

**World Fellowship for Schizophrenia and Allied Disorders**

**Second Quarter 2006**

**Carer Assist – A New Opportunity for Carers**

**By Robert Ramjan, CEO**

**Schizophrenia Fellowship of New South Wales, Australia**

The role of carers of people with a mental illness is an extremely difficult one and one which is rarely appreciated by governments and bureaucracies. After much advocacy from carers and non government agencies such as ourselves, the Schizophrenia Fellowship of New South Wales (the Fellowship), change has been secured and the commitment of government is irrevocable.

In the lead up to the 1999 New South Wales (NSW) state election, the Labor Party which was in government announced an election platform for carers. Following the election, the NSW Department of Aging and Disability established the Care for Carers program in liaison with NSW Health. The target group included those who care for frail older people, people with a disability, people with a mental illness and people with a chronic illness. The Government committed \$12.9 million (Aus\$) over four years to this program, which will be used to expand and strengthen carer supports, and to promote the broader community’s support for carers. Of this, \$1 million dollars per annum was allocated for carers of people with a mental illness. The three priority areas for the program were:

- ◇ personal supports, including counselling, support groups, and training;

- ◇ practical supports, including respite and transport to access the personal supports;
- ◇ building better responses to carers among health and community care workers.

This program has now been incorporated into the state budget and greatly expanded. Last year saw the amount increased to \$3.9 million per annum with further increases expected in the next budget. Further funding has been provided for government mental health services to assist them to transform themselves into “family friendly” services. The government has placed strong reporting and compliance controls on this funding to their own services.

Part of this original funding was made available to non government agencies to provide a range of pilot programs for carers. The Fellowship is the largest, by membership, non government organization in the state. We are a coalition of consumers, carers, mental health workers and supporters that operates services across the state. This year will mark our 21<sup>st</sup> anniversary.

In an open tender process the Fellowship secured about 25% of the funding to provide carer services in four areas. Nine other

*(Continued on page 2)*

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Personal Story .....	4
NAMI NYS White Paper.....	6
News Digest .....	7
Books .....	8

Events/Expressions.....	11
Members’ Update.....	12/13
WFSAD News.....	14-16



# Cover Story

## A New Opportunity for Carers (Continued)

projects were funded. At the conclusion of the first 12 months, our funding was doubled and a number of the other projects ceased.

Originally our program was called the "Carers Support Unit" but is now known as Carer Assist. The model is as elegant as it is simple. It stands on four legs. The service provides information, education, support and advocacy for carers. We may not understand the implications of  $E=MC^2$ , but we know what carers are demanding.

The workers in this program are called Carer Advocates and they are located within the communities that they serve. Carer Advocates have almost always been carers themselves and therefore have personal knowledge of the experience and difficulties. Each Carer Advocate has a steering committee drawn from their local community. These committees give advice, open doors, gather or recruit local resources and assist with the delivery of the service. Most Carer Assist services have their local member of parliament as their patron. The whole program is administered through the Fellowship via a state steering committee which includes representatives from our Board, area mental health services, the funding body, the Centre for Rural and Remote Mental Health Studies and carers.

Each Carer Advocate is visited by either the manager of the program or one of the Fellowship's senior staff on a regular, usually three monthly, basis. These visits provide on site support and assist in the development of linkages and partnerships. All staff are provided with an annual appraisal that looks at personal growth and the individual's current needs. Finally

there are regular refreshers provided for the whole team that also have the benefit of building a team culture and commitment.

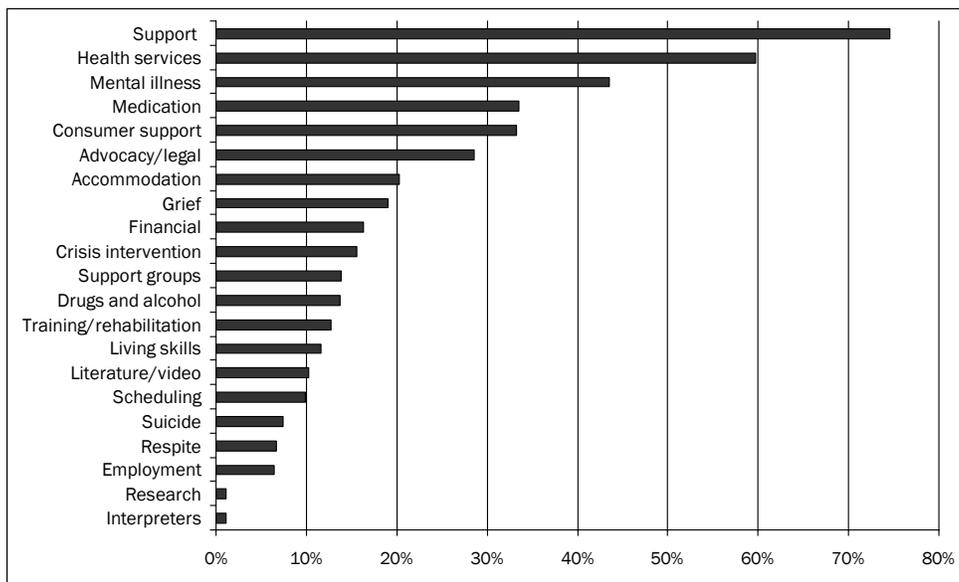
Linkages have been very important to the success of the program. In most areas we have partnerships with local government, local mental health services, educational institutions and such like. The local media have been surprisingly interested in reporting our work which also helps. Each Carer Advocate has been able to establish a Carers' Resource Centre, mostly through partnerships with local government, where printed information is kept, books and videos can be borrowed and there is someone to talk to.

Further each is involved with a number of education programs, especially the Well Ways Program developed by our Victorian colleagues (see sidebar on page 3 for details).

In the 2004-5 financial year, over 2,000 carers received service from Carer Assist and there were over 1,000 contacts through the Well Ways educational program. Tens of thousands of fact sheets have been distributed to carers throughout the state. Numerous stories appeared in the media about the service. A wonderful development in the process of achieving family-friendly mental health services has been the spread of requests for our Carer Advocates to provide training to government mental health staff. In one area health service, all psychiatric registrars receive training from the Carer Advocate.

One of the most critical areas of service is that of advocacy. It is

*(Continued on page 10)*



**Table 1**

Shown at left is the percentage of calls which asked for support or information on the topics given.

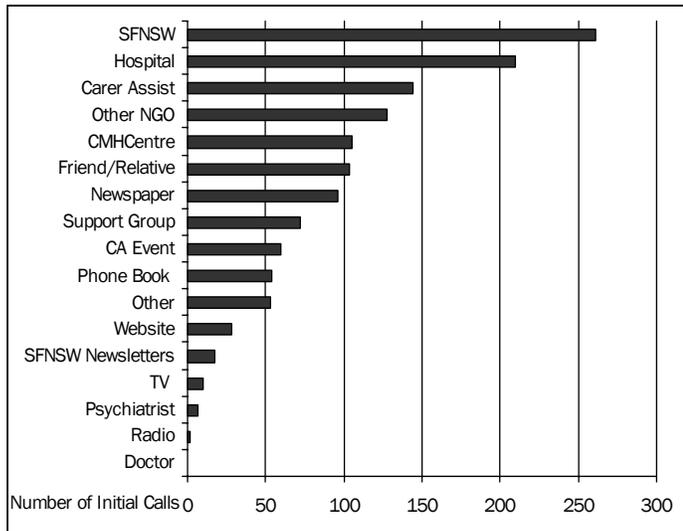
**Table 2**

Shown above right are the main ways in which carers heard about our service.

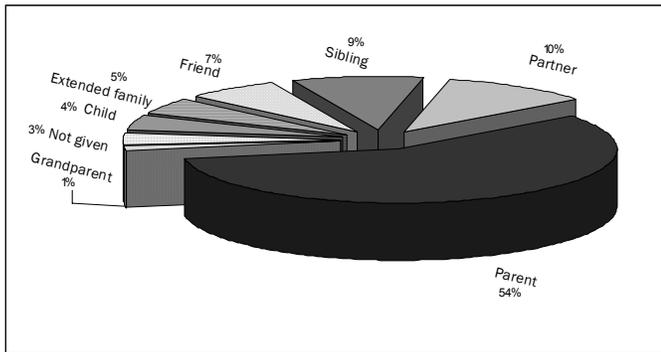
**Table 3**

Shown in the middle is the distribution of relationships of the carer to their loved one.

**Table 2**



**Table 3**



Carer advocates and carers shown at a recent facilitator training for Well Ways.



A group of participants at the end of a Well Ways course run in Northern Sydney late last year.

## Well Ways Program Builds Carer Capacity and Strength

The Mental Illness Fellowship of Australia (MIFA) is the national peak body for the Mental Illness and Schizophrenia Fellowships across the country. It was established in 1987 and formally incorporated in 1996. This federation of bodies has been most effective in advocating at a national level and has developed a number of national programs.

An exciting addition to the services provided through MIFA members has been the development by the Mental Illness Fellowship Victoria of a program called Well Ways, A Traveller's Guide to Wellbeing for Families and Friends of People with Mental Illness. The program is delivered by carers who have been trained and mentored. It recognises the "lived experience" as a powerful medium for education, support and change.

A full suite of fact sheets that has been developed by the Mental Illness Fellowship of Victoria are utilised during the training program while also standing alone as a resource to carers. The program runs over eight weeks with each week being a three-hour session. Each session is run by two trained Well Ways' presenters and each course brings forward more carers who wish to be trained.

The Well Ways Program is designed to increase the capacity of families, carers and friends to care effectively for themselves, other family members and their relative living with mental illness. The program provides a broad and sensitive perspective to the many issues facing families as they manage the impact of mental illness on their lives. It is a program that builds carer capacity and strength. Well Ways provides an opportunity to share experiences, learn from others' experiences and develop ongoing support and information mechanisms.

We have also found that Well Ways builds ongoing community linkages amongst the carers who attend. As I write this (end of March, 2006), one of our Well Ways courses will conclude today and already those carers who were involved have planned a celebration dinner tonight and have arranged for ongoing support meetings. If they follow the pattern of other groups, this will be the start of a long-term supportive relationship between the graduating members of this group.



# PERSONAL STORY

## Overcoming Isolation

*Last November Pinky Rodriguez gave a talk at the World Association for Psychosocial Rehabilitation meeting in the Philippines about how she overcame isolation due to her mental illness. The following excerpt from her speech begins at a point in her treatment where she meets her current psychiatrist.*

Three things my doctor did on my first consultation. First, since my hallucinations and delusions are mystical and spiritual in nature, my doctor, being a practicing Catholic, moderated my spiritual practices and readings and made me give up mysticism consciously, which made me more practical and down-to-earth to my approach to things. She also permitted me to go to Mass everyday, which invigorates and strengthens me and made me feel serene. I also became aware of scheduling my time. Secondly, my doctor gave me full freedom to research my illness. It's such a great feeling that my doctor trusted me enough to educate myself. I feel my mind is active again. Thirdly, she made me commit to taking my medication and having consultations regularly. In turn, she committed herself to do her best not to make me go back to the hospital again, which made me very glad.

This commitment to a regular and punctual follow-up with my psychiatrist made me look forward to the future because I always feel an excitement for every visit. It makes me hold on. It's a four-hour commute from our province to Manila, but the frequency of my visit made me enjoy the scenery and familiarity with strangers. I had overcome my fear of travel and my paranoid and suspicious tendencies. I have learned to trust myself in traveling alone and to trust that others would treat me well.

Then, in order to get in touch with myself, my doctor suggested that I write my thoughts, feelings and activities in a diary. It made me aware of the workings of my mind, heart and body; aware too of my immediate environment and the memories of my past and plans and hopes for the future. The diary made me listen to myself and be conscious of the reactions and feedbacks of others as I read it to my therapist. I feel I am not alone. I have someone to share my life with and found a mirror to see myself clearly. I found myself daring to make myself be known and really face the reality of who I really am. I also found out that I have a talent in expressing myself in writing.

My expression in writing helps me express verbally too. I was able to talk to my sister on a heart-to-heart level and was able to encourage her to go with me to my therapist. I felt that my sister has been more supportive of me and frequently communicates with the rest of my family about my condition. When I sensed that others already shared a bit of understanding about

my illness, I slowly opened up to them emotionally and shared bits of my thoughts. I have learned to be sensitive to the feelings and needs of my family.

Since my family is very sociable, especially my sister, they taught me how to be comfortable with my friends who were then mentally ill too. It also made me exert an effort to mingle with the friends of my family, especially those of my sister.

When I was confident of the support of my sister to me, we founded "Kapit-Palad", a family support group organized by my doctor. Kapit-Palad aims to understand more about mental illness and to strengthen family support. It made me widen my circle of friends which also includes family and friends of theirs.

When my sister had to go abroad to work, I had moments of feeling abandoned and being hopeless. With my only sister separated from me physically, and my mother with Alzheimer's Disease, my doctor acts as my support and clarified for me the roles of my sister. I also consider my doctor as my best, true friend. But believe me, she is the most objective person I ever met and very professional too.

Kapit-Palad has its foundation on friendship. We believe that what makes each member of the family open and vulnerable with each other is when each one considers him/herself a friend.

My doctor and Kapit-Palad helped remind me to be independent and optimistic. I intensified my research on schizophrenia which includes the internet and developed my communications skills. I also exposed myself socially and intellectually by attending conferences and seminars on mental health and advocacy, widening my horizons in reaching friends and families and in turn, learning a hundredfold.

My friends who also have mental illness made me understand more of the nature of illness and were able to separate individuality and their own unique personality from the disorder. At first, we are schizophrenics, but as we travel on our road to recovery, we realize that we have schizophrenia. We are not the disease. There were lots of moments when we tend to laugh at each other and ourselves for being sick and it doesn't bother us anymore. We are more than our disease. We are persons.

I concentrated on scheduling my priorities and had a deep soul searching in realistically assessing my talents and potentialities. Before, I used my talents for their own sake, never for God and others. But I found out that using them for their

own sake is just the beginning. My talents should be shared with others for the greater glory of God.

Surprisingly, genuinely helping others in their needs through my talents pays! I have no more insecurity when it comes to finances as long as I maintain living in simplicity.

I focused more on taking care of myself and holding responsibilities for my own actions which prompted me in taking care of others and being responsible for them. I realized that freedom and spontaneity should be within the boundaries of truth, goodness, and beauty which come from God. I dared making my own decisions thus becoming aware of my imperfections and not being ashamed of needing other people's help and support in times of trials and difficulties. For instance, when the community needed help, I realized that my help is not enough that I also need the help of my friends and families to help them, anchored in prayers and sacrifices. I learned that in weakness we are strong because we have God and each other as support.

In our group, we bear in mind that although schizophrenia is "incurable", medication and avoiding harmful stress can help us live normal lives. We also realized that having schizophrenia is not anyone's fault so we stopped blaming God, others, and our-

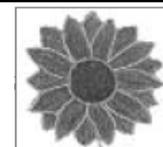
selves for having it, and in consequence, we feel no need to apologize or feel shame for being sick.

I am very happy with my family now. Whereas before I considered them my stress, now they are my friends. I had learned to listen and understand them and they do the same with me. I am now sure they love me "unconditionally" as I feel the same with them because we both learned to forgive and forget. We can now laugh at our share of "craziness" as the tragedy we consider before are now considered a blessing. As I am a practicing Catholic, my family is more open in respecting me in my spirituality and is now very happy for me to the point of following some of my practices too. I now find my life beautiful and worth living, being contented and fulfilled ...

How does one combat social isolation? I think it's in the power of loving and being loved. In love, we find meaning in life. In love, we believe. In love, we hope. There is joy amidst pain and there is light even in darkness. I think I now know the meaning of being "at peace" with God, with others, and with oneself. God indeed is "alive"! He is in the depth of our hearts if we can only try to be really honest and sincere about ourselves and about life. There is nothing impossible with love.

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## WFSAD Asian Forum Appoints Steering Committee



Kuala Lumpur, Malaysia, was the location of the fourth Asia-Pacific Advocacy Skills Workshop and Steering Committee meeting held from March 20 to 24, 2006. The event, which was sponsored by Eli Lilly, attracted a record attendance of 60 people. March 21<sup>st</sup> was the Steering Committee meeting, hosted by Jim Crowe, Chairman of the Asian region, WFSAD. The advocacy skills workshop was held on March 23<sup>rd</sup> and 24<sup>th</sup>. Watch for more details on this event in the next issue of this newsletter.

Members of the Asian Steering Committee

### China:

**Ms. Wang Ju** – Vice President Shanghai Disabled Person's Federation, President Shanghai Association for People with Psychiatric Disability their Families and Friends

**Mr. Yan Zhenghau** – President, China Association of Mentally Ill and their Families

### Hong Kong:

**Dr. Marcus Chiu** – Founded the Family Link Programme that is being used in some parts of Asia. A social worker by profession.

### Korea:

**Professor Susie Kim** – Instrumental in getting Korea to accept a new Mental Health Act and instigated the establishment of community support groups.

### Malaysia:

**Dato' Hj. Dr Abdul Aziz** – Head of Psychiatry Program Malaysia and Head of Psychiatry Department Hospital Kuala Lumpur

**Dr. Abdul Kadir Abu Bakar** – Senior Consultant Psychiatry, Director of Hospital Sentosa, Sarawak, Malaysia

### Philippines:

**Dr. Marissa de Guzman** – Psychiatrist and very strong supporter and advocate for families of the mentally ill.

Singapore

**Mr. Chandra Nair** – Past President Singapore Law Society, Nominated Member of Parliament and involved in many influential committees. Member of the Action Group for Mental Illness. Family member.

### Taiwan:

**Ms. Evan Teng** – Chief Executive Officer for the Taiwan Association for the Mentally Ill.

### Thailand:

**Dr. Pairat Pruksachatkunakorn** – Psychiatrist, Family & Youth Court Justice. Strong advocate for better services for families affected by a mental illness. Weekly radio and TV broadcaster.



## FEATURE

# NAMI New York State Advocates for Systematic Services for Families

### **A White Paper: Families of Mentally Ill Need Integrated System of Support**

*In line with the theme of the lead article of this newsletter we report a White Paper recently published by the National Alliance on Mental Illness (NAMI) of New York State (NYS). It is designed as a working document emphasizing the importance of systematically establishing family services. It is part of a collaborative effort with the Family Institute and the Office of Mental Health to bring a unified program of family services to providers across New York State. The White Paper is prepared by Jeff Keller, Deputy Director of NAMI-NYS, who acknowledges the contributions of a number of senior NAMI members. In short it describes how families help their loved ones, why and what help they need from the system and how that help can be provided. We summarize the paper below.*

The White Paper urges that “Families have strengths that should be developed, weaknesses that should be mitigated, needs that should be met and limits that, once they have been reached, require someone else to take over”.

There is a lack of family mental illness services as well as gaps in service. An integrated system that provides services appropriate to family needs does not exist. Thus many families provide services like crisis intervention, case-management, counselling, basic needs support (housing and financial), socialization, rehabilitation and advocacy. They can also provide insight for professionals into their loved ones’ illness.

To explain why families need help the Paper describes families’ reactions to the onset of mental illness – a catastrophic event in their lives that few know how to adjust to immediately. Along with the realization of what has happened comes grief that the person is not the same and the uncertainty of what the future will bring for family life, for treatment and no certainty that recovery is possible. The report refers frequently to NAMI’s Family to Family comprehensive education program (described in this newsletter issue 2003-3, page 6). It also describes the stages that families go through as they adapt to the new reality. It also describes those families who “get stuck”. “Finding out why and taking a proactive approach to help them should be of primary importance. Many times it is because they have reached an impasse with the system and can’t get the help they need”, according to the Paper.

A section deals with “Family Burden” – the worries and limitations that mental illness puts on both carers and their unwell relatives. Under Roles of Family Member (Page 15) it describes how some

carers are neglected:

“The majority of family members that service providers see are parents, with their recognized roles as providers and caregivers. The spouses, siblings and children of persons with serious mental illness are often overlooked and neglected. Spouses need help in figuring out how they are going to continue the partnership created by their marriage. Siblings need help in going on with their own lives while maintaining their crucial friendship with the loved one. Children need help in simply having a childhood. Of these relationships, the experience of the children and the spouses can be the cruellest by far, because they depend so much on the loved one”.

And a final note on family burden says:

“It never ceases to amaze families that providers don’t seem to “get it” about their feelings. They can’t comprehend how providers can be so blind to their pain, grief and anxiety about their loved one. It’s as if providers consider the ill family member to be of the family, but not *in* the family, or they think it is not their job to deal with family pain. Families say it is very difficult to find a provider who understands their devastation and offers genuine comfort. On this score, a great deal of provider education is needed. And the right to work with staff trained in and sensitive to the needs of families should be spelled out and enforced. Being regarded as “ancillary” simply adds to the pain.

“Another fact that seems incredible is that many providers simply don’t know how to talk with families. They don’t know what to say, as if they themselves don’t have a family of their own. They lack the basic communication and people skills they are assumed to have as human services professionals. Again, a great deal of provider education is needed to address these problems”.

Significant concepts described in part III are “collaboration, education and support”, of which collaboration is the most significant. Important areas for collaboration are discharge and treatment planning, seeking case histories from the family; informing families on the treatment regimen; reporting to families; consulting; establishing channels for family grievances; validation of families’ knowledge and maintaining close contact through times of crisis. Collaboration should recognise that families are competent and have strengths, resources and expertise and that the relationship should be a true partnership for the welfare of the person who is unwell. Achieving collaboration must be a policy decision requiring vision, policy, planning, attitude change and policy implementation, and should reach beyond the treatment team to community providers.

From page 18:

“As for the providers who are already practicing, education is needed to change the organizational culture of their agencies. The Family Institute has proposed a major initiative to tackle this problem. It combines education on the principles, processes and practices of a family-oriented system with a process of Continuous Quality improvement. The process includes the development of a Family Services Development Team within each participating agency. Such teams would be part of a regional “learning collaborative” supported by a research panel. The teams would be trained in three one-day training sessions, and agency clinical staff would be trained in a two-day workshop.

“A key element of the proposal is that it would designate ‘change agents’, Family Services Development Teams, in each organization, supported by technical assistance. Designated change agents are essential. Without their obtaining effective results, we might as well create a system of family services that is separate from the rest of the system (see page 34). Such change agents should not only promote a family-oriented system, but also advocate on the behalf of specific families on a case-by-case basis”.

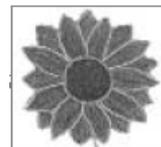
In this section the misinterpretation of “confidentiality” laws is discussed along with the need to fully examine the question with families and their ill member. Families are not looking to undermine the rights of their ill loved ones, but simply trying to facilitate their care. This can result in families being left out of discharge planning, a practice that can result in inappropriate discharge and sometimes even discharge to “homeless shelters” or other inappropriate locations.

Throughout the report laws and regulations are referred to and suggestions made for their betterment or implementation. The need to improve families’ relations with community support and rehabilitation providers are described as well as the need for professionally provided education services and family psychoeducation.

The latter section quotes the Goals and Principles for Working with Families developed by the World Fellowship for Schizophrenia and Allied Disorders in sessions with Professors Leff, Falloon and McFarlane (WFSAD’s Families as Partners in Care). It highlights the multi-family psychoeducation model introduced into New York State through the Family Institute and the Office of Mental Health in 2002 and now available through 41 project teams at 34 participating agencies statewide (see WFSAD Newsletter 2003-2, page 14 for McFarlane model ). Various models of support are mentioned including Family Mentoring, a model developed by the Co-

(Continued on page 9)

## NEWS DIGEST



### Atlas Documents Status of Child and Adolescent Mental Health Resources

WHO in collaboration with its Regional Offices and the International Association for Child and Adolescent Psychiatry and Allied Professions and the WPA Global Presidential Program on Child Mental Health has for the first time systematically documented the status of service development, training and policy for child and adolescent mental health worldwide and published the findings in *Atlas for Child and Adolescent Mental Health Resources*. The themes covered include: Rights of the child and adolescent, policy and programs, information systems, need for services, service system gaps, integration of services, barriers to care, care providers, training for care, financing of care and availability and use of medications. Visit [www.who.org](http://www.who.org) to purchase a copy.

### New Website Aims to Increase Understanding of Schizophrenia

Researchers and the public are welcome to visit the Schizophrenia Research Forum (SRF) at [www.schizophreniaforum.org](http://www.schizophreniaforum.org). The new website aims to help in the search for causes, treatments and understanding of schizophrenia by fostering collaboration among researchers by providing an international online forum where ideas, research news and data can be presented and discussed. SRF intends to bring together scientists working specifically on schizophrenia, scientists researching related diseases and basic scientists whose work can shed light on these diseases. It is hoped that SRF will be a catalyst for creative thinking in the quest to understand this deeply complex disease.

The website is free of charge to users, independent of industry sponsorship and open to the public. Although it is geared to researchers, the editors welcome other visitors – people with mental illnesses, families, the media and others who need accurate information on research into schizophrenia.



## Coping with Schizophrenia

Specifically written for people with a diagnosis of schizophrenia, their caregivers and loved ones, *Coping with Schizophrenia* reassures patients that they do not need to rely solely on medication and psychiatric services to function successfully, but can do many things *themselves* to live full and active lives.

The authors of the book – Dr. Steven Jones and Dr. Peter Hayward – are experts in the field of Cognitive Therapy.

*Coping with Schizophrenia* is “a sympathetic and sensible book which not only removes much of the fear, loneliness and stigma that surround schizophrenia, but gives ... practical encouragement to those faced with such a diagnosis”, said Marjorie Wallace, Founder and Chief Executive of SANE UK.

For more information and a sample chapter of *Coping with Schizophrenia*, visit the publisher’s website at [www.oneworldpublications.com/books/coping-with-schizophrenia.htm](http://www.oneworldpublications.com/books/coping-with-schizophrenia.htm)

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## Discover the Road

### New Book on Schizophrenia Launched

A new handbook that provides information for anyone who has been affected by schizophrenia or psychosis has been launched.

*Discover the Road Ahead* provides information on the early signs of the condition, how to deal with a diagnosis and the recovery process.

The book, which is a cross-European initiative, is being made available free of charge throughout Ireland and Europe.

“We know that knowledge is power and as a person affected by schizophrenia, if you are not informed about your illness, your access to information on the recovery process is severely reduced”, explained John Saunders, Director of Schizophrenia Ireland. “This book helps to provide information on how best to foster recovery, looking at the holistic range of experiences and needs of the individual. For more information go to [www.sirl.ie](http://www.sirl.ie).

## Nine Lives - Personal Stories of Mental Illness

Two organisations in Brisbane, Australia – Open Minds and the Brook RED Centre – have launched an inspiring book which is a compilation of stories, poetry and art from local residents living with a mental illness.

The book, entitled *Nine Lives*, was developed by the two charities who felt it was important that Brisbane residents gain a better understanding of those in their neighbourhoods who are living with a mental illness.

A number of writing workshops were conducted at the Brook RED Centre in South Brisbane to teach participants the skills needed to write personal stories. This allowed participants to explore and share many areas of their lives in written form that they may not have otherwise been able to verbalise.

Open Minds CEO Jo Denvir said that rather than being dark and depressing, the book is very inspiring and motivating.

“Those who have participated have fascinating lives and experiences that are remarkable: the book is amazing.”

Mental illness is extremely common with statistics revealing that approximately 1.8 million Australians (9.6% of the population) have a long-term mental or behavioural problem that had lasted, or was expected to last for six months or more.

“It is our intention to encourage the community to see first hand that people with a mental illness have skills, abilities and stories to tell that are very valuable,” Ms Denvir said. “The issue of mental illness is no longer something that we can think of as happening to other people, because it occurs in our own backyards.”

The book was made possible through a grant from Brisbane City Council and Disability Services Queensland.

Ms Denvir said the book is a fantastic outlet in which individuals can explore different areas of their lives and share their experiences with the greater community.

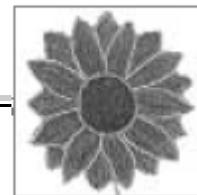
“I just love that it is about the people of Brisbane... my community,” Ms Denvir said. “I think it is so important to recognise that these experiences are real and are happening in our neighbourhood... but most importantly, that they can be overcome.”

*Information regarding the book and Open Minds can be obtained via their website on [www.openminds.org.au](http://www.openminds.org.au).*

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## Early Intervention Studies

The Special Theme of the July issue of the Schizophrenia Bulletin is “What Have We Learned From the New Generation of Prospective Studies on First-Episode Psychosis?” Seven studies on this topic are reported.



## NAMI New York State White Paper (Continued)

(Continued from page 7)

lumbia University “Parent Partners” research project at a children’s mental health clinic.

Section IV talks about how family services should be provided, highlighting the “Family Support for Families of Persons with a Serious Mental Illness Act. P.L. 1995, Chapter 314 of the State of New Jersey. The Act established “a program of family support services in the Division of Mental Health Services designed to strengthen and promote families who provide care in the community”. Services in New York are being provided in a fragmented “almost random” basis and this should be rectified. Laws which now exist should be made stronger to give families “rights” rather than “opportunities” to participate in the system. The report recommends that a statement of family rights should be spelled out and enforced as follows:

### The Rights of Families

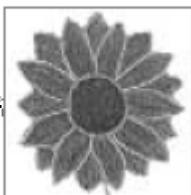
1. The right, to the fullest extent possible\*, to collaborate as partners with mental health providers, including the right to be treated with the same consideration and respect as any other member of a loved one’s treatment, rehabilitation or other service team.
2. The right, to the fullest extent possible\*, to collaborate with providers in the creation of a loved one’s discharge, treatment, rehabilitation or other service plan.
3. The right to an effective process to communicate concerns, complaints, appeals and disagreements about the loved one’s care to a mental health agency or organization that is providing services to the loved one.
4. The right to an effective process to advise an agency or organization that provides services to the loved one on its policies and practices.
5. The right to psychoeducation, family education, and/or support groups wherever appropriate.
6. The right to work with staff trained in and sensitive to the needs of families.
7. The right to an orientation and action plan that provides information and a blueprint to enable families to collaborate as full partners in a treatment, rehabilitation or other service team.

The White Paper concludes with Principles for a Program of Family Services:

1. Improvement by the loved one to the fullest possible extent should be the overall goal of services for families.
2. Collaboration between families and professionals is essential to the effectiveness of both in helping the loved one.
3. Families have a right, a need and a duty to be educated in how best to help their loved ones recover from a serious mental illness.
4. Families need support to give them the emotional and practical wherewithal to help their loved ones.
5. All family services should be based on the same approach: a strength-based approach to the recovery process, providing families with the latest “best practices” to help their loved ones improve.
6. Family services should be coordinated through an orientation and action plan according to the specific needs of individual families. This plan should serve as a blueprint for an ongoing partnership with those families.
7. As a basis for successful collaboration, education and support – and the provision of services in general – the relationship between families and mental health professionals should be based upon a statement of family rights.

\* means: to the limits of the law

*We are grateful to Judith Carrington, a member of the team who prepared this paper, for providing it to WFSAD. Should you wish to contact her the email address is: mbresources@nyc.rr.com*



## Cover Story Continued

*(Continued from page 2)*

a truism around the world that the best of services can make mistakes and those affected by these mistakes need a skilled spokesperson to assist them. This is certainly true with regard to Carer Assist. Some matters are straightforward, assisting a carer in a Mental Health Tribunal hearing, talking with the director of a mental health service, or assisting in the preparation of a letter of complaint to the Minister for Health. Some are more difficult and emotionally taxing such as forensic matters, attempted and successful suicides. Some contacts are one-off for information and referral, some require more than 30 contacts to resolve the issues involved. Where matters become too difficult for the Carer Advocate or they require external advocacy, the matter can be referred to the Fellowship's own advocacy program.

Since its inception, there have been many benefits from Carer Assist for carers and consumers. Evaluations have demonstrated reduced stress on carers and consumers, high levels of satisfaction with the service and a need for further educational activities. To the eye of one who is a carer and thinks beyond the "evidence base", the truly substantial benefits have been the establishment of a string of support groups following a Well Ways course, the support networking that has developed between and among car-

ers who were previously isolated and the comfort that is given to a carer who is sure that the person they speak to at Carer Assist will understand where they are coming from.

As for the future, the whole Care for Carers program is in a tender process through the NSW Government. Our wish, our hope and our expectation is that the Fellowship will get a large proportion of this tender and deliver this very successful service to more carers in more locations. Our dream is that every carer throughout the state will eventually have access to these services to help them in the care of their relative with mental illness.

*To learn more about the Schizophrenia Fellowship of New South Wales,*

### Wish List: Hope House

Hope House: Two years ago, we reported on the success of Hope House, a residence in South Africa for those with mental illness. (2004-1, page 10.) WFSAD recently received an update from Hope House telling of the continuing success of the facility. They have plans for building a much-needed extension this year. If you would like to contribute funds for this important work, the address is Hope House, Amajuba, 41 Klipper Road, Rondebosch, 7700, South Africa.

**WFSAD is not supported by any level of government and relies on your generosity.**

Please help to maintain our programs:

**Support and Advice**

**Advocacy**

**Families as Partners in Care**

**Family Organization Development**

**Education: "A Reason to Hope"**

Send a cheque or money order in

**US\$, Canadian \$, or Euros to**

WFSAD, 124 Merton Street, Suite 507,  
Toronto M4S 2Z2, Canada **OR**

**DONATE ON LINE: WWW.WORLD-SCHIZOPHRENIA.ORG**

If mailing your donation, please fill in the information below so that you will be assured of a receipt and send your donation to address in left column.

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You may also pay by credit card:

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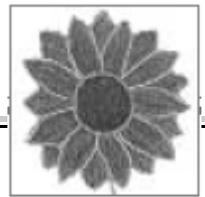
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## Upcoming Event — Nepal

Second International Conference of SAARC Psychiatric Federation

**When:** November 17-19, 2006

**Where:** Kathmandu, Nepal

**Co-Sponsored by:** World Psychiatric Association in collaboration with Psychiatrists' Association of Nepal and Department of Psychiatry and Mental Health, Nepal  
 Content: Psychiatric practice in the context of developing countries; psychiatric education in undergraduate medical programs; "telepsychiatry"; emerging trends in psychopharmacology; expansion and strengthening of research activities in psychiatry; and genetics and psychiatry. Learn more about the conference at [www.spf2.org.np](http://www.spf2.org.np)

## Upcoming Event — India

Law and Rights of Persons with Mental Illness

**When:** May 5 and 6, 2006

**Where:** Bangalore, India

**Sponsored by:** Action for Mental Illness (ACMI)

The primary focus of the workshop is to examine the existing legislations for persons with mental illness from the perspective of rights and needs of the client patients and their family carers. According to one of the organizers, Dr. Nirmala Srinivasan: "It is the first workshop of its kind wherein consumers, family members, psychiatrists, mental health professionals, government officials and lawyers will come together to explore ways and means of amendments to outdated Mental Health Act 1987 and Persons with Disabilities Act 1995."

## EXPRESSIONS

### Loneliness

By P. Spragg

I once felt a kind of warmth  
 In the company of friends  
 Like the kind of warmth  
 That filters through the  
 lace curtains from the morning sun.  
 Now it's harder for the sun's rays to reach me.  
 It's like I'm clouded in a shroud of darkness  
 Feeling its icy talons  
 Piercing my flesh.  
 Just like loneliness  
 How it strikes.  
 Like an assassin in the night.

*(Reprinted from December 2005 issue of the newsletter of the Schizophrenia Fellowship of Queensland Inc.)*

## New Website for Schizophrenia Ireland



Schizophrenia Ireland has created a new website, [www.recover.ie](http://www.recover.ie), which launched on October 12, 2005. Recover.ie is the first of its kind in Ireland and is intended to be a user-friendly database of up-to-date and comprehensive information for persons with self-experience of schizophrenia, their caring relatives, the general public and healthcare professionals.

Look for the following services at Recover.ie:

- Carefully selected information on a variety of topics related to schizophrenia, with the aim of providing accurate and current information. It will also offer a platform for professionals within Ireland to share knowledge and centralize the relaying of information
- Several resources and links
- A user-friendly search engine that will allow visitors to sift through information both at Recover.ie and the World Wide Web

Schizophrenia Ireland is the national voluntary organisation of Ireland dedicated to upholding the rights and addressing the needs of all those affected by schizophrenia and related illnesses. It promotes and provides high quality services while also working to ensure the continual enhancement of the quality of life for the people it serves.



### Overcoming Stigma in Nicaragua

*Rimke van der Geest, who is a psychiatric nurse from the Netherlands, submitted the following report of the activities for the new group just recently established in Nicaragua.*

I did an anthropology study on schizophrenia in poor Nicaraguan families two years ago. From there the idea grew to start this self-help group. With the help of the sister city of Matagalpa (Tilburg), I wrote a project plan and Tilburg raised some funds. Last October I went back to Nicaragua (after first visiting Fucopez, Costa Rica) and the whole thing started. I sent Rosalba, Elba and Raul to the congress in Costa Rica. (How nice and what a coincidence it was, that Fucopez organized this congress with WFSAD just when we were starting our project!)

At present we are focusing on schizophrenia as a priority. Of course this means that some families won't be interested. We hope those families can begin groups more relevant to their needs. Nevertheless we will keep touch.

Rosalba and I have been working hard together to organize ourselves and have found some enthusiastic volunteers.

Every Sunday we organize "share-reunions" and in the week we're visiting families with a schizophrenic family member all

over Matagalpa.

So far we have also conducted three workshops. One was for children on how to act when your loved one is in crisis (we used theatre), and the last one on schizophrenia. Twenty seven people came, almost all family members. The location we used has already become too small!

We are also working on the legal aspect of our project. At this moment we operate under the wings of a local NGO (they are the main counterpart of Tilburg) "Comité Mano Vuelta". The president of this Comité is a psychologist and she is willing to pay the individual membership of WFSAD. (I hope we can be a full member from the next year on.)

There is a serious stigma in Matagalpa. There are a number of families here who are totally denying they have a psychotic family member, although the whole neighbourhood knows. It's really very sad. Another thing I realized is that the "patients" themselves do not always like our visits, especially those who are without treatment who feel like the whole world is against them and that it is ridiculous that their family is so worried about them. Difficult, difficult, difficult ....



Rimke and Rosalba with mental health display at the health fair.



Planning strategy in the office.

### Coping Tips from Nicaragua

"Yesterday a mother told me that she's finally succeeding in changing her own attitude towards her daughter who has a psychotic disorder. The daughter said: "Mama, I'm going to sleep on the floor", and the mother answered "Of course, that will be nice and fresh". Normally she would have said: "No, you cannot, you will get sick, etc. etc.". The mother had to admit that the outcome of this attitude was a lot better (the daughter preferred her bed after all), and I of course was very happy to notice that our workshops are making a difference. *Rimke—Nicaragua*

## Tanzania Increasing Awareness Making Connections

Joyce Bamwenda, Chairperson of the Dar es Salaam Voluntary Association in Tanzania continues to work diligently for mental health awareness. Last December 19 to 24<sup>th</sup> was designated as “awareness week” for the association, and they marked it by distributing more than 100 pamphlets including to local companies, local and international institutions, diplomatic missions, and hospitals. They also distributed pamphlets to motorists along the Ally Hassan Mwinyi Road (see photos).



We have put Joyce in touch with the Uganda Schizophrenia Fellowship and the Kenya Schizophrenia Foundation. The Dar es Salaam Voluntary Association is in great need of funds to continue their work.

If you think you can help or to learn more about the association’s work, contact Joyce at [voluntaryassociation\\_15@hotmail.com](mailto:voluntaryassociation_15@hotmail.com)

## NFMI India

### Moves Head Office to Chennai

The National Federation for the Mentally Ill (NFMI) in India held a successful annual general meeting on February 12, 2006. It was unanimously decided to shift the Head Office of NFMI from New Delhi to Chennai. The following new office bearers were elected unanimously:

#### Officers:

- **President:** Mr. Mukul Goswami
- **Vice President:** Mr. Anil Vartak
- **Secretary:** Ms Ratna Chibber
- **Joint Secretary:** Mr. P. Jayapala Menon
- **Treasurer:** Mr. K.K. Srinivasan

#### Members:

Mr. S.D. Raheja; Mr. Namdev Gawas; Mr. Victor M.; Ms. Savita Apte-Nadkarni; Asmita Mokashi; Mr. P.N. Krishnan. An additional member is to be appointed by the President.

## Bangladesh Newsletter

**জানালা খুলে দাও**

সিঙ্গোফ্রেনিয়া আক্রান্ত ব্যক্তিদের কল্যাণে  
দ্বিমাসিক মুখপত্র।  
১ম বর্ষ, ২য় সংখ্যা • ১লা মার্চ ২০০৬

**সম্পাদকমন্ডলী**  
সম্পাদক ডাঃ এম এ সোবহান,  
মনোরোগ বিশেষজ্ঞ।  
সদস্যবৃন্দ  
ডাঃ মোঃ মাহমুদুর রহমান,  
ত্রিভঙ্গিয়া মনোরিহাসনী।  
ডাঃ মোঃ আসাদুজ্জামান,  
মনোরোগ বিশেষজ্ঞ।  
নির্বাহী সম্পাদক বনজলা মাস্তান

**উপসম্পাদকমন্ডলী**  
অধ্যাপক আব্দুল্লাহ আর সায়ফিন  
অধ্যাপক ডাঃ মোঃ শাহিদুল্লাহ চৌধুরী,  
মনোরোগ বিশেষজ্ঞ।  
ডাঃ মোঃ জিহুর রামান,  
মনোরোগ বিশেষজ্ঞ।  
অধ্যাপক ডাঃ হোকাইয়া বেগম,  
ত্রিভঙ্গিয়া মনোরিহাসনী।  
অধ্যাপক ডাঃ এ এস এ আউতুর রহমান,  
সমাজ কল্যাণ ও গবেষণা ইনস্টিটিউট, ঢাকা।

**এই সংখ্যার আবে**

বিষয়	পৃষ্ঠা
সম্পাদকীয়	১
কেস রিপোর্ট / আত্মকথন (ধারাবাহিক)	২
সিঙ্গোফ্রেনিয়ায় মানসিক চাপ (ধারাবাহিক)	৩
সমাজকল্যাণ ব্যবস্থাপনা	৫
সিঙ্গোফ্রেনিয়া জনিত প্রতিবন্ধিতার খাতর	৬
দেশের বহর	৮
স্মারকস (পূর্ব প্রকাশের পর)	৯

**লেখা পাঠান**

- ভুক্তভোগী ব্যক্তিগণ, সেবাশ্রমস্বাকারী, অকিডাবক, সন্তান, ভাইবোন সিঙ্গোফ্রেনিয়া জনিত মনের/কণ্ঠের কথা, প্রকাশ্যের কথা ইত্যাদি পাঠান।
- মনোরোগ সংশ্লিষ্ট পেশার নিয়োজিত ব্যক্তিরা অজিজ্ঞতার কথা, জ্ঞান সমৃদ্ধ লেখা ও কেস রিপোর্ট পাঠান।

নিউজ পোর্টাল বুকপোর্টে গেলে পাঠানোর ধরত বাবদ এক বসতের জন্য (৬ সংখ্যা) ১০ টাকা মাসি অর্ডার করে সম্পাদক বরাবরে পাঠান।

প্রকাশনাঃ :  

**সোসাইটি ফর ওয়েলফেয়ার অফ দি স্কিটসোফ্রেনিক**  
 ২৭/১২ হোসপাতানা রোড, ঢাকা-১০০০, ফোনঃ ৯৫৮০৪৯০, ৯৫৫৮০১৬  
 ই-মেইলঃ [rajan@bangla.net](mailto:rajan@bangla.net), ওয়েবসাইট [www.sws-bd.org](http://www.sws-bd.org)

জানালা খুলে দাও

This photo above shows Issue 2 of *Janala Khule Dao*, a new bi-monthly newsletter of the Society for Welfare of the Schizophrenic of Bangladesh. This issue highlights Mr. Mohsin Siddique, who is considered the pioneer of the movement for the mentally ill in Bangladesh. The newsletter is written in Bengali, the official language of Bangladesh, in an effort to increase awareness of the challenges the mentally ill face, and consequently help remove the stigma and indignation in society that is keeping families hiding.



Thursday, 27th September 2007

## Training College Prior to Conference

### Training College Stream 1

#### Families as Partners in Care

##### For Mental Health Providers

A number of mental health services are now introducing the concepts and principles of WFSAD's families as Partners in Care into their treatment programs.

Our view is that multidisciplinary teams should include family workers if their programs are to be called "optimum" or "comprehensive". We invite you to take part in training to enable you to deal competently with families within your service.

Training will be given by expert clinicians working in the field.

During the training you will be introduced to WFSAD's new manual on implementing comprehensive care which will be launched at that time.

Up-to-date training materials will be provided.

A reception for course participants will enable you to mix socially and do some networking with graduates from both streams of the Training College.

The fee for the day will be \$150 (Canadian \$).

### Training College Stream 2

#### A Reason To Hope

##### For Families/Family Leaders

Family education, information and training are becoming well established as useful, even essential tools to help families who are coping with mental illness at home.

**A Reason to Hope** is a program designed to help families in both developing and developed countries and to assist them in the establishment of education courses within their territory. In our travels we have found that circumstances and cultures can be very different. Our revised course is being designed to reflect this.

We want our members to benefit from this revision and are therefore showcasing it in Stream 2 of the Training College at our Lighting the Path Conference in 2007.

The training will focus not only on course content but also on course delivery, a significant factor in engaging and supporting families, and in the education process.

Course participants will be provided with the new Reason to Hope Trainers Manual, as well as materials for use in the field.

A reception for course participants will enable you to mix socially and do some networking with graduates from both streams of the Training College. The fee for the day will be \$150 (Canadian \$).

We are grateful to AstraZeneca for support of this initiative.

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## A Preliminary Look at Conference 2007

### Lighting the Path

For the first time in Canada, the World Fellowship for Schizophrenia and Allied Disorders (WFSAD), in partnership with the Canadian and Ontario organizations, is hosting its 2007 International Conference in Toronto. This exciting and informative international event will focus on improving the future for those with depression, bi-polar disorder and schizophrenia.

Top science and research experts from around the globe will share their leading-edge knowledge with an audience of psychiatric professionals, psychologists, mental health agencies, public service organizations, government officials, NGOs, corporate human resource specialists, consumers and families. Lively plenary sessions

and interactive workshops will address vital psychosocial and employment issues, family interventions and cultural attitudes. Enthusiastic response from delegates and experts around the world promises to make the learning sessions and pre-conference Training College insightful and an exploration of new territory. Information, including registration forms and fees, will be posted on our website as it becomes available. Go to: [www.world-schizophrenia.org](http://www.world-schizophrenia.org). "Lighting The Path" is certain to be an outstanding forum. Join influential members of the world community. Share their different viewpoints and engage in open discussions about the impact of mental illness in day-to-day living.

## Families as Partners in Care

### WFSAD Continues its Quest to See Implementation of Optimal Comprehensive Care

The World Fellowship is looking into why comprehensive integrated care is taking so long to be implemented around the world. Despite all the research findings indicating the benefits of care that includes the family and takes a multi-disciplinary view of optimum care, only a few centres around the world are indeed implementing this work. The introduction of First Episode or Early Intervention Clinics has improved the situation as these enterprises frequently, though not always, work with families as an integral part of the care team to assure that the patient progresses. However, these programs are time limited whereas comprehensive care is, by nature, long term.

WFSAD plans to identify and engage key persons working or training in comprehensive care to pinpoint some of the key issues some services have begun to use these methods, while the majority only pay lip service to family involvement or exclude the family entirely. This work is now going forward.

The first meeting of key persons will take place during

May this year. If you have any views on the matter we would truly appreciate you providing information to us. Write to Diane at [pr@world-schizophrenia.org](mailto:pr@world-schizophrenia.org)

The next phase of the project will be to develop an implementation manual that will give practical information to service providers in setting up or modifying services to include families and close friends who are caring for an ill relative.

This manual will be available to trainees in our multi-disciplinary training on working with families to be given as a day-long course prior to the Lighting the Path Conference on 27th September 2007.

The project is being supported through an educational grant from Eli Lilly & Company.

## ACKNOWLEDGEMENTS

The board, the staff, the volunteers and the members of the World Fellowship for Schizophrenia and Allied Disorders give their sincere thanks to all those who have given support to us for 2006. In particular we would like to acknowledge the following corporate and foundation donors and grantees:

AstraZeneca PLC; AstraZeneca Canada

Eli Lilly (Global and Asia)

The Skoll Fund

Novartis Nona and Bill Heaslip

In addition we thank those many individuals who are contributing to our mission to help "alleviate the suffering caused by schizophrenia and related disorders".



The World Fellowship for Schizophrenia and Allied Disorders  
World Conference

Lighting the Path

Carrying the Torch for Mental Illness

Hosts: WFSAD, Schizophrenia Society of Canada, Schizophrenia Society of Ontario

# Toronto

## 28–30 September 2007

Training College 27th September

at the Delta Chelsea Inn in the heart of Toronto



### Pre-Conference Training College (see page 14 for details)

#### 27 September Course Stream 1

WFSAD Families as Partners in Care Program:  
Implementing Comprehensive Care that Includes Families—  
in a multidisciplinary approach to optimum care plus the  
launch of WFSAD's manual on this subject.

#### 27 September Course Stream 2

WFSAD Strengthening Families through Empowerment  
Program: Getting the best out of a family education course.  
Families are invited to train as trainers for this cutting edge  
program developed with the participation of international  
experts in the field. This is the launch of this training  
program.

### Conference (see page 14 for details)

An exciting and informative international event focusing on  
building a future for those with schizophrenia, bipolar  
disorder and depression.

Leading experts in Science and Research,  
Psychosocial and Employment initiatives, Family  
interventions and more.

**Visit our website to learn more  
about the conference,  
to find out about sponsorships  
and to register.**

**To be a sponsor, to register for the conference or to present a paper, contact**

**our Toronto office: email: [pr@world-schizophrenia.org](mailto:pr@world-schizophrenia.org) Web: [www.world-schizophrenia.org](http://www.world-schizophrenia.org)**

**Phone: (+1)416 961-2855 or Fax: (+1)416 961-1948**

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