle Early Psychosis Declaration 'came of age' and was released as an International Consensus Statement about Early Intervention and Recovery for Young People with early Psychosis, jointly issued by the WHO and the IEPA.

In her address the Health Minister, Rosie Winterton stated: "For the 7,500 young people who develop psychosis each year in England, the Early Psychosis Declaration provides a fresh way of thinking about the services and support they need. I congratulate the service users, family members, and expert practitioners whose vision and drive have led to the development of the Early Psychosis Declaration. The Declaration can help to build on that investment by defining a direction of travel informed by a better understanding of young people's needs. It helps us make the connections between education, health, housing, occupation and to understand the many other crucial links that are needed to support recovery. In particular the Declaration provides a framework for forging new partnerships and alliances between individuals, families, services and systems. I believe it can also help us to think about other groups of disabled and socially excluded people."

In a filmed statement Dr. Benedetto Saraceno, Director of Mental Health for the World Health Organisation praised the collaboration between NIMHE, Rethink and the International

Early Psychosis Association in driving forward this important work. He outlined that: "the task ahead of us now is to make this Declaration a concrete tool for the benefit of people affected by early psychosis, their family members and the wider community" and announced that: "the World Health Organisation is making available its network of Government agencies, international non-governmental organisations, collaborating centres and its experts" to support this work globally. He reminded us to make a difference requires us all to work together: "We need committed people, we need good will people, we need grass-roots people, because as indicated in the suggested actions of the Declaration, this is a task for us all, each one with their possibilities and capabilities, but all together, and first of all with service users."

May 19th provides a watershed for the development of services for young people with emerging psychosis and their families. The policy platform and government investment provide a secure base for taking forward the aspirations of those many people who have contributed to the Early Psychosis Declaration. As co-directors of the NIMHE / Rethink development programme we warmly invite your further involvement and collaboration.

Dr. Jo Smith joda@lineone.net

Dr. David Shiers david.shiers@nimhe.wmids.nhs.uk

NIMHE/Rethink Joint National Directors for Early Intervention

To view the Declaration: www.nimhe.org.uk/priorities/eip.asp

We hope shortly to be publishing a briefing about the Early Psychosis Declaration through NIMHE



'Too little' mental illness help in Europe

Rethink and 17 other mental health groups in Europe have joined in an effort to improve the amount of mental health information available. The group, which will be known as the International Network for Mental Health Education (INFORMED), is publishing 100,000 copies of a handbook to help both patients and relatives. The collaboration and newly formed group comes on the heels of a Rethink survey that found that 27% of the 1,500 questioned felt they had been denied access to help and that carers wanted to know more about medication, specific mental health problems, new treatments, local service provision and coping strategies.

A new survey finds one in four people caring for relatives with schizophrenia say they have been given no information to help them over the last three years and that the information currently available was either found in leaflets which did not provide sufficient depth of information, particularly for people newly diagnosed, or on the Internet and in textbooks which could be much too detailed.

Story from BBC NEWS: Published: 2004/10/08

Child and Adolescent Mental Health Policies and Plans Module available from WHO

The World Health Organization (WHO) has recently updated their electronic version of the module on Child and Adolescent Mental Health Policies and Plans is available for download on their website.

As part of the WHO Mental Health Policy and Service Guidance Package, which provides practical information for assisting countries to improve the mental health of their populations, this particular module "demonstrates the need to promote the development of all children and adolescents, whether or not they have mental health problems. In addition, it is important to provide effective interventions and support to the 20% of children and adolescents believed to be suffering from overt mental health problems or disorders. The burden associated with mental disorders in children and adolescents is considerable, and it is made worse by stigma and discrimination. In many situations, mental disorders are poorly understood, and affected children are mistakenly viewed as "not trying hard enough" or as troublemakers."

The completion of this module brings the total to 10 modules which can be used separately or as a package. The following additional modules are planned for inclusion in the final guidance

package:

- Mental Health Information Systems
- Human Resources and Training for Mental Health
- Research and Evaluation of Mental Health Policy and Services
- Workplace Mental Health Policies and Programmes

More information:

http://www.who.int/mental_health/policy/en/

WHO Report on Neuroscience of psychoactive substance use and dependence

After intensive consultation and receiving contributions from dozens of international experts, the World Health Organization has published a report on the Neuroscience of psychoactive substance use and dependence. The report was launched in March 2004 in Brasilia, Brazil.

The report discusses new developments in neuroscience research and shows that psychoactive substances have different ways of acting on the brain, though they share similarities in brain mechanisms involved in motivation and emotions. It also discusses how genes interact with environmental factors to sustain psychoactive substance-use and provides the basis of new diagnostic tools and behavioural and pharmacological treatments.

While it serves as a major reference for people interested in the current knowledge on neuroscience of addictive behaviours, the report addresses some of the major implications of this knowledge for public health policy. For example, it supports prevention, treatment and policy approaches that are based on sound scientific evidence, and the development of interventions that do not stigmatize patients, are community-based and cost-effective. In order to achieve these goals, the report calls for increased awareness of the complex nature of these problems and the biological processes underlying drug dependence by professionals, policy makers and the lay public.

The Neuroscience of psychoactive use and dependence and a 40-page summary in seven languages (Arabic, Chinese, English, French, Russian, Spanish and Portuguese) are available on the WHO website and directly from WHO.

The inaugural launch of the report in Brazil was hosted by the Brazilian Ministry of Health and the Ministry of the Secretary for the Institutional Security Cabinet, with the close collaboration of the regional and the country offices of PAHO/WHO. Though the launch in Brasilia was widely reported by the local and international media, three additional events were held in Brasilia, Rio de Janeiro and Sao Paulo which contributed to the widespread

dissemination of the report in the country.

The global launch was not the end of publicity for the report. One of the plans for continued dissemination of the report to organize a symposium on the management of psychoactive substance use problems at major meetings and conferences during which the report will be presented to participants and the media. The first of these has already been held in the African region with a successful presentation during the East African Regional Meeting on the World Psychiatric Association in Arusha, Tanzania. For the remaining part of 2004, the neuroscience report was presented in WHO-organized symposia in South East Asia, Eastern Mediterranean and Western Pacific.

On the day the report was released in Brazil, it was distributed to representatives of member states attending the last Convention on Narcotic Drugs (CND) in Vienna. Both the Department of Mental Health and Substance Abuse and the Publications Unit of WHO have also distributed the report to thousands of individuals and libraries across the world and continue to respond to requests for it.

Department of Mental Health and Substance Abuse, WHO
Geneva, Switzerland

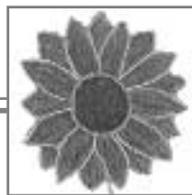
NEW ACTION GROUP AIMS TO SET UP FUND TO HELP PATIENTS

SINGAPORE: A newly-formed mental health advocacy movement is studying the feasibility of setting up a fund to help mentally ill patients who cannot afford to pay for treatment. The Action Group for Mental Illness (AGMI) says it is now in consultation with the Health Ministry and relevant organizations.

The group's Chairman, Dr. Ang Yong Guan, says they hope to set up the National Mental Health Fund in a year's time. Dr. Ang hopes that the fund will raise \$5m annually through donations. Other projects in the pipeline for AGMI are to push for insurance policies to cover mental illnesses and for the lifting of the cap on Medisave fund for mental illness treatment.

AGMI was formed by a group of psychiatrists and volunteers to raise awareness of mental illness. A recent study by the Singapore Institute of Mental Health has found that only about half of mental patients sought help while the rest suffered in silence.

By Julie Ng, Channel NewsAsia/NewsRadio 93.8



PUBLICATIONS

We have just finished translating some of our publications into Farsi/Persian (7, 17a, and 18). We hope to be able to continue providing our most pertinent and requested documents in a variety of languages. Ordering information is available on the WFSAD website.

No. Title

- 1 About Schizophrenia
- 2 Recent Information on Medications
- 3 The Family & Schizophrenia
- 5 Classifications of Schizophrenia
- 6 Quest for Smarter Drugs
- 7 Maintaining Your Own Health**
- 9a Biological Basis for Schizophrenia
- 9b The Promise of Research
- 10a Families in Limbo - M. Leggatt*
- 10b The Contribution of Families - D. Froggatt*
- 10c Consumers, Carers, Clinicians in Collaboration - M. Leggatt*
- 10d A Million Stories - D. Froggatt*
- 11 What is Bipolar Disorder?
- 12 40 Questions about Sz (for High-School Students)
- 13 Self Help Pointers from Consumers (UNDER REVISION)
- 14a Support for Families: Self Help
- 14b The Stages of Self-Help Groups
- 15 Dealing with a Crisis
- 16 Advocacy: How to Lobby
- 17a Schizophrenia: How Should One Behave?**
- 17b Schizophrenia: Guidelines for Families and Friends
- 18 Schizophrenia: Myths, Signs, Statistics**
- 19 List of Recommended Books
- 20 First Warning Signs/Signs of Relapse
- 21 About WFSAD
- 22 My Brother My Sister
- 23 Schizophrenia and Suicide
- 25 What to Ask the Psychiatrist
- 26a Families as Partners in Care - A Work In Progress**
- 26b Families as Partners in Care - Principles
- 27 Core Principles of Good Practice
- 28 Leave My Stuff Alone (Sz Explained to Teen Siblings)
- 29 How to Deal with Schizophrenia
- 30 Schizophrenia: Information for Families***
- 31 When a Parent Has Mental Illness: Helping Children Cope
- 32 What Is Schizo-Affective Disorder? (UNDER REVISION)
- 33 What Is Depression?
- 34 Proceedings of WFSAD's 5th Biennial Conference, 2000**
- 35 Rays of Hope: Manual for Families & Caregivers****

* Address by a WFSAD official to an international gathering.

** By special request only.

*** Available from the World Health Organization.

**** By the Schizophrenia Society of Canada—also available in French. US\$10 donation required to cover the cost of shipping.



PERSONAL STORIES

Being on Both Sides of the Fence

By Meredith Spicer

I am a Mental Health Professional who has a variety of mental health difficulties, one of which is Schizo-Affective Disorder and a recovering alcoholic. I have also received over 100 electroshock therapy treatments (ECT). The impact of my illnesses has been devastating - to the point that I am no longer working in the field of mental health. However, there was a time when I was active in the field of mental health; as a researcher, care coordinator and peer coach. I traveled throughout Europe collecting and compiling information about various mental health self-help groups and how they tied into mainstream mental health organizations. My research took me to Scotland, England, the Netherlands, Germany and Poland, where I presented three papers at an International Mental Health Conference called TOPOS "Mental Health Our Problem". My Senior Thesis for my two Bachelors of Science in Sociology and Women's Studies was entitled *Women with Mental Health Difficulties and the Effects on their Children; a Comparative Analysis of Mental Health Organizations in England, Scotland and the USA*.

During these times I had healthy periods of time where I could fully function within the professional mental health community. "Having been there", I was on the "cutting edge" of knowing what it was like to have a mental illness and be a professional who worked closely within the mental health population. However, I had a severe setback in the year 2000. I was chronically depressed and suicidal, spending most of my time in hospital. At one point, the doctors did not know what to do with me, so they considered putting me away in a state mental hospital as they thought I was not fully aware of the seriousness of my illnesses. The only alternative was ECT which is considered to be very controversial. It literally saved my life. With outpatient ECT I stayed out of hospital for longer periods of time. I began therapy in which I addressed the issues and behaviour of BPD, that led to some painful discoveries.

Historically, Borderline Personality Disorder is a basic coping

mechanism for those who have been abandoned and/or abused at a young age. The children are too young to know the rules and regulations of the parent/adult. And the rules kept changing erratically. Every child has a window of development; meaning between the ages of 2-6 one learns to know/understand the rules set before them. Sadly, in dysfunctional families the rules change for different reasons, like physical and/or sexual abuse, including abandonment of care for the physical/emotional needs of the child. I am one of these children, even at the age of 50. Both of my parents were involved in the abuse, and I still have issues of

abandonment. Although I have advocated different issues for many people, I did not feel that I was worthy to have any kinds of support system of my own. A hollowness skulks deep within me to protect and salvage the potentially whole person.

For now, in the present I have come a long way from the way I was (complete denial and lack of insight to my self-destructive behaviours). Although I still slip, overall I have become medication compliant and see my community care worker, therapist and medication psychiatrist on a weekly basis. But most importantly of all, I have gained insight to my

illnesses and the symptoms that accompany it. This includes acting out behaviours that lead to self-mutilation, depression, suicidal ideation and compulsive obsessive behaviours and thoughts. The borderline snag of my illnesses is a major factor in learning to cope in the real world. I have not had a drink or drug in three years. Due to an intensive Dual Diagnosis Program, I have begun to learn to set boundaries for myself and others that I never learned as a child. Although I have been hospitalized twice this year, I am recognizing my own limitations and weaknesses. Although I have worked very hard on my borderline behaviours, the child in me rears up it's head, digs in it's heels and acts out. Yet, I have learned to see and understand the childlike behaviours that seem so comfortable when I am in crisis do nothing but aggravate the problems set before me. Fortunately I have a brilliant therapist that guides me through my borderline traits and

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personalities. The hearing of voices also aggravates the rest of the mental health difficulties.

I hope this commentary will help some folks who have been diagnosed with more than one disorder and/or who has been on both sides of the fence. As for now, I am on the border.

Getting Through School with Schizophrenia: Those are the Breaks

By Steven Einhaus

On December 11, 1995 my world changed forever. I was on Christmas break from the college I was attending at the time when I felt my mind slipping into la-la land. I thought the television was talking to me and that I was the Anti-Christ. I truly believed I held the fate of the world in my hands. That night I snapped and ended up in the Legal Offender Unit in a psychiatric ward. The diagnosis: schizophrenia. As a result of my behaviour, I could not look myself in the mirror for over a year and I spent the first Christmas of my adult life wondering how I would live to see the age of 21.

Getting back into the ebb and flow of society was, and still is, extremely difficult. I felt like a perpetual "deer in the headlights". Information kept shooting over my head and could not seem to keep up with it. I was faced with dealing with everything from welfare to the expenses from my hospital stay and had no clue how to process all this new, critical information.

I re-entered school and had been struggling with coursework for four quarters when my medicine failed and I ended up back in the hospital. This time my break consisted of two suicide attempts and an attempt to assault some police officers on campus. This turned out to be the turning point of my so far dismal adulthood. I was stabilized on medication and began the long road to recovery for a second time. I got out of the hospital and into public housing, which was a god send. I began looking for a way to rebuild my shattered life. I have a close friend who told me to give school a try again. This was the motivation I needed to get back in.

I landed a telemarketing job, got back into college and started the reconstruction of a life destroyed by schizophrenia. My first quarter back, my grandmother, who I loved more than life, was diagnosed with cancer. She had raised me and passed a month into the toughest academic quarter of my college career.

Counseling was the lynchpin to my success at the time and going forward. It helped me get through my grief of losing my grandmother and the rigors of school. To make a long story short, I graduated from college with a degree in economics. I held down my job as a telemarketer until recently and am now working with individuals with developmental disabilities. Thanks to my faith in God and the support I received, I made it.

I have been on every atypical antipsychotic known to man. Through it all, the Lord has been faithful. There have been plenty of nay-sayers along the way. I remember distinctly when my probation officer told me that college was "not for everyone". This fired me up to the point of wanting to prove him wrong. I've learned that sometimes others underestimate the capabilities of those impacted by mental illness. This is a stigma I am trying to break one person at a time. In the words of a Muslim leader in the 1960's: "wherever there is a platform I will speak". The message I have is: People with mental illness can live a full, productive lives. Not everyone achieves success on similar levels, but people with mental illness can succeed in their own way and beat the odds.

The Story of My Superman

By Jes'se Ng'ang'a

My name is Jes'se Ng'ang'a. I am the third son of Mr. Martin Ng'ang'a - a man who has been challenged by schizophrenia for 34 years now. I would like to share a little of my experience of living with a dad who has schizophrenia.

My family is made up of ten members-four siblings and another four adopted siblings. It's a special privilege and a special challenge to have a member of the family struggling with a mental illness. He is a passionate and a loving father. His best friend is his wife Lydia Ng'ang'a. They are always together! Personally, I think there are a lot of things which my dad does that even the so called 'normal dads' cannot and that is why I prefer to call him a 'Superman'.

I have to admit that our case is much easier than it would be for many others since my dad is able to do things other patients are not able to like getting married, rearing children and working. Although he has never done a white collar job he has been doing handicrafts which he sells to sustain the family. He has been doing several other types of handicrafts such as purses, pouches and women's handbags but for now he has decided to concentrate on simple wooden key chains which resemble popular African pots. He is the one who designs them.

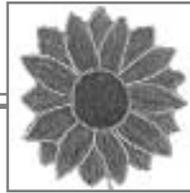
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It is not easy to see the good traits of mentally ill people unless you stay and observe them keenly. That is why through time we (mum, sister Lena and I) have become experts in accessing dad's condition. There have been good times as well as trying moments. I would like to mention one in particular. Due to the delusions and false perceptions that are solidly fixed in people with schizophrenia, he used to accuse mum of cheating on him and that she was searching for a way to destroy him. Although we knew it was false we could not find a way to convince him otherwise. Sometimes those beliefs were so strong that in search of a safe place to hide from mum he would run out of the house in the middle of the night. This sometimes caused a lot of anxiety for us. Sometimes when he got back to his senses he narrated how he met with gangs of muggers and how he managed to escape!

Often we felt powerless and hopeless but after we started attending Schizophrenia Foundation of Kenya Family Group meetings, we met others who had encountered such problems and we were strengthened. Also we met Dr. Fred Owiti who is the group's doctor and dad's personal doctor who has been treating him free of charge for the last four years.

Ever since Dr. Owiti started treating him, we have experienced tremendous change. Now he is almost completely healed. We give a lot of thanks to Dr. Owiti and the Schizophrenia Foundation of Kenya. I know there are people out there who are still struggling in the darkness with their loved ones. I want to give them hope because there is hope. Although it may be a dark tunnel now, there is light at the other end. Don't ever give up - the best way is to start again.

For more information about Martin's wooden key chains or to place an order, please contact Patricia Telesnicki at the WFSAD office.



EVENTS



World Psychiatric Association Regional Congress: Advances in Psychiatry (in collaboration with the Hellenic Psychiatric Association)

March 12-15, 2005
Athens, Greece

For more information contact:
Organizing Secretariat: Era Ltd.
Tel: +30 210 3634944
Email: info@era.gr
Web: www.era.gr/wpa2005athens.htm



XIII World Congress of Psychiatry: 5000 Years of Science and Care

September 10-15, 2005
Cairo International Convention & Exhibition Center,
Egypt

Further information can be found at:
Web: www.wpa-cairo2005.com



NAMI Annual Convention: On the Frontier of Recovery

June 18-21, 2005
Austin, Texas, USA

Further information can be found at:
Web: www.nami.org

Send us your events to be included in this section of the WFSAD newsletter.

E-mail: info@world-schizophrenia.org
Phone: +1.416.961.2855



WEBSITE - WWW.ACMIINDIA.ORG

Action for Mental Illness (ACMI) seeks to bring about policy change to impact quality and availability of support services to mentally ill persons and their families in India. If you have links that ACMI could add to their site, please email them to acmi_india@yahoo.com. Today there are 40-50 million people in India who are experiencing some form of mental illness.



UPDATES

Last year we reported about Hope House in Cape Town, South Africa. The successes of this home dedicated to those with chronic schizophrenia have not stopped. This excerpt from Hope House's letter to donors shows that they have been busy in Cape Town, making sure that Hope House will continue to help those who need it.



Hope House in Cape Town, South Africa

"This year the rewards of Hope House have been endless. Rotary, Cape Town restored and renovated our pool, allowing the residents both the enjoyment and therapy of swimming. The Pool People continue to look after the pool, at no cost. Constantia Garden Club assists regularly with plants and even gold fish! Jill treats the girls to shampoo and cut in her salon. And the residents continue to enjoy the high quality of food donations from Woolworth's, Meadowridge. There is an ongoing Roster of supporters collecting and delivering the food for us. Marlene of Weightless generously gives of her time to visit Hope House weekly to assist the residents with trying to control their weight problem and Monica, Senior Occupational Therapist, Valkenberg, visits and supports both the residents and Zainab, our skilled therapist, with her job.

The year has finished with very exciting monetary donations. Last month one person donated R100,000.00 and the previous month a national estate agency R25000.00. This will assist us in going ahead with plans for the renovation and additions to an outbuilding, which will greatly benefit our residents.

Other donations and fundraising have enabled us to start a bursary fund to accommodate a resident unable to contribute fully to the monthly expense of staying at Hope House. A wish the Trustees have nurtured for a long time."

Hope House thanks those listed above and others for their generous support.

The board and members of the World Fellowship for Schizophrenia and Allied Disorders would like to convey their sincere thanks to the following corporations and foundations for their support of our programs during the past year.

The Pfizer Foundation

Pfizer Neuroscience

Astra Zeneca

Nona and Bill Heaslip

Novartis

Eli Lilly (Asian Region)

The Phrenz Group

Without your support, we could not possibly deliver the growing number of programs that we are committed to. Below are examples of the programs that have received support:

Families as Partners in Care

Mutual Exchange / Outreach - Asia

Mutual Exchange / Outreach - Africa

Mutual Exchange / Outreach

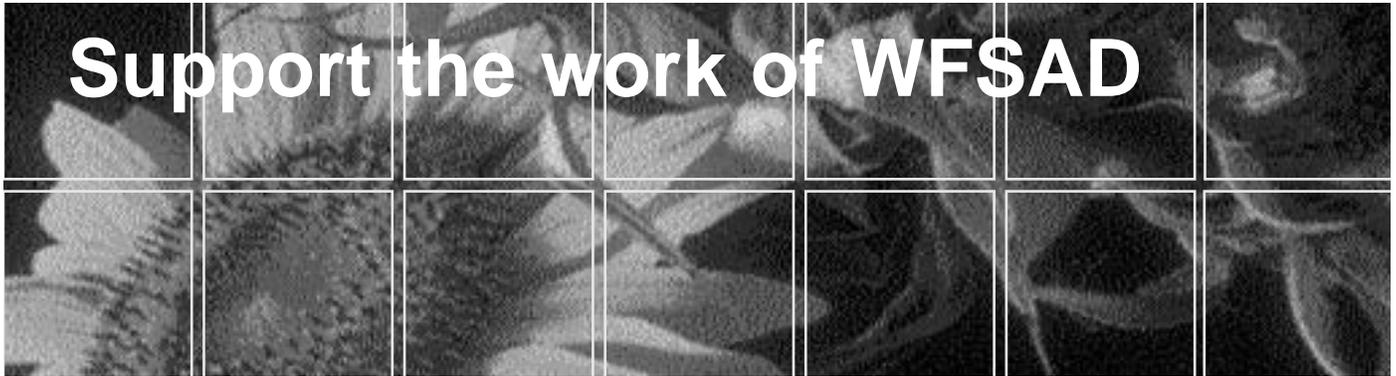
South America

Mutual Exchange / Outreach - Russia

Education and Support

Website Program

Publications Program



By donating to the World Fellowship for Schizophrenia and Allied Disorders, you will be helping WFSAD to provide:

- *Friendship and Support*
- *Information and Education*
- *Training and Encouragement*

We are the world's voice for the families of the mentally ill. WFSAD offers you sincere thanks for your contribution.

Registered Charity number: 120860911 RRO001

~~USE THIS FORM IF YOU WOULD LIKE TO SEND A DONATION BY MAIL~~

I value the work of WFSAD and submit the following donation:

\$10 \$25 \$50 Other \$ _____

Please debit my credit card. Visa *Mastercard*

Name on card: _____

Expiry Date: _____

I have enclosed a Money Order in Canadian/U.S. funds.

You can now also donate online at www.world-schizophrenia.org