



Newsletter of the World Fellowship for Schizophrenia and Allied Disorders

Omar speaks passionately about mental illness

Opening Ceremonies, Sahanaya Conference, Colombo

Inside this issue:

Chainama Mental Hospi- 3
tal, Zambia

Give Us A Break — 5
Harrasment & Mental Illness

Obituary—Bill Jefferies 6

A Letter to Bulgaria's 8
President

Early Intervention Clinics 9

A Beautiful Mind— 10
Russell Crowe comments

Calendar 11

It takes a great deal of courage to come out in front of several hundred people and talk about your experience of mental illness. Yet, Omar, a consumer member of Sahanaya did so eloquently, and greatly moved his audience of government officials, the Norwegian Ambassador and other dignitaries at the International Conference of the Sri Lankan Council for Mental Health, Columbo recently. He was kind enough to give us a transcript of his speech.

Mental illnesses are a curse upon human kind. Just as only the blind know what it is to live in perpetual darkness, only those with mental disor-

ders truly understand the pain, the stigma, the frustration, rejection, the feeling of utter loss, the loneliness and sadness that mental illness brings.

Having said that, I have to admit that my illness has taught me a lot: It has taught me about life, about people, about how people reject anything they don't understand, it has taught me to accept things that cannot be changed, it has taught me to respect people who respect me in return, it has taught me to have empathy with all beings who suffer. But most of all, my illness taught me the value of drawing



strength from within me.

Sri Lanka is a developing country. So, naturally, the amount of resources that the Government can set aside for mental health is limited. Fortunately for us, people like Professor Nalaka Mendis had the vision and courage to do their own thing. Today we commemo-

(Continued on page 4)

Director's Report

From Newsweek to a visit to HPE Austria and more

The American news magazine *Newsweek* cover story for the issue of March 11, 2002, was a seven-page article entitled "The Mystery of Schizophrenia". It gave an unbiased account of the disorder from the subject of the award winning film "A Beautiful Mind" to personal stories of other sufferers, plus some scientific information. A side bar on page 49 exclaimed "Some

2.5 million Americans have the disease, which eludes even the **lovingkindness** (sic) of family."

I had the pleasure of visiting the offices of our Austrian national member Hilfe fur Psychisch Erkrankte Vereinigung der Angehörigen und Freunde (HPE) during a trip to Vienna last November. I

met with Executive Director Edwin Ladinser and volunteer Hedwig Nechtelberger and toured the offices. My host for part of my stay was an old friend, former WFSAD board member and founder of HPE, Dr. Maria Simon.

Maria invited Edwin and Hedwig to dinner at her home and

(Continued on page 2)



Director's Report—continued

HPE receives only project funding from government, which means that they must constantly be writing proposals.

2nd Announcement for our Kyoto conference 2002.

See special insert in this issue!

(Continued from page 1)

we exchanged information. HPE is very active. They employ two social workers who counsel families. Their regular half-hour and one-hour appointments are always booked. HPE receives only project funding from government, which means that they must constantly be writing proposals. Of course, this is better than getting no funding at all, as is the case for many of our members (and indeed ourselves)!

HPE has developed an education project to be delivered in schools, but are unable to convince the school system of the need to fit this into the curriculum. "No course is interested", Edwin told me. "Not even psychology." He also told me of the challenges HPE faces. "We read in the journals about case managers and social workers in the mental health field, but no such work exists in our system so it is difficult to explain it to gov-

ernment and difficult to advocate for it because no one understands what it is."

I was in Vienna for a Janssen Pharmaceutical focus group relating to the upcoming release of their new injectable risperidone. It was a pleasure to exchange information with other family members/ consumers and the representatives of Janssen who took part.

Our press release commenting on the sad loss of life in Tamil Nadu, India (see last newsletter) was reported in the *Times of India*. Only a month later we heard of abuses in Bulgaria through Mental Disability Rights International (www.mdri.org). We responded with a letter in both Bulgarian and English [see page 8]. The translation was made by Marina Kozareva and her family.

Then, we heard of a situation which must lend itself to abuse in Zambia (see opposite page). We hope this situation is amenable to some positive interna-

tional input. As soon as we get a clearer report on the needs we will contact medical colleagues who may be able to help.

Our president, Jim Crowe, and past president, Margaret Leggatt, visited the Republic of South Africa, Kenya and Uganda, giving lectures, workshops and training sessions to both professionals and families. At the same time, Dr. Radha Shankar and I went to Colombo, Sri Lanka, where we conducted workshops with families, both inside and outside the International Conference on Mental Health and Psychiatry. The conference was organized by Sahanaya, (meaning serenity), the major mental health agency in Colombo, run by Dr. Nalaka Mendis. Reports of these visits will appear in a future newsletter. For the time being we report the speech to the inaugural session of a very brave consumer, Omar [see page 1].

Plans for the Kyoto conference are fairly advanced now and you will find the Second Announcement for international delegates included with this newsletter. Please respond in the envelope provided. You may also register and get details of this meeting on our website: www.world-schizophrenia.org

We hope many of you will take this opportunity of taking part in our meeting and visiting the ancient and wonderful city of Kyoto.



Maria Simon and Edwin Ladinsler at the offices of our Austrian national member Hilfe für Psychisch Erkrankte Vereinigung der Angehörigen und Freunde (HPE) in Vienna last November.

Chainama Mental Hospital, Zambia

In August 2001 Mr. John Mayeya, Mental Health Advisor to the Zambian government arrived in Australia, supported by the University of Queensland through Professor Harvey Whiteford, chair of the International Consortium for Mental Health Policy and Services and the Mental Health Advisor the World Bank. Mr. Maleyeya's objectives included raising awareness of the appalling conditions faced by people with mental illness in Zambia, to seek financial support, to gain assistance in accessing desperately needed medication that is costly and difficult to obtain and to build collaborative links between non-governmental organizations, researchers and mental health service providers in Australia. Conditions in Zambia for people with mental illness are sometimes difficult for others to conceptualize. In the Chainama hospital, Lusaka, the only major psychiatric hospital for a population of 10 million, conditions in the psychiatric wards are extreme. There is one consultant psychiatrist who is not only responsible for providing treatment, but also for all training of future psy-

chiatrists in the country. This doctor is in his seventies and suffers a serious medical condition that could force his retirement at any time, with no successor. Without support from more resource-rich countries, the likelihood of future psychiatrists and other mental health specialists in Zambia is grim. In response to this situation, the University of Queensland, through the Kratzmann Chair of Psychiatry (Dr. Whiteford), in partnership with Toowong Private Hospital, has commenced a fundraising programme. All monies donated will be held in trust by The Schizophrenia Fellowship of South Queensland, and will go directly to the Chainama Hospital through the World Federation for Mental Health in Zambia.

The organizers would welcome any donations of money and equipment that anyone may wish to make to the Chainama appeal. The organizers also seek further fund raising opportunities and encourage business, organizations and individuals to consider how they can make some contribution to mentally ill individuals

and families who are suffering in Zambia today.

For more information on fund raising, direct donations or involvement in collaborative projects please contact Clare Townsend, Manager, Technical Centre, International Consortium for Mental Health Policy and Services at claret@wph.uq.edu.au
From *Sz Fellowship of S. Queensland Newsletter*, 10/01

Mr. Peter Darling, President of the South Queensland Schizophrenia Fellowship advises us that the first modest donation is being used for repairs to the facilities, including getting the toilets and water supply working again. The next lot of funds will be needed to cover the cost of transporting a shipping container of surplus equipment, donated by a Queensland psychiatric hospital that has recently had major extensions and refurbishment carried out. Clare Townsend is to visit Chainama in April and provide further updates. Can you help? Contact Peter Darling at darling@bigpoint.com or Clare Townsend at claret@wph.uq.edu.au

In the Chainama hospital, Lusaka, the only major psychiatric hospital for a population of 10 million, conditions in the psychiatric wards are extreme.

There is one consultant psychiatrist who is not only responsible for providing treatment, but also for all training of future psychiatrists in the country.

Youth's Greatest Disabler

A Regional WHO publication

"In almost all developing countries, over 95% of the chronic mentally ill live with their families. The family often finds itself in the unenviable position of being criticized by other family members and friends. The physical and emotional efforts involved in looking after the patient can be

both rewarding and burdensome. Hence, families need considerable inputs and support from professionals to help them manage the patient as well as their own lives."

From a recently issued publication by the World Health Organization, Regional Office for South-East Asia,

entitled "Schizophrenia: Youth's Greatest Disabler". The booklet was authored by Drs. R. Thara, Hidayetul Islam, Nalaka Mendis and D. Sucharitul.

For more information on how to receive a copy of this booklet, please contact our offices.

A Nurse talks about her schizophrenia clients

Betty Gillard, RN specializes in community mental health

The client may be upset and having trouble coping, but it is not always an issue of medication.

"One of the first things I noticed was that they had serious hygiene problems," says Betty. Some hadn't showered in months. Their body odour was very strong and their clothes and shoes were from charity stores and didn't fit. The question for Betty was, did the clients want to live this way, or was there another factor at play?

"I noticed that it wasn't easy for them to have a shower or bath because of the environment they were living in, or because of the mental illness."

Betty began a hygiene program. She encouraged her clients to come to the centre where she helped them shower and found them clean clothes that fit. It took time and patience to discover each client's

needs and concerns, but eventually all 16 clients began to come to the centre on a regular basis. What seemed like a small change began to have a big impact on the clients. They were more easily accepted by others, found it easier to go to the drop-in centres and restaurants. They began to feel more confident.

Another important issue for Betty's clients is medication. Betty works with the clients' psychiatrists to determine when medication changes are needed and in some cases when hospitalization is necessary. Again, it's a matter of taking everything into account before making a decision about what's needed for the client. "The client may be upset and having trouble coping, but it is not

always an issue of medication. They might be having trouble with housing or with people in their community."

By knowing when to call in a psychiatrist or when to turn to other resources, Betty has created a relationship with the doctors based on trust and mutual respect, which facilitates working with the clients.

Dealing with a client's hygiene issues, medication and addictions, or need for hospitalization, are important parts of Betty's job, but another equally important role is to act as an advocate for her clients in the legal system. Some of her clients have had run-ins with the law and Betty works with the Court Diversion Program to help them stay out of our jail while they await trial.

Omar's speech — continued

(Continued from page 1)

rate 20 years of such a vision put into reality. We will always be grateful to Professor Mendis for his tenacity and dedication.

I am completely satisfied with the programmes offered at Sahanaya. Perhaps the future Sahanaya will have a programme for our politicians. Now, I am not saying that our politicians should visit Sahanaya because they are all mentally ill! Don't worry ladies and gentlemen, our politicians have an excellent sense of humour. But seriously, if our policy makers were more aware of the reality of mental disorders, I am sure they would do more - even with the limited resources they have

at their disposal.

If one person could have had the vision, that would ultimately give birth to a haven for those who have mental disorders, if one person could have seen through 20 years of continued operation of that haven, if one person could have changed such a lot in so many lives, just imagine, ladies and gentlemen, what a lot the 250 of us gathered here today can achieve.

I am sure you have learned many things here today, you have relearned many things today, you have unlearned many things today, but remember, as you go home or to your hotels, together with the

knowledge you'll be taking the responsibility, the responsibility to take action. It may be just sharing something you learned today with another, it might be giving employment to someone whose mental disorder is under control, it might be trying to understand a person who is employed with you and has a mental disorder and is just trying to hang on, it might be helping with funds for the new Resource Centre. Whatever you do, I wish you all the very best from the very bottom of my heart. And don't forget we will be right behind you - at all times.

Thank you
Omar

"I am completely satisfied with the programmes offered at Sahanaya. Perhaps the future Sahanaya will have a programme for our politicians."

Give Us A Break

Exploring harassment of people with mental health problems

NSF Scotland recently sent us the results of a two-year project undertaken by the Nuffield Centre for Community Care Studies at the University of Glasgow, in partnership with NSF (Scotland) and the Scottish Users' Network. Below is an excerpt from their research and their findings.

330 people were interviewed in Scotland, living in housing estates, urban towns, cities and rural areas. Half the people interviewed had mental health problems and were receiving a service from their local Community Mental Health Team. The other half were members of the general public of the same age range and gender, living in the same areas and in the same types of housing.

The Findings...

When compared with the general public, more than twice as many people with mental health problems had experienced harassment. 41% of the people with mental health problems we interviewed told us about har-

assment they had experienced living in their community, compared to 15% of the general public.

Of the people that had experienced harassment, the top three features were...

- Verbal abuse
- Having their mental health problems exposed
- Unwanted interference

The Impact of Harassment...

91% of the people with mental health problems who had experienced harassment said that their experiences had an adverse effect on their mental health.

Half the people said the experience had frightened them.

Who are the Harassers...

Teenagers were committing 36% of the harassment. Neighbours and community members were committing 31% and families 21%.

Why people think they were being harassed...

90% of the people experienc-

ing harassment felt they were targeted because they were known to have mental health problems.

What Needs to Happen...

Recognition - the harassment of people with mental health problems needs to be acknowledged across all agencies, including police, housing services and health and social care providers.

Education - a range of anti-stigma initiatives should be ongoing e.g. in schools and the media, including advice on combatting harassment.

Prevention - strategies to eliminate harassment should be promoted, including identification during assessments and the strengthening of legislation.

For more information on this project, contact NSF Scotland at info@nfs Scot.org.uk or visit their website www.nfs Scot.org.uk

90% of the people experiencing harassment felt they were targeted because they were known to have mental health problems

"The Impact of Harassment...half the people said the experience had frightened them."

News Digest

Bangalore, India. AMEND has published pamphlets about schizophrenia in the language of Karnataka province: Kannada, where only 0.5% know English. The government is helping to distribute some 150,000 of these.

Moscow. The regional society of parents and friends of people with mental illness, called "Family Club" was instrumental in establishing the All-Russia

Society of Persons with Disabilities (ARSP): "New Choices" which was finally registered with government last June.

In October, Nellie Levina reports that three parents, including herself, were invited to visit the Calgary Chapter of the Schizophrenia Society of Alberta (SSA) in Canada. They studied the experience and programs of this remarkable organization and we were

pleased to become acquainted with its indefatigable leader Fay Herrick.

Yokohama, Japan. Professor Norman Sartorius has informed us that the XII World Congress of Psychiatry [see pg. 11 for more details] has, as its main theme, partnership between people affected by a disease—families, governments, professionals and others.

He met with leaders in other countries and together they forged the World Fellowship for Schizophrenia and Allied Disorders with my father as the first President

The Clarke Institute said to me, 'Go on with your life. Your brother is lost to you'.

OBITUARY

Bill Jefferies, Founder of WFSAD, Dies after long battle with Parkinson's

When I first took on the role of executive director of WFSAD in 1987, Bill was strong and tall and had just contacted Mikhail Gorbachev to see if we might forge alliances with Russian psychiatrists and families. Bill was a warm and wonderful man and we shall remember him with gratitude and love. Below are excerpts from the oration of Bill Jefferies' son John at his father's funeral.

NEETA COLA NEY
HUMPFEE NEEAM
NEEEHNEH SHOPEH X2
(Hear ye, hear ye we are about to hold a council Our Great Chief has died). Words of the Indian Council Ring at Forest Bay Camp where my father spent so much time. . . .

. . . Then came the moment my brother Jim became sick. I was in medicine but was of very little help. My parents searched everywhere for help, megavitamin Rx., elimination diets. Jim cooperated with it all. The Clarke Institute said to me, "Go on with your life. Your brother is lost to you". I visited him at Lakeshore Psychiatric Institute. My Dad cried when he didn't recognize me. But here Jim sits in the bosom of his family, a nicer guy you

couldn't meet. Beloved of his nieces and nephews, with a service award for 18 years of continuous work, he walks to work, he saunas and dares to jump into the cold lake and boats, helped by faithful adherence to his novel medications and because the *Ontario Friends of Schizophrenics* decided that they would turn grief into action and open the window onto despair. His son was not leaving his home without a fight.

. . . He came back to his roots, his medical colleagues. After I told him that I had heard Dr. Philip Seeman speak on tranquilizers, their clinical potency as reflected in their banding coefficient at the dopamine receptor, he took over. He contacted Phillip and his psychiatrist wife Mary.

. . . He started with the families in Oakville in this church building and together with time and talks generously given by these researchers and psychiatrists, such as Dr. Erhard Busse of Oakville, he forged his alliance – the *Friends of Schizophrenics*.

. . .The war on the greatest disabler of youth the world had

ever known was begun and he used the language of war – an all out fight – to win, using all the means at our disposal – legal, political, educational, sociological and above all, medical research. It has to encompass the whole country and so started the phone programs across the country, the large and small meetings in halls and churches, the first provincial conferences and national conference, including representatives from the United States, for example, Madison, Wisconsin. This was a world war and he traveled extensively with my mother, starting in 1975. He met with leaders in other countries and together they forged the World Fellowship for Schizophrenia and Allied Disorders with my father as the first President. My mother took over as President of the local chapter.

. . .He like dancing to Frank Bogart at the Granite, because he didn't stop living, he enjoyed life to the fullest...

News from Korea

By Suzie Kim

The Korean Family Association's new president, Mr. Chun, and the organization's new officers are doing well. The organization is more active and is expanding its branches in many places. The Family organization has a full time administrator and three part-time staff,

who are in the process of rehabilitation from our Center (The Nest of Love Mental Health Rehabilitation Center). I and my colleagues translated into Korean Dr. Falloon's Integrated Mental Health Care training manual, which we were given at the WFSAD

training session in Umbria, Italy, in 1999. We published 300 copies with the help of the Korean Janssen Pharmaceutica, for training psychiatric nurses and social workers. We did pilot training with our center members and their families along

(Continued on page 7)

Human Rights of people with mental illness in Mexico

The problems facing Mexico, in developing a humane system of mental health care, seem overwhelming. Large numbers of people held in unsanitary conditions, devoid of modern health care standards are documented in a report published in 2000 by Mental Disability Rights International. MDRI is an advocacy organization dedicated to the international recognition and enforcement of the rights of people with mental disabilities. To the present, MDRI has reported on mental health and human rights in Uruguay, Hungary and Russia (Children's institutions). The current report documents both negative and positive conditions and makes recommendations. The Afterword reports Mexican reaction to the report, including a promise to better fund the system and in one case to demolish a mental "asylum".

It is difficult to know where to start in summarizing the report, because the system seems to be deficient in all areas of care and human rights in many (not all)

of the psychiatric facilities. A major fear is that in reforming the system, the closing of the asylums will result in "patient dumping" into the community, rather than planning and funding community services to accommodate the large populations displaced from largely custodial care institutions. MDRI witnessed some extreme violations of human rights: People restrained uncomfortably for long periods of time; a lack of freedom to use toilets and therefore unsanitary conditions in bare, comfortless wards; few occasions to be outside the ward; long periods of inactivity; no possibility of asserting your human or civil rights. Many people were detained solely because they had no place to go. Ten black and white photographs by Eugene Richards are a testament to the desperation of the inmates of the facilities in which they are incarcerated.

On the treatment side, large doses of outdated medications were reported; inadequate staffing and generally under-funded

care. On the bright side, were the rehabilitation efforts now being introduced as a result of the citizens committees now allowed in every hospital, mostly as a result of the tireless work of Virginia Gonzales Torres, founder and president of FMREM - Fundación Mexicana para la Rehabilitación del Enfermo Mental.

Human Rights & Mental Health Mexico - A report by Mental Disability Rights International (MDRI)

By Rosenthal, Okin, Matinez et al. \$20US Text in English and Spanish. Available from MDRI, 1156 15th Street NW Ste. 1001, Washington, D.C. 20005. Email MDRI@mdri.org webpage: www.mdri.org

Editors Note: WFSAD hopes that a representative of MDRI, executive director and founder Eric Rosenthal, or one of his colleagues, will give a presentation at its Fifth Biennial Conference in Kyoto this October.

Ten black and white photographs by Eugene Richards are a testament to the desperation of the inmates of the facilities in which they are incarcerated.

Korea — continued

(Continued from page 6)

with friends. It was very good and many desirable results are happening.

On World Health Day last April, our government conducted its first health fair nationally. Mental health was an important part and occupied one full day during a week long event. It was a challenge for Korean people.

We had our 3rd Annual Music Festival in July and 57 men-

tally ill people participated with zeal, and the Theatre of Ewha Womans University was packed with people. It was a very successful concert. The receipts were donated to the rehabilitation training program to pay the fees of our members.

I am very glad to report that the physicians' strike (which included psychiatrists) which lasted six months, came to an end in late November. Many people, especially needy patients and family

members, suffered from this. Under the leadership of Korean Association of Psychosocial Rehabilitation (professionals) we had the second national anti-stigma campaign day. Along with its campaign, all four major professionals participated, demonstrating social adjustment training, talent entertainment shows and art & craft exhibitions.

Susie Kim

"We had our 3rd Annual Music Festival in July and 57 mentally ill people participated with zeal..."

Letter to Bulgaria's President

November 1, 2001
President Petar Stoyanov
President of Bulgaria
Dondukov 2,
1123 Sofia, Bulgaria

Dear Mr. President,

The World Fellowship for Schizophrenia and Allied Disorders is a non-government, non-profit organization dedicated to humane and therapeutic treatment for those with mental illnesses. WFSAD strives to reduce the fear, stigma, discrimination and abuse that all too often accompany these difficult conditions.

WFSAD and its member organizations focus on the humane treatment of people with schizophrenia and other psychiatric conditions that are often misunderstood and mistreated. There is need for appropriate hygiene, treatment, housing, care, rehabilitation, recreation, compassion and a decent life for people who suffer through no fault of their own.

We express our extreme concern for the plight of the mentally ill in Bulgaria. We

particularly refer to those incarcerated in inhumane conditions in the institution called the "Sandinovo Home for Mentally Disabled Women".

The practice of keeping 20 women segregated in degrading conditions, where hygiene and care seem of the least importance is abominable. Their situation is worse than the poorest care given to animals. Imagine **yourself** being housed in a cage for an indeterminate amount of time, with no access to a toilet, with arbitrary distribution of food and water and no attention to either your physical or mental health.

We deplore such practices and urge you to take immediate steps to ensure that the women of Sandinovo and any other people who may be kept in similar institutions are treated in a professional and humane manner, consistent with international standards laid down by the United Nations. We urge you to provide better care through increasing the staff ratio and employing staff trained in standard methods of

care. We urge you to terminate the barbaric practice of caging a human being.

We urge you to close this institution permanently, but before doing so, to ensure that the women are safely and appropriately housed in humane conditions.

How is it that in the 21st century people could be so exploited because of their vulnerability? This is the standard by which the world will measure Bulgarians, unless you set actions in motion that will drastically improve the plight of such people.

The gross neglect of these human beings is a crime against humanity.

Yours sincerely,

Jim Crowe, President
Diane Froggatt, Executive Director and Board of Directors, World Fellowship for Schizophrenia and Allied Disorders.

cc: Minister of Health
Prosecutor General

We express our extreme concern for the plight of the mentally ill in Bulgaria

For our French speaking members, there is a website devoted to debunking psychiatric myths and removing obstacles to improvement of the fate of chronically mentally ill persons.

www.mens-sana.be

What is First-Episode Psychosis?

Adapted from Early Psychosis Prevention and Intervention Centre, Melbourne Australia.

First-episode psychosis simply refers to the first time someone experiences psychotic symptoms. People experiencing a first-episode psychosis may not understand what is happening. Symptoms are highly disturbing and unfamiliar, leaving the person confused and distressed. If they have no real facts about

mental illness, their distress is often increased by negative myths and stereotypes.

A psychotic episode occurs in three phases. The length of each phase varies from person to person.

Phase 1: Prodrome

The early signs are vague and hardly noticeable. There may be changes in the way people describe their feeling, thoughts

and perceptions.

Phase 2: Acute

Clear psychotic symptoms are experienced, such as disorganized thinking, hallucinations, or delusions.

Phase 3: Recovery

Psychosis is treatable and most people recover. The pattern of recovery varies from person to person.

Early Intervention Clinics

Many families are wondering how *Early Intervention* clinics work, since oftentimes it is difficult to recognize real illness, particularly when it happens in an adolescent. Look at most of the early warning signs and they could be the signs of someone growing up, a rebellious adolescent. What we really need, say families, is a test that might be done in the schools, which would determine if a particular mental disorder was in its early stages.

Researchers are searching for this marker, which might then be used as such a test, but until that becomes a reality a number of psychiatric departments are doing their best to provide treatment [which might not be as early as we would like, but hopefully will be earlier than happens usually].

The PRIME Clinic, which op-

erates from the Centre for Addiction and Mental Health in Toronto, is one example of such a service for “individuals aged 12—45 years who are at risk for developing a first episode of psychosis”. The clinic brochure gives some bullet points for identifying who is at risk.

“People experiencing the early signs of risk often have:

- Confusion about what is real or imaginary; déjà vue; preoccupations with religion, superstitions
- Exaggerated self-opinion and unrealistic sense of superiority
- Suspiciousness or paranoid thinking
- Altered perceptions, such as hearing voices or seeing things
- Odd thinking and speaking processes; racing thoughts or slowed-down thoughts; talking about things irrelevant to context
- Lack of close friends or confidants
- Difficulty with social activities (for example, passively going along with most activities in a disinterested or mechanical way)
- Flat emotions, decrease in facial expressions, monotone speech
- Difficulty performing functions at work or school

Individuals who are experiencing difficulty functioning, and who have a family member who has a psychotic illness such as schizophrenia, are also considered to be at risk.”

Look at most of the early warning signs and they could be the signs of someone growing up, a rebellious adolescent.

The family as a resource

...Moreover, it is now accepted that families of the mentally ill can and should be considered a ‘resource’. Even for the minority of patients who do not live with a spouse or relative, family members typically have a practical and supportive involvement with the patient that predates and tends to outlast the involvement of a particular service or service provider.

These relatives can (among a larger set of contributions) offer the clinician: i) expert and longitudinally developed information about the patient, which is helpful for an appreciation of psychosocial deficits as well as for the assessment of current mental status; and ii) consultation in relation to and practical involvement with, case planning and case plan implementation.

Because of this, relatives are now increasingly considered to be treatment and rehabilitation team members.

From “Reconciling the patient’s right to confidentiality and the family’s need to know” by Mark Furlong and Margaret Leggatt. Australian and New Zealand Journal of Psychiatry 1996; 30:614-622

...family members typically have a practical and supportive involvement with the patient that predates and tends to outlast the involvement of a particular service or service provider.

A Beautiful Mind—Russell Crowe comments

The following is taken from an article by Jamie Portman, The Gazette (Montreal) December 14, 2001.

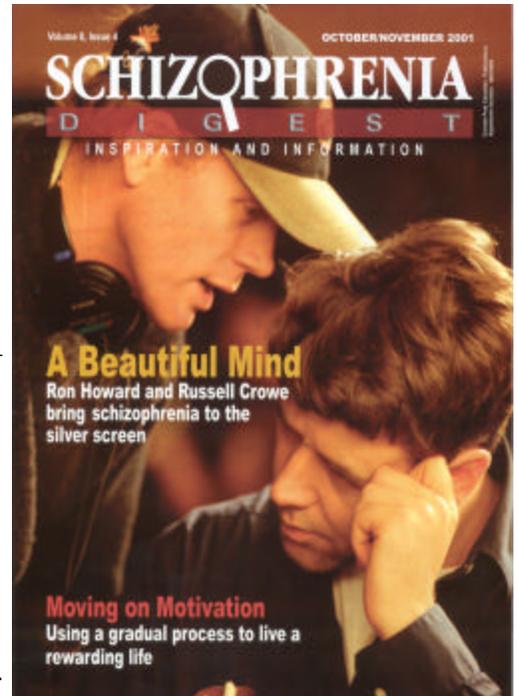
Russell Crowe is only a few minutes into the press conference, and already he's getting irritated with the questions.

He thinks they're frivolous, and he doesn't think there's anything remotely frivolous about his new movie, *A Beautiful Mind*, in which he plays a Nobel Prize-winning mathematician who has schizophrenia.

He's scarcely made it to the platform before a reporter asks him about the fabled link between genius and madness. Crowe makes short shrift of that one. "I think it is a romantic notion to think there is a connection between genius and madness," he says tersely. "There are many studies which I think indicate to you that whereas intelligence doesn't protect you from madness, a lack of intellect doesn't protect you either. It's across the board and it's in all social and economic areas of life." The Oscar-winning actor likes the follow-up question even less. Has he himself ever "lost it?" "I think like everybody in life I've had my moments, but in the true sense of the terms of insanity - no." He pauses. "I think it cheapens the seriousness of the disease even to go into that area." He glares down at the reporter who's asked the question.

A Beautiful Mind is inspired by events in the remarkable life of John Forbes Nash Jr., an eccentric genius who seemed headed for great things when he arrived at Princeton University in the

late 1940s. But the promise he showed as a boldly original mathematician was shattered when he developed paranoid schizophrenia and endured decades of emotional pain and despair. But Nash fought back, continuing his work through sheer force of will and eventually winning the 1994 Nobel Prize for his mathematical theories. Everyone connected with this film - Crowe, director Ron Howard, screenwriter Avika Goldsman - has taken pains to emphasize that *A Beautiful Mind* is not a literal account of Nash's life. For one thing, Nash himself has no memory of the delusions that tormented him as a young man. But Crowe says he has worked hard to capture the essence of the man, and bristles when it's suggested he must be finding it a "schizophrenic" experience to be portraying a real-life person while also filming key scenes that may be fictional. "Can we just do something?" he says slowly, and deliberately. "Schizophrenia is a really, really serious disease. OK? The social misunderstanding of schizophrenia is that it's about split personality, whereas in reality it's about thinking on totally different planes of reason. This film is not a medical statement about the disease, but at the same I wouldn't want anyone to think that we



The cover of the Canadian magazine "Schizophrenia Digest" October/November issue 2001

were stepping away from treating it as seriously as it needs to be treated."

"There are three big story points you've got here. You've got genius and madness and the Nobel Prize. Then you've got a hook - the developments and complications of the life of this guy built around the stuff that shows the spirit of the story."

Crowe concentrated on what he calls the "emotional path" of the story. He admits he was not up to understanding a mind that was able to evolve epoch-making mathematical theories. "You can't really take all that stuff in. You can take in as much as you can. But to sit up here and say that you've examined every bit of it and understand the processes of John Nash's mind would be an absolute oversimplification."

Schizophrenia is a really, really serious disease. OK?

Calendar - planning guide to upcoming meetings

BARCELONA, SPAIN 26-30 May, 2002

11th International Congress for Integral Psychosocial Rehabilitation within and with the community.

For more information visit their website www.arapdis.org/congress2002 or email congress2002@arapdis.org

ROME, ITALY 6-8 June 2002

WAPR Italia, International Conference on Psychiatric Rehabilitation Challenges and Controversies

For more information contact: MGA—viale Mazzini 145-00195 Roma, tel. ++39 0639730343 fax++39 0639730338 email info@mgacongressi.it

YOKOHAMA, JAPAN 24-29 August, 2002

XIIth World Congress of Psychiatry

Organized by the World Psychi-

atric Association (WPA) in collaboration with the Japanese Organizing Committee. For more information visit www.wpa2002yokohama.org

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 *5th 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 [\[schizophrenia.org\]\(http://schizophrenia.org\) or visit our website \[www.world-schizophrenia.org\]\(http://www.world-schizophrenia.org\)](mailto:info@world-</p>
</div>
<div data-bbox=)

NEW YORK, USA 19-20 October, 2002

1st Annual Conference—Family Perspectives on Borderline Personality Disorder.

Columbia University—College of Physicians and Surgeons, New York City.

For more information contact National Educational Alliance for BPD (914) 825-9011, or NEABPD@aol.com

MELBOURNE, AUSTRALIA 21-26 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

MEMBER FAMILY ORGANIZATIONS AND COLLEAGUES

ARE YOU HAVING A

CONFERENCE

CONVENTION

WORKSHOP?

WE'D LIKE TO PUT IT IN OUR

CALENDAR

PLEASE EMAIL, WRITE OR FAX US

See address back page

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

Work continues in Argentina and the continent

As a result of the work of APEF and the WFSAD visit to Argentina, there has been a great deal of interest in forming family groups in different parts of Argentina. Martha Piatigorsky, Dr. Edgardo Engelman and S. Beatriz Perez Feijoo spoke to an audience of 40 family members and were interviewed by journalists during their visit to Concordia in the province of Entre Rios.

During our visit to Argentina, we were pleased to meet with Dr. Maria Calvó from the north western province of Jujuy, which borders Bolivia. As a result of her interest in family work, the APEF outreach workers Martha Piatigorsky, Joan

Besch and Dr. Engelman visited this region and met with 50 family members, who were motivated to attend because of a whole page article in a local newspaper.

The APEF group was able to meet with families who were relieved to be able to discuss some very difficult problems, and gain encouragement from the knowledge that they are not alone. They were very grateful that APEF came. We offer our thanks to Pfizer CNS, New York and Pfizer, Argentina for their support of this outreach and mutual exchange work. We look forward to a new relationship with the Pfizer Foundation, who have provided WFSAD with a

generous grant to develop consumer/family organizations in this and other regions.

We are pleased to announce that WFSAD is organizing a symposium about working with families at the **South American Psychiatric Association Conference** in Guatemala 8 - 13 July. Our vice president Martha Piatigorsky will be coordinating this event, to which we hope to invite members of CATES-FAM, Venezuela, APEF, Argentina, the family association in El Salvador and other family groups in Latin America. Speakers will include Prof. Julian Leff and Prof. Dale Johnson, WFSAD President Elect.

President
Jim Crowe

Past-President
Margaret Leggatt

President Elect
Dale Johnson

Vice-President
Martha Piatigorsky

Executive Director/ Secretary
Diane Froggatt

Treasurer
Brian Kerr

Editor
Patricia Skelly

Founding President
A.W. Jefferies

World Fellowship for Schizophrenia and Allied Disorders
 869 Yonge Street, Suite 104,
 Toronto, ON M4W 2H2
 Canada

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.



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.

A Sincere Thanks to our Sponsors and Donors

The board and members of the WFSAD offer their sincere thanks to the following foundations and corporations for their support of our programs in the past two years:

- JANSSEN PHARMACEUTICA, Beerse, Belgium**
- PFIZER CNS Inc.**
- THE SKOLL COMMUNITY FUND**
- THE PFIZER FOUNDATION**
- NOVARTIS PHARMA**
- NONA & BILL HEASLIP**
- INTERFACE LTD.**

Thanks to the following Associates/ Individuals for their support:
Peter Arp, Stan Bozdech, Victoria Conn, John Cunningham, Dr. Jean Desclin, Jonathan Evans, Dr. Gordon Froggatt, Ross Kidd, Leah Knapp, Michael Kuderewka, Prof. Harriet Lefley, Geraldine Marshall, Dr. James Miles, Moncton Schizophrenia Society, Margaret Oberlander, Kiyoshi Okada, Kenneth Parsons, Graham Price, Jill Sadowsky, Elenor Smith, Craig Thompson, Masayuki Watanabe, James Weber, Dr. John Wing, Susan Wuhrman, J. Zelen-

Join our Membership or Become a Donor

We welcome your support

- \$25
- \$50
- \$100
- \$Other

Total: _____

Method of Payment

- Cheque (Cdn or US Funds)
- MasterCard
- Visa
- Money Order in Cdn Funds

 Name

 Address

 Phone

 Credit Card # Exp. date

 Signature

 Please print name as it appears on card