



## A World Perspective for Members of NAMI

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*Jim Crowe, President of WFSAD, was part of a WFSAD symposium at the National Alliance for the Mentally Ill (NAMI) convention in July. Below is an excerpt from his talk: Innovative Services and Family Support Models in other Countries—A Reflection.*

WFSAD was founded in 1982 by National bodies from around the world. In that time it has grown from strength to strength. Overall there are 56 countries involved, of which 26 have full voting rights. WFSAD encourages the for-

mation of National Family Organisations to strengthen the family movement, which helps forge a strong working partnership with professionals.

WFSAD is a family organisation founded by families for families. In the countries I have visited the stories I hear are very similar. Family organisations have started because of the need for families to share experiences and hope in the future. Families have a need to be listened to and respected for the knowl-



edge that they have unfortunately acquired because of a mental illness within the family. WFSAD brings together a host of such organisations which, in turn, can lead to empower and enable international advocacy for, and on behalf of, families.

*(Continued on page 5)*

## Ravi's Personal Story

*Reprinted from the Schizophrenia Society of Ontario, Toronto Chapter Newsletter, September 2001. Ravi Sarin spoke to the May 2001 annual meeting of the Toronto Chapter SSO. Here are some excerpts of his talk.*

Mine is a good news story. Good news, because there has been in the past too much pessimism and bad news about the illness of schizophrenia. As you know, that is changing with the new developments and new treatment approaches

for this brain disease. However, let me first give you a bird's eye view of the severity of my illness for the first six years. After finishing Grade 10, I began to have difficulty concentrating, and went from an A student to a barely passing student. I began to have a relentless buzzing in my ears, day and night, soon to be replaced by voices of angels. I vividly remember my first psychotic episode: the skies opening right above me and Satan sitting beside me laugh-

ing at me. Faces of people were all distorted. They appeared like apes. They too were talking about me, without moving their lips, and laughing at me. I was in a state of total terror. Later, a peculiar surge of power came into my body like lightning. I began to feel powerful. I thought I was the Messiah sent to save the world. But I was confused as to how to go about it.

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**The Power of the  
Family Movement:  
Catalyst for  
Change  
WFSAD  
Fifth Biennial  
Conference  
hosted by  
ZENKAREN  
9-11 October, 02  
Kyoto, Japan.  
—see page 13**

## Focus on Uzbekistan

**The important thing seems to me to stay in touch...be ready to support initiatives from the professionals within the country that provide real help for individuals with mental illness and their families in Uzbekistan.**

The ancient cultures of the Silk Road are showcased in the architecture of cities such as Samarkand and Bhukara

**The impression I received was that community mental health care was very basic, with families undertaking most of the care of their mentally ill relatives, as best they could.**

*Brenda Harrison, Ph.D., a psychiatric nurse from Australia, has worked for many years in a self-help support organization set up entirely to help family carers. Below she reports on her trip to Uzbekistan.*

On a recent trip through China and central Asia on the 'Silk Road Railway' I visited Tashkent, calling in on Dr. Nikolai Vasnetsov. Some of you may remember Nikolai from the conference in Jerusalem in May 2000. Since his return home after visiting Jerusalem, Nikolai has been involved in the assessment of young people with mental illness. However, he, his wife Tatiana and friends retain contact with and support individuals with mental illness and their families in the Tashkent community. It was good to meet with some of these people and realise how the support they received affected the quality of their lives.

For some years now Nikolai has been endeavouring to get an organisation focused on family care of individuals with mental illness formally recognised within the country. When I was in Uzbekistan this process was still going on. However, in the months since then, I understand the organisation has now been formally recognised and registered by the government of Uzbekistan. This is no mean feat in a country where, like many others around the world, mental illness is not the highest priority for a highly bureaucratic government.

Whilst in Tashkent, Nikolai took me to visit the Tashkent Mental Hospital where he used to work. The Director of the hospital was most welcoming and I had the opportunity to see around the hospital and meet with some of the nursing and medical staff employed

there. Having minimal first hand experience of mental health care outside of the United Kingdom and Australia – where I've spent my working life – it was a privilege to meet and engage with colleagues from Tashkent.

Russian is still the main language used in mental health care in Uzbekistan and by many of the population. With Nikolai as translator, I was able to talk with other nurses about common issues in care delivery and medical staff about treatment issues. The discussions were vibrant and we identified many common dilemmas and issues in treatment, nursing care and teaching of mental health professionals.

Visiting the longer stay wards was an eerie experience. Many of the patients there had a chronic psychotic illness and their general presentation was very similar to that of patients I have nursed over the past thirty years. Whilst the staff were aware of the progress in pharmaceutical treatment of mental illness and the new 'atypical antipsychotics' available in some western countries, both cost and availability of drugs was obviously influential in the treatment these staff were able to provide both in the short term and long term.

I formed the opinion that the situation in Tashkent was little different from that in many countries where a large proportion of the general population are subsisting with difficulty and the government's economic present and future economy is far from robust. It is a fact that in such places, mental health care is not a high priority for public spending.

Tashkent Mental Hospital was built in 1896 and the one hundred years anniversary of its

existence was celebrated in 1996 with a publication highlighting the work of many of the staff. The layout of the hospital is typical of its era – substantial ward buildings spread throughout the extensive and once beautifully tended grounds. Now there is a 'feeling of yesteryear' about the place. Many buildings are little changed – inside or out – from when they were built. But the place is spotless and the staff have a right to be proud of the quality of basic care they provide. The compassion and care for patients was consistent through the wards I visited and staff I spoke with.

I asked about mental health care outside the Tashkent Mental Hospital. The impression I received was that community mental health care was minimal. It seemed that in many rural areas mental health care was very basic, with families undertaking most of the care of their mentally ill relatives as best they could.

Uzbekistan is a country of contrasts. The Russian influence is still strong in many aspects of life – from the metro in Tashkent, to the blocks of flats the Russians built after the 1966 earthquake that devastated much of Tashkent city and killed thousands, to the dominance of Russian as the language of communication in the country. The ancient cultures of the Silk Road are showcased in the architecture of cities such as Samarkand and Bhukara, and there is a fledgling tourist industry that is beginning to cater for westerners. However, the country generally is not wealthy and does not have major exports to attract foreign exchange. Whilst that is the case, it might be reasonable

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## Ravi's Story—continued

(Continued from page 1)

...My family found it hard to communicate with me because my talking made no sense. I could not follow a conversation. There was no way of reaching me. I went through a variety of medications, always in very high doses. Although they reduced the severity of my symptoms, they immobilized me with side effects. I was a walking Zombie. Walking was stiff—I'm told my face was expressionless and I drooled. Wouldn't that scare anyone? I had ten hospital admissions over five and a half years. Life was empty; there was no enjoyment. I was spending much of the time in bed, unable to take part in any household activities, doing nothing much beyond eating and sleeping. All the friends I had at school were not to be heard from again. I was afraid of being called crazy or a nut. I didn't know what to tell anyone about my illness, how to ex-

plain what was happening to me. I was slipping, and losing all hope, and wanted to end it all—and I made suicide attempts. I'm sure you get the picture!

My recovery didn't begin until I was stabilized on an atypical antipsychotic, clozapine, along with antidepressants. Once stable and free from any positive and negative symptoms of schizophrenia, I was developing enough insight to move on with my life.

As my thinking and concentration improved, I could read again, and carry on an intelligent conversation. I began to work hard on improving myself...

...My first step was to catch up with my formal education because I had lost 6 years of education...

...I enrolled in the Redirection through Education program at George Brown College. It felt great to be back in the mainstream, I had a student number and I felt part of the student body at the campus.

There was no intimidation, there was no stigmatization. Next I had extensive aptitude and skill testing to learn that my interest lay in the Health Care field. I then took a Health Care Aide course. Studying was really hard, I had to spend hours in learning, things didn't come easy...  
...I remember telling my parents when I was preparing for my exams that I was never going to do another course. But passing that course, with honours too, was very rewarding and gave me more confidence in my mental capabilities...

...In January last year I was hired to work with the Assertive Community Treatment Team (ACT) of Toronto East General Hospital, as a Peer Support Counsellor. Engagement is the first crucial phase of ACT care and critical to the final outcome. As Peer Support Counsellor, I consider this to be one of my main roles—to facilitate engagement of the

(Continued on page 14)

***I was a walking zombie—I'm told my face was expressionless and I drooled...wouldn't that scare anyone?***

***"Passing that course, with honours too, was very rewarding and gave me more confidence in my mental capabilities..."***

## Focus on Uzbekistan—continued

(Continued from page 2)

to expect that mental health care will not be a high priority for the government of Uzbekistan.

I came away wondering what could be done to support individuals with mental illness and their families in Tashkent and other parts of the country, and how mental health professionals could be supported. What I am sure is that imposing our (western) ideas and ways of doing things will not necessarily be the best thing. We need to be open to the ideas and

guidance of concerned professionals within Uzbekistan. Even getting resources into the country could be difficult – and this may or may not be helped by the current (post September 11<sup>th</sup>) situation. The important thing seems to me to be to stay in touch, be supportive and be willing to learn from those inside the country how we can help best. Whilst this may sound like a cop-out it isn't. It comes with a heartfelt plea from someone who has been to Uzbekistan and been ex-

posed, to some small extent, to how the country operates. The message has to be don't forget these people, do the little things that we can, and be ready to support initiatives from the professionals within the country that provide real help for individuals with mental illness and their families in Uzbekistan.

*Brenda Harrison.*

*You may contact Brenda Harrison at [buda@standard.net.au](mailto:buda@standard.net.au)*

## World Health Report 2001

**A copy of this report should be placed on the desk of every legislator and health and human services director**

*The World Health Report 2001 Mental Health: New Understandings, New Horizons.*

The World Health Organization from time to time issues reports on what is known about various diseases in the world. This is the first on mental illness although in 1989 there was a report on consumer involvement, including families, in mental health and rehabilitation services, and there have been reports on psychiatric treatment (1993) and on rehabilitation (1995). The present report is more comprehensive as it deals with what is known about each disorder considered and also about stigma and political issues.

The focus of this report is on depressive disorders, schizophrenia, mental retardation, disorders of childhood and adolescence, drug and alcohol dependence, Alzheimer's disease and epilepsy. These were selected because severe disability is associated with all of these disorders. Each disorder is described and relevant prevalence and incidence data are summarized. For example, given that the point prevalence of schizophrenia is 0.4% it is estimated that 24 million people in the world suffer from the disorder at a given time. To put this number into perspective, this is more than the combined populations of all the Scandinavian countries.

Two major points are made: 1) we now have the knowledge and techniques necessary to

improve the quality of life of people with these disorders, and 2) governments are not doing an adequate job of providing needed services. These two points need to be brought to the attention of mental health policy planners and service providers everywhere. A copy of this report should be placed on the desk of every legislator and health and human services director. The report states that many developing nations do not have a mental health policy; they might have added that neither does the United States, and people with mental disorders suffer needlessly as a consequence. It is hoped that nations will take the recommendations seriously and will develop workable mental health policies and plans that will then be put into action.

The recommendations made are realistic as they take into account the financial and human resources of the various nations. It is recognized that in many nations there is little money for any kind of health, let alone mental health which everywhere gets the smallest portion. In these countries certain relatively inexpensive services such as low-cost medications and case management or nursing services can still be made available. The situation is, of course, different in the wealthier, industrialized countries. Here, the problem is one of inadequate management of service delivery systems and the failure to provide full coverage to all people in need. It is of interest that in the treat-

ment and rehabilitation section the approach taken is one that emphasizes a public health orientation and that evidence-based treatment is given priority throughout. For schizophrenia the two examples of effective treatment mentioned are medications and family interventions. Although not specifically said, it is clear that they refer to the more extensive form of family psychoeducation that is recommended in the WFSAD Families as Partners in Care program.

The topic is enormous, but the anonymous authors have adopted a highly condensed style to bring forward the gist of the many topics considered. There is ample use of tables and figures. It makes a good read and as a reference book it is indispensable.

The report is available in book form from WHO and in electronic form at the WHO website: [www.who.int](http://www.who.int)

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*WFSAD President-Elect*

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For schizophrenia the two examples of effective treatment mentioned are medications and family interventions

**Check the WHO website for a copy of the report [www.who.int](http://www.who.int)**

## World Perspective—continued

(continued from page 1)

WFSAD is constantly looking ahead for new opportunities which will provide a better future for families. Where possible we link countries together, which enables them to share information and support. This, we believe, is very important for countries where it may have been difficult for families and professionals in the past to obtain up-to-date information. Families deserve the best and we endeavour to seek out what we believe are the best models of treatment and recovery. Through education internationally, the WFSAD strives to increase understanding and compassion and reduce the fear, stigma, discrimination and abuse that accompany these difficult conditions.

WFSAD, and its member organisations, focus on the humane treatment of people with schizophrenia and on their primary care, which falls frequently upon the family, most often the parents, and lasts a lifetime. There is need for housing, rehabilitation, recreation and a decent life for those with this brain disorder, for which there is no known cure. It is estimated that some 40% of sufferers have no contact with formal mental health systems (WHO). Support, training and education is necessary for families who have an enormous and continuing burden to shoulder.

The WFSAD Programme, **Families as Partners in Care** includes all who work with and support a person affected by a mental illness. It is a way forward for everyone to work together for a better future for the individuals and their families. Only by working together can we ac-

complish this goal.

Approaching the topic, Family Support Models in other Countries, caused me to reflect on how one understands the use of the term family. Generally speaking, in most western societies we tend to talk about family and consumers. We seem to separate out persons with mental illness from their family members. From my experience, in areas such as South East Asia, when the family is spoken of it is inclusive of all members of the family. In those countries almost 98% of people with a mental illness will live with their family. When we visit families in these countries we are aware of how the term family means the whole family. At family support meetings most often the person with a mental illness is also present and participates.

Some of the other noticeable differences between what happens in non-western countries and the West may be as a result of the lack of services, resources, and funding available from government. Health services can be very limited and provide little care. The availability and cost of medication is also dramatically different. Ritual and traditional beliefs may continue to play an important part in people's lives.

We in the West need to be very aware of these differences and of the needs, beliefs and cultural practices when we visit countries different to ours. One should never just arrive into a country and start to address the needs of its

people without first meeting with them. When Margaret Leggatt and I visited Chennai (6 families) and Bangalore (7 families) in India we made a point of visiting families at home. We found it to be an incredible learning experience. To visit those families was extremely important. When it came time to meet with the professional mental health services, we then had a picture of community needs from the family perspective.

At this point I would like to mention some of the projects in other countries which we thought stood out. But I would like to say this will be only a very brief glimpse into what is happening in the countries mentioned. There are so many countries I would like to mention who are doing so much with so little.

India

In Chennai (Madras) there is a voluntary organisation called The Banyan. It's a project founded and run by two women who stood aside from a professional career. The Banyan started when they noticed a woman being abused in public. They learned that the woman, called Kali, was mentally ill. From that event they began to look for other homeless, mentally ill women. A house for the people was then started, they now have two houses with 50 (approx) homeless women staying with them.

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***In most western societies we tend to talk about families and consumers...we seem to separate out persons with mental illness from their family members...***

***...when the family is spoken of it is inclusive of all members of the family...***

**World Mental Health Day 2002—10th Anniversary**

**The theme will be "The Effects of Trauma and Violence on Children"**

## World Perspective—continued

**The family care program in a rural area often lacks medications... There were stories of community efforts to buy them.**

**"Bureaucracy is a word that the people from The Banyan have not yet found out its meaning, and prefer not to."**

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The two women also stay in those houses to look after, support and help rehabilitate the residents. Banyan then sets out to attempt to reunite the women with their families. This is sometimes very successful. Extraordinary when one hears that the people in Banyan come from all over India. Mentally ill women in India have no standing. The family, not understanding what is happening to the mentally ill person, tend not to support them. This reflects the lack of information and education about mental illness.

The people from The Banyan do what they can with very limited resources, mainly donations. It is an inspiring place to visit. So much is being done with so little. Bureaucracy is a word that the people there have not yet found out its meaning and prefer not to. They have a vision and it will become a reality. (Nor have they formed a committee.)

We also visited an organisation called The Family Fellowship. It is situated in a poor region some 60 kilometres from Bangalore, and was started by a psychiatric social worker, himself a family member. This is a residential facility for some 40 people. The whole facility is run by family members. The house and rather large grounds have been rented to the organisation for a very low rental. There is a hope that the owner may eventually donate it to the

Family Fellowship.

Expenses are kept low because the burden of care is shared by the family members. The building itself is not in good repair. The psychiatric social worker intends to devote all his time to the project when he retires in about two years time. This project is a community one, there is no government involvement. Both I and Margaret Leggatt feel that this astounding example could quite easily be introduced into other impoverished areas of India. Why could we not do similar things in the West ?

Philippines

A family care program in a rural area often lacks medications. There were stories of community efforts to buy them. Nevertheless, paying for them was a huge struggle. Medications took a quarter of the family's income.

One psychiatrist trained health center personnel, who in turn trained community based volunteers in the management of psychiatric patients. They taught them how to handle focus group discussions and hold meetings between health center personnel and significant members of the family with a mentally ill relative. The psychiatrist who initiated this project now stays in the background; regular meetings with families are convened where the health center personnel take the lead, but where the family members have now become very active. Attempts

are being made to go beyond the resources of the health center to find money for medication, and for the development of livelihood projects.

This was an excellent example of finding resources that were not costing government any money. It was our belief that this model was one that needed replication throughout the rural areas of the Philippines.

Mini-OLYMPICS 2000.

I would like to briefly mention the Mini Olympics which was organised in the name of the World Association for Psychosocial Rehabilitation, 'for the improvement of the quality of life of individuals and families affected by mental disabilities.' Four teams from the mental hospital/clinics competed as athletes in tug-o-war, basketball, and athletics. It was a day in which patients with chronic disabilities, psychiatrists, O.T.s, nurses, bureaucrats, famous personalities, patients and families all participated enthusiastically. Could we not do something similar?

I mention this because of the enthusiasm that I saw expressed by all who participated. It was a wonderful day. Fun filled and a very normal activity. The people who participated were in different stages of recovery. It was their day.

*...this speech will be continued in the next issue of the WFSAD newsletter, 2nd quarter, 2002.*

## Borderline Personality Disorder

I'm Elizabeth Ferrari, my partner is Doug Ferrari the comedian. Together, we've worked for nearly six years now to get appropriate treatment for his Borderline Personality Disorder, support for ourselves as a family, support and recognition for the many families just like ours who wrestle with this situation barehanded at home.

When I read of WFSAD's *Families as Partners in Care* program, I saw instantly that such a project would change life as we know it, those of us engaging BPD.

By way of introduction, in California where we live, there is a vocabulary that pathologizes those who informally do much of the care for people like my husband. We are *codependent* or *victims* or other negative terms. *Carer* is not a word we use here. Our very idiom reflects how little families like ours are known, addressed in a constructive way, or tapped for our experience and strengths. We are not expected to survive as a family; we are in fact actively encouraged to disband. Although BPD is a neurological situation, once it is interpreted by one or more brains, it manifests characteristic dynamics. These require a particular environment to work, to *thrive* as it were. Isolation, relational fragmentation and inconsistency, negative or unrealistic feedback are among those.

To date, the fragmentation of most treatment plans duplicates the dynamics of the disorder itself. Because, currently

in the United States, there is no coordination among the elements of treatment needed by BPD sufferers. So, a person struggling with BPD, -- with a sometimes discontinuous memory, with personal boundaries that shift and destabilize relationships, is very, very hard-pressed to carry information from one doctor to another, from a case manager to a therapist.

When I look at the treatment systems that Doug and I have had to navigate, most exacerbate -- if not duplicate very precisely -- these dynamics. Sadly, the Borderline Personality Disorder is blamed for its *resistance* to treatment; the underlying logic of the failures of treatment goes unnoticed. The biggest obstacle to successful treatment for BPD is the failure to enlist and to support the family. This is a large claim, but I believe, one that can be proven.

I'm a Shakespearean who accidentally was educated in Object Relations. I'm not a clinician; I have, however, spoken to hundreds of families dealing with BPD over the last 5 years, and in those years learned exactly how relational BPD is in its expression. Distress is nearly always voiced in terms of an intimate relationship. It's possible that no other disorder can be so keenly read via the family and the home. So, any treatment plan that does not actively enlist the family has very little chance of success, because it ignores the relational arena where the disorder presents itself.

Because BPD sufferers routinely try very hard to present a calm face to the world, only the family may know thoughts, feelings, behaviors that indicate a need for much more serious care, medication, even hospitalization at times. The family must have an avenue to share this information usefully with clinical staff, with the certainty that the report will be carefully considered.

Our borderline loved ones sometimes struggle with suicidal impulses; others turn their distress outward. These are extremely dangerous situations -- needlessly so. If our families had a way to communicate the onset of such a moment, so much needless suffering could be prevented, contained, diffused. Currently, we are told to call 911 in an emergency. This is tantamount to driving our loved ones to the nearest jail because their limbic system is committing a chemical crime.

We all struggle to maintain some coherence in our family lives. Too often, our families are broken up because we exhaust ourselves in the process. We watch our partners make little or no headway; more often, we see them slip out of a treatment plan that never truly addressed the basic situation -- instead unwittingly reinforcing unreality, black and white solutions, distrust, disrespect. Our families get the message, "Shut up" or

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Soon to be published in *Current Opinion in Psychiatry... a technical review by the World Psychiatric Association on the Usefulness and Use of Second Generation Antipsychotic Medications*

"...there is a vocabulary that pathologizes those who informally do much of the care...we are co-dependent or victims...carer is not a word we use here."

## *Borderline Personality Disorder—continued*

*(Continued from page 7)*

"Disband" even as we are tacitly expected to lead lives impossibly disrupted by illness on one side, by cultural blindness on the other. Even as we are asked implicitly to hold this situation, we are told that we should abandon it.

There is a better solution, and I see it in the program *Families as Partners in Care*. It is possible to call up the strengths in a borderline family; indeed, it is incumbent upon anyone in the borderline business to do so. The technology to help borderline sufferers exists; our real

challenge is to get it delivered. In the case of BPD, the family is the bridge the borderline sufferer can utilize to achieve a more positive and fruitful life, with relationships that are more stable, with a sense of self that can grow stronger and more resilient.

So, in a very concrete way, *Families as Partners in Care* is very exciting to me and my family, because we've learned that we can learn; that our efforts can improve not only the quality of our lives -- but that of others, of life on this pear shaped planet.

Here in the U.S., we're on the eve of our Thanksgiving Holiday. I thank you for promoting this project, and on behalf of many, many families who seek peace and health with all their might. For our part, we will work to disseminate the goals of this project so everyone in our network knows how essential it is to our community.

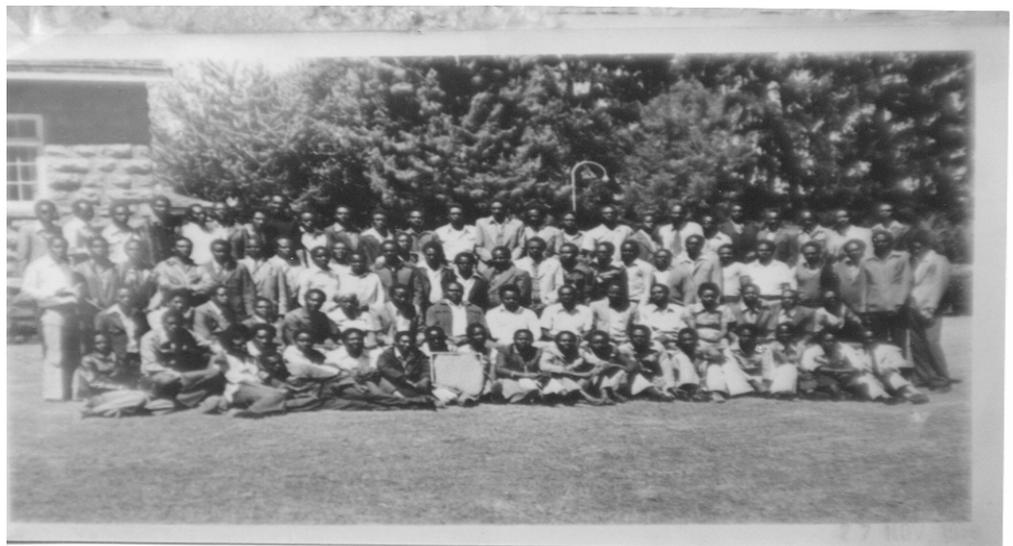
*Elizabeth Ferrari*

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Applications for regulatory approval of a long-acting injectable formulation of Risperdal (risperidone) now are being filed internationally by Janssen-Cilag. If approved, it would be the first atypical antipsychotic medication available in a formulation suitable for long-term use that requires administration just once every two weeks, instead of daily doses.

*Beerse, Belgium—4 Sept. 2001*

## *Schizophrenia Foundation of Kenya, Nyahururu Branch—Group Members Picture*



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## Mental Health System Reform in Japan

*Zenkaren responds to Economist article*

“A one sided, anachronistic and narrow view” was how ZENKAREN (the Japanese Alliance for the Mentally Ill) described an article in the November 22 issue of The Economist. According to Zenkaren the article entitled “The Dark Ages” is itself years behind and has not taken into consideration recent successful attempts at reform of the Japanese mental health system. Zenkaren, however, is quick to point out that though reform is in motion there is a lot that still needs to be done. Stigma is still prevalent despite the efforts of the family movement. [Both Zenkaren and WFSAD are determined that this issue will be raised and publicized at our joint conference in October.\*] In the fight against stigma it is still going to be difficult to eliminate discrimination in jobs, housing and social milieu.

Definite improvements have taken, and are still taking place. Abuses of human rights are unlikely to remain hidden any more, especially with the consumer and family movements, the media and other supporting organizations, says Zenkaren. In addition laws now protect the mentally ill against abuse. The listing of electric shock, forced abortions and beatings, described as though they are in current use by the article, need to be documented and brought to light if the author has evidence of them.

The Economist laments the slow pace of reforms which should have brought about community care of the mentally ill rather than the present institutionalized care. “Japan has three times as many mental-hospital beds per person as Britain, and seven times as

many as the United States. In America, patients stay in mental hospitals, on average, for eight days; in Japan, for more than 400.” Zenkaren agrees that stays in hospital are still very long, but feels that to absolutely deny the changes that are beginning to influence thought and action in mental health is to set these reforms back. “Since the reform of 1987, attempts at less institutionalization and at community-based care have brought some fruits slowly but steadily and no one concerned would say ‘Nothing seems to change’. It is not enough yet but it is unfair if the various efforts to realize the idea of reform are not counted or valued at all.”

The article refers to a battle with the unions to maintain hospital bed numbers. This is not a Japanese phenomenon alone. As mental hospitals in

the west have been forced to downsize there have been monumental battles with unions to protect the hospital workers’ employment. The difference appears to be that in the west, governments directly own mental hospitals and in Japan these are privately owned.

Under Japanese law “mental hospitals are entitled, per patient, to only one-third the number of doctors and two-thirds the number of nurses that regular hospitals are guaranteed”, states the article. As these hospitals reduce their size, it would seem, therefore, an excellent time to re-evaluate and adjust this ratio.

The reform of mental hospitals is a world-wide need and not just a Japanese problem. With vast numbers of people being treated in these hospitals it is no wonder that changes are occurring slowly. While the author of the Economist article wants changes now, it would be wise not to make the mistakes of many western countries, which are downsizing and closing their mental hospitals without providing appropriate home and treatment settings, not only for the patients in the hospitals now, but for those who will continue to become sick and need services in the future. Removing mental hospitals does not remove mental illness.

\* ThePower of the Family Movement: Catalyst for Change. October 9 – 11, 2002, Kyoto, Japan. For information and registration contact WFSAD. See column on page 13 and address on back page or email: [info@world-schizophrenia.org](mailto:info@world-schizophrenia.org)

## Schizophrenia Days—Turkey—A memory



*It is almost a year since Schizophrenia Days took place in Istanbul, yet the memory of the conference and of the walk for schizophrenia which took place at the conference are still very strong in the minds of the participants. Public ignorance of mental illness made the carrying of the banner and the distribution of information a courageous activity.*

## Wellness Recovery Action Plan—A Review

*We gave the Wellness Action Recovery Plan to Lucy Hudkins to read, one of our regular, efficient volunteers, and asked her what she thought. Here is what she said.*

The book was very good for manic depression, but doesn't deal with schizophrenia much. The first part (developing a wellness toolbox, daily maintenance plan) was very good. The "Crisis Planning" section was quite helpful—this would be good for schizophrenia.

I wonder how effective power of attorney documents are for one's wishes now? I've heard the government can just override them—is that true? I believe families should pay attention to the patient's wishes when they are sane.

The plan works better for people who have insight into and accept their illness. Early warning signs fail to mention hearing things or seeing things, feeling persecuted, etc. But they are good as far as it goes. Some of this is mentioned in "when things are breaking down", but this happens to me before things actually break down. I get the angry outbursts when I breakdown and schizophrenic symptoms too, sometimes. These parts in the book are pretty helpful.

Ideas as to what to do (to cope with early warning signs) are good too—relaxation, using lights in the winter for depression, calling the doctor, counsellor, getting meds adjusted. She suggests these and it helps me to do these.

Section on getting five friends is difficult for me and other schizophrenics. Most loonies just want to talk about their own problems from my experience—they don't want to help me with mine. It's hard for me to keep friends because of my outbursts, from what I've read, other schizophrenics have these problems with making friends too. So I think the peer-counselling section isn't practical for us.

The best part of the book for me is the Crisis Planning Section.

*Wellness Recovery Action Plan by Mary Ellen Copeland  
Mail order to: PO Box 301, West Dummerston, VT 05357-0301  
Phone 802-254-2092  
[www.mentalhealthrecovery.com](http://www.mentalhealthrecovery.com)*

Ken's parents don't come out of this book looking very good. They are an example of what not to do when your son develops symptoms of mental illness

## The Day the Voices Stopped—A Review

*The Day the Voices Stopped (A Memoir of Madness and Hope) by Ken Steele and Claire Berman. Basic Books, 2001. ISBN 0-465-08226-2 \$25 U.S.*

From the dust cover: "Taunted by voices from the age of fourteen, in and out of hospitals and halfway houses for three decades, schizophrenic (sic) Ken Steele eventually emerged from madness to become a leading mental health advocate. This is his remarkable story ...." Written by Ken Steele and Claire Berman, this is a heart wrenching story that makes those of us that have gone through the roller

coaster ride of mental illness say to ourselves at every twist and turn in the story "Oh no, let it not happen this way!" Ken's parents don't come out of this book looking very good. They are an example of what not to do when your son develops symptoms of mental illness, and what not to do over the years of his suffering. Could one excuse them for their neglect of Ken because of the times in which they lived and the lack of information to lead them to better caring? I am not sure. It comes across that he was a nuisance to them, someone who inconvenienced their lives and they

wanted to be rid of him. This is Ken's subjective view, so they cannot defend themselves. We do not know the extent of the difficulties that Ken presented to his family, though we do know that he maintained contact with them all through. Since writing his autobiography Ken Steele has died of a heart attack. One could only wish that he had lived much longer to reap the benefits of the good life he had only just begun as a respected advocate for the mentally ill in the United States.

## *I Am Not Sick I Don't Need Help—A Review*

### ***I Am Not Sick I Don't Need Help!***

By Xavier Amador with Anna-Lisa Johanson  
Vida Press 2000  
(www.vidapress.com) \$17.95 U.S.

This book addresses, firstly, those families who have not sought education or information regarding the consequences of illness in their family member, and secondly those who have been unable to interact successfully with their loved one who is sick with a serious mental disorder. The first chapters therefore address the YANA realization: You Are Not Alone.

Mr. Amador is a clinical psy-

chologist whose brother has been sick for many years. He draws on his own experience as a brother and his experience as a therapist. The idea that a person's non-compliant behaviour is motivated out of stubbornness or denial is debunked and explained rather as a consequence of brain dysfunction. Poor insight is therefore considered as a symptom of illness and discussed in detail at the end of the book.

He explains that the neuropsychological defects have left the concept of self, beliefs about what a person can and cannot do, stranded in time. This results in the belief that things are still possible when all the

people around them realize that things are very different. "Four steps to creating a treatment agreement": Listen, Empathize, Agree, Partnership makes up the major part of the book. Amador describes the listening process, warning the reader about the damage that negative comments can do. Involving the patient and seeking his view is a major part of the plan.

Several things bothered me as I read the book. Amador seems to assume that all professionals are like him, while in reality, half the problem is often the attitudes of professionals to families. Examples show that

*(Continued on page 15)*

***The idea that a person's non-compliant behaviour is motivated out of stubbornness or denial is debunked and explained rather as a consequence of brain dysfunction.***

## *From the Journals*

### *Who Cares for the Carers?*

A column in the second issue of a newsletter from the Division of Psychological Medicine, Institute of Psychiatry, London, with the above title reports that schizophrenia affects the mental and physical well being of caregivers from its earliest stages. The findings are being used by researchers to develop new strategies to support people who care for sick persons, to prevent them from developing further mental illness.

The caregivers, mainly mothers of the person experiencing psychosis, were often distressed by the symptoms. They found difficult behaviours and social withdrawal of

their relative hardest to cope with. Many carers also had difficulties getting the help they needed from mental health services.

Guidelines in the new National Health Service Plan (UK) state: 'Local health and social care communities should ensure that each carer's needs are assessed and that carers receive easy to understand information about the help available to them, and the person they are caring for'.

Previous studies have consistently shown that approximately one third of caring relatives have elevated levels of anxiety and depression connected with the caring

role. This is one of the first studies to investigate 'burden' among caregivers of people with first episode psychosis.

At the early stages of their relative's illness, carers were no more likely than the general population to suffer from mental illness but they were found to visit their GP's more frequently. This suggests that even in its earliest stages, dealing with psychosis can be stressful for carers and that if unchecked, can develop into more serious illness.

*Tennakoon et al(2000) The experience of caregiving: relatives of first episode psychotic people. British Journal of Psychiatry. 177, 529-533.*

***...even in its earliest stages, dealing with psychosis can be stressful for carers and that if unchecked, can develop into more serious illness***

## From the Journals—continued

### Glutamate

“Multiple lines of evidence suggest that although the psychotic phase of schizophrenia usually does not appear until adolescence, there may be a significant developmental component of the disease. Because glutamatergic signaling is an important influence on the development of neural cir-

cuitry, altered glutamate function, either primarily or as a downstream consequence of some other event, may be part of the pathogenic mechanism leading to psychosis.” This passage is quoted from an editorial by Tamminga and Frost entitled “Changing Concepts in the Neurochemistry of Schizo-

phrenia”. The September issue of the *American Journal of Psychiatry* contains several articles on glutamatergic transmission: Goff and Coyle; Smith et al., Dracheva et al and Lewis et al.

### Rehabilitation as part of Treatment

#### The Psychosocial Treatment of Schizophrenia: An Update

is a 12-page article by Bustillo, Lauriello, Horan and Keith which seeks to update the randomized controlled trial literature of psychosocial treatments for schizophrenia. A review of 18 studies showed support for family interventions. The efficacy and variability of “case management” is discussed. The studies reveal that “social skills training improves social skills but has no clear effects on relapse prevention, psychopathology, or employment status. Supportive employment programs that use the place-and-train vocational model have important effects on obtaining competitive employment.

*American Journal of Psychiatry* 158:2 163-175

#### Evidence-based psychotherapeutic interventions in the community care of schizophrenia

is the title of a shorter article by Graham Thornicroft and Ezra Susser which describes the various ways that treatment may be administered in the community. Much of the subject matter is similar to the previous article. Including support for family interventions for which “there is now strong evidential

basis”. We reproduce part of the concluding paragraph:

“The experience of recent decades suggests that even fully proven interventions for schizophrenia will not be implemented widely unless accompanied by vigorous advocacy and institutional incentives for adoption. Efficacious medications tend to be taken up, because pharmaceutical companies see to it, but for other treatments such as psychotherapy it is left to professionals, patients and family members to play this role. Presently we are ill prepared to undertake it. In terms of the field of psychological intervention for schizophrenia, the data now provide substantial evidence for efficacy and weaker evidence of effectiveness and cost-effectiveness, but the barriers to routine implementation have barely begun to be addressed; we should urgently do so.”

*British Journal of Psychiatry*  
Vol. 78 2-4

#### Social functioning and the course of early-onset schizophrenia (five year follow-up)

Lenior, Dingemans, Linzzen, de Haan and Schene report the following in the discussion section of their report. “The

results show patients with schizophrenia or a schizophrenia-like disorder to have considerable social limitations. For the young adults in our study parents appear to play an important role in supporting their offspring, in activities of daily living as well as in matters of follow-up treatment. Structural activities were rather scarce in this patient group: patients had no structural activities for almost 3 of the 5 years. This indicates that more attention should be paid to opportunities to activate and to support individuals who stay in the community to find structural activities, whether paid or unpaid. Voluntary, unpaid work appears to be an important activity. The number of months that this type of work was done was higher than the number of months in paid jobs. Voluntary jobs are important, because they give patients a feeling of worth and raise their sense of accomplishment. They also offer patients the opportunity to structure their life. The study also concluded that working with the parents of the patients helped them to support their children and diminished inpatient hospital care. *British Journal of Psychiatry*, 2001 179, 53-58 July

...more attention should be paid to opportunities to activate and to support individuals who stay in the community to find structural activities, whether paid or unpaid.

## From the Journals - continued

### Bi-Polar & Unipolar Disorder

#### Excess mortality in Bipolar and Unipolar Disorder in Sweden

“Increased mortality is one of the major adverse effects in individuals with mood disorders. In bipolar disorder, many studies found a mortality rate approximately 2 times and a suicide mortality rate approximately 10 times that of the general population, with suicide being the leading single cause of excess mortality. In major depression, several stud-

ies found an increased total mortality with a suicide mortality about 20 times that of the general population. The aim of this study was to assess mortality, compared with the general population, in 2 large cohorts comprising all patients in Sweden with an inpatient diagnosis of bipolar or unipolar disorder. This study of over 15,000 patients documented increased standardized mortality ratios (SMR) for suicide in patients with bipolar and unipolar dis-

order. The SMR for all natural causes of death was also increased, causing about half the excess deaths.

*Archives of General Psychiatry/*  
*Volume 38, September 200. 844-850*

#### Bipolar Symposium

We would like to alert readers to the June 2001 supplement of the BJP which reported the Proceedings from the First European Stanley foundation Bipolar Symposium.

It is curious that journalists view waiting lists for medical and surgical emergencies as hot news, whereas the same problem affecting psychiatric patients does not seem to merit exposure. The disadvantage of a low or invisible profile in the media is that governments feel little pressure to find a solution.”

Julian Leff—Why is care in the community perceived as a failure?

*BJP [2001]*  
*179, 381-383*

### Public Attitudes

“Unfortunately, the linguistic distinction between mental and physical illnesses, and the mind/body distinction from which this was originally derived, still encourages many lay people, and some doctors and other health professionals, to assume that the two are fundamentally different. Both are apt to assume that developing a ‘mental illness’ is evidence of a certain lack of moral fibre and that, if they really tried, people with illnesses of this kind

ought to be able to control their anxieties, their despondency and their strange preoccupations and ‘snap out of it’. It is true, of course, that most of us believe in ‘free will’; we believe that we ourselves and other people can exercise a certain amount of control over our feelings and behaviour. But there is no reason, justified either by logic or by medical understanding, why people suffering from, say, phobic anxiety or depression should

be able to get more control over their symptoms than those suffering from myxoedema or migraine. There is a further and equally damaging assumption that the symptoms of mental disorders are in some sense less ‘real’ than those of physical disorders with a tangible local pathology.”

*A quotation from “The distinction between mental and physical illness by R. E. Kendell. British Journal of psychiatry, 2001 178, 490 – 493*

## The Power of the Family Movement: Catalyst for Change—WFSAD Biennial Conference 9-11 October, 2002

We are pleased to update you on the WFSAD Biennial Conference which will take place this year in Kyoto, Japan. Our host is ZENKAREN, the Japanese Alliance for the Mentally Ill and a major member of the WFSAD. A Preliminary Program is avail-

able from WFSAD for international guests. For those in Japan wishing to attend, a program will shortly be available. We are preparing a list of exciting speakers which will be announced in the next newsletter (April, 2002). ZENKAREN holds an annual conference for its members and

this year’s meeting was held recently. Over 3,000 delegates attended. We anticipate that our joint meeting will draw an even larger number and will confirm “the power of the family movement”. There will be simultaneous translations in the large halls and consecutive

translation in the smaller rooms where appropriate. Kyoto is a very ancient and beautiful city which is particularly beautiful in the Autumn. Please join us for the conference and trip of a lifetime. Send for information: info@world-

## News from the Groups—Uganda

It was a sunny day of 10<sup>th</sup> November 2001, when Uganda marked the celebrations of World Mental Health Day held at Kampala city Centenary Park. The theme for this year was “Mental Health and Work”.

This day was the climax of the previous week’s activities.. Mental health promotion was the theme of the day; to assure people with mental health disorders that there are modern drugs and optimal treatment available. Activities included a march around the city, drama, dance and songs plus exhibitions by organizations such as Butabika Hospital, Psychiatric clinical officers’ school, Uganda Schizophrenia Fellowship, Mental Health Uganda, Uganda Herbalists Association-Transcultural Psychosocial organization etc.

We had many visitors to our stall; U.S.F members of Jinja joined us lead by the chairperson Mrs. Mawaali Margaret. It was really a day of learning new

things about mental health and inspiring hope to those who are affected. The chief guest was Minister for Gender, Labour and Social Development, who was represented by the Minister Of State for Youth and Children.

He noted that today most are increasingly appreciating people with chronic illnesses like HIV/AIDS, T.B and mental health disorders, and that stress is also increasingly identifiable. He left us with a piece of advice. “We should work together in order to alleviate mental health disorders.”

Another important event on this day was the launching of the Global campaign against Epilepsy in Uganda. People with epilepsy, like Schizophrenia, have been denied the opportunity to modern medicine, employment, and education because of stigma.

Another interesting news on that day was from the Minister of State for Health, who said

that programmes are underway to integrate, mental health services in general health services and primary health care. Present on the day were members of parliament, representatives of WHO, other political leaders, senior health workers, Director of Butabika hospital who was the chairman, National organizing committee of which I was a committee member and other distinguished personalities. I am indeed happy the day was a success; our banner flew in the atmosphere with our slogan “Families as Partners in Care” throughout the day.

*Walunguba Thomas  
Chairman U.S.F (Uganda Schizophrenia Foundation)  
You may reach Mr. Thomas at  
comnet@africaonline.co.ug*

**Ed. Note: WFSAD President and Past President will be giving workshops hosted by the Uganda Schizophrenia Fellowship in early March, 2002.**

Programmes are underway to integrate mental health services in general health services and primary health care

## Ravi’s Story—continued

*(Continued from page 3)*

client. I have been there, I know what it’s like to have schizophrenia. I find that the comfort and trust level of clients is high, and they are more willing to talk to me. What is amazing is that often I may not have even disclosed about my illness yet, but a client knows that I have schizophrenia....

...So my recovery and employment are a balancing act. I

have to pay attention to my health. I realize that I have to take my meds for the rest of my life to correct that chemical imbalance in my brain. No different than a diabetic needing insulin, who has to take it for the rest of his life. I have to take charge of my illness, and that is what I impart to my clients...

...I continue to need at least 9 hours of sleep. I can only participate in limited amounts of

social activities, and I have learned to say so...

...The scope of the job is exciting. No two situations, no two clients are alike. That is what is most challenging. There is ongoing learning which is mostly experiential, hence a place for personal growth. I also want to stress the fact that my illness, my recovery from it, and my employment are very much intertwined.

## Calendar

**NAIROBI, KENYA  
KAMPALA, UGANDA  
CAPE TOWN, S. AFRICA  
24 Feb—11 March, 2002  
WFSAD Workshops**

Kenya Schizophrenia Foundation; Uganda Schizophrenia Fellowship; Schizophrenia Foundation of South Africa. For details contact: Kenya: Dr. Owiti at clmcpsyc@insightkenya.com Uganda: Walunguba Thomas at comnet@africaonline.co.ug South Africa: Brenda Brett at brenb@Yebo.co.za

**YOKOHAMA, JAPAN  
24-29 August, 2002  
XIIth World Congress of  
Psychiatry**

The XIIth World Congress of Psychiatry is organized by the World Psychiatric Association (WPA) in collaboration with the Japanese Organizing Committee, representing leading Japanese societies active in the fields of psychiatry and mental health.

Conference Secretariat c/o: Convention Linkage Inc., Akasaka Nihon Bldg., 9-5-24 Akasaka, Minato-ku, Tokyo 107-0052 Japan. Phone: 81 3 5770 5549 Fax: 81 3 5770 5532

**COLOMBO, SRI LANKA  
4—7 April, 2002  
International Conference on  
Mental Health and Psychiatry—Recent Developments in  
Community Psychiatric Practice\*** Hosted by Sahanaya - the National Council for Mental health

\* **Dr. Radha Shankar and Ms Diane Froggatt of WFSAD will be giving a presentation on working with families.**

**COPENHAGEN,  
DENMARK  
25-28 September, 2002  
3rd International Conference  
on Early Psychosis: A Bridge  
to the Future.**

Website: www.ics.dk  
Fax: 45 3946 -515

**KYOTO, JAPAN  
9-12 October, 2002  
Fifth Biennial Conference of  
the World Fellowship for  
Schizophrenia and Allied  
Disorders: The Power of  
the Family Movement:  
Catalyst for Change**

Hosted by ZENKAREN, the Japanese Alliance for the Mentally Ill. For more information, contact WFSAD at info@world-schizophrenia.org or visit our website www.world-schizophrenia.org

**MELBOURNE,  
AUSTRALIA  
23-28 February 2003  
World Congress of the  
World Federation for Mental  
Health**

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

### **A planning guide to stimulating and topical events around the world**

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

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## *I'm Not Sick—continued*

(Continued from page 11)

families can be defensive and frustrated but not until much later in the book does the author point out the need for the family to find a therapist with whom they can work, a point that should have been made much earlier.

Useful tips about how to conduct a conversation with your loved one in order to show empathy are helpful. I felt the technique of "reflective listening" in which you respond with a question that tries to affirm what has already been determined: "So

you would agree that.... Would you?" was a really practical aid. Equally helpful is the idea of writing down the matters of mutual agreement, which may be brought into play again at a later date. Amador does not expect miracle "turn arounds" from his techniques. He points out that this work must be done over many weeks and months as trust builds between family (or therapist) and the ill person. A section on obtaining involuntary commitment, a procedure which has given heartbreak to so many families, shows the family that it is "O.K." to go this route.

For a small book it gives much practical advice and Amador can be forgiven for appearing to suggest that going off medication is the only reason people have exacerbations of their conditions.

Because this book is written in the United States there is considerable information about commitment laws at the end that will not be of interest to people outside this country. There are good lists of journal articles that one can pursue further. Altogether a useful handbook

DF

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

**WE'RE ON THE WEB!**  
**WWW.WORLD-SCHIZOPHRENIA.ORG**

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

*Schizophrenia is a very common illness, affecting one person in one hundred around the world. It affects people from all walks of life and usually strikes young people between the ages of 15 and 30. Although an exact definition evades medical researchers, the evidence points more and more conclusively to a severe disturbance in the brain's functioning.*

*The World Fellowship for Schizophrenia and Allied Disorders involves voluntary organizations of relatives and friends of people with schizophrenia and other serious mental illnesses, which are specifically concerned with the welfare of these people.*

*Individuals, mental health professionals, or non-profit organizations whose members deal with problems similar to those faced by people with schizophrenia and its allied disorders and their families are also welcome in the Fellowship.*



**Sunflower Petal Circle**



*Join our circle of donors by making a regular gift to WFSAD through your MasterCard or Visa. You may make quarterly donations of \$25, \$50 or an amount of your choice, or a one-time gift for the year. A member of our staff will be glad to help you with this (contact details above).*

**Planned Giving**

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

I give, devise and bequeath to WFSAD, located at Suite 104, 869 Yonge Street, Toronto, On M4W 2H2, Canada the sum of \$ \_\_\_\_\_ or \_\_\_\_\_% of (real or personal property herein described), to be used for the general purpose of the organization, at the discretion of its board of directors.

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