



# FAMILIES AND MENTAL HEALTH: Progress in Moscow

BY MARGARET LEGGATT, PHD, PAST PRESIDENT, WFSAD

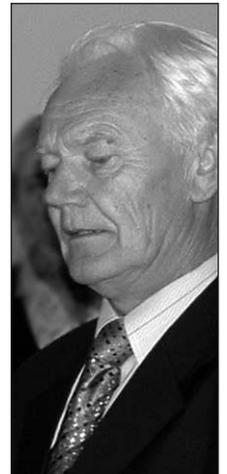
On September 5, 2006, I was the guest of Professor Vassily Yastrebov, the Head of the Scientific Department, Research Center for Mental Health and “retired” Vice President of the Russian Psychiatric Association. We were invited to visit Psychiatric Hospital Number 14 situated in Moscow.

Professor Yastrebov gave details of an exciting development in Russian psychiatry. From September 2005 to March 2006, a series of round table discussions were attended by patients, members of their families, and professionals from clinical and research psychiatry. Representatives came from Moscow, the Moscow region and other country regions. These informal meetings were organized by the Chief Psychiatrist of the Ministry of Social Development, with help from Astra Zeneca.

The meetings focused on many aspects relating to psychiatric treatment and care. Some of the topics under discussion were problems associated with the stigma surrounding mental illness, protection of the rights and interests of patients, the need for improvement in the living conditions of patients in residential facilities, and the need to change the image of mental illness in the mass media. The discussions drew on experiences from foreign as well as local sources such as the WFSAD and National Alliance for the Mentally Ill, and from the World Health Organization, the World Psychiatric Association and consumer organizations.

## New Federal Council Formed

The end result of these discussions was the formation at the federal level of “The Public Council on Mental Health Problems”. This Public Council aims to connect all professional and non-professional organizations in mental health for the purpose of improving



Professor Vassily Yastrebov

all aspects of help and support to mentally ill people and their family members.

Professor Yastrebov, who is the chairperson of the Public Council on Mental Health Problems, described its immediate priorities as being:

Dr. Leggatt writes about her recent visit to Russia and the progress there, including:

- A recently formed organization called “The Public Council on Mental Health Problems”, which brings together professional and non-professional organizations in mental health to improve all aspects of help and support to mentally ill people and their family members. The council’s activities include developing and promoting psycho-educational programs, de-stigmatization programs and mental health days.
- Another organization – “Family and Mental Health” – offers several initiatives to address the needs of patients, their relatives and the family as a whole.
- A tour of Psychiatric hospital Number 14 revealed a home-like atmosphere on wards, with patients allowed to stay as long as needed.

- **The promotion and development of psycho-educational programs** – Through enhancement of the Russian Federation public psychiatric sector, to support patients and help members of their families.
- **De-stigmatization programs** – These programs aim not only to de-stigmatize people with mental illness, but to raise the profile of all people who work in psychiatry, and psychiatrists in particular.
- **Mental Health Days** – To be held in October, Mental Health Days will be an opportunity at federal, regional

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and municipal levels to involve directors and other employees of psychiatric facilities and services, patients and their family members, the mass media, other authorities and representatives involved in psychiatric service development.

The formation of the Public Council was brought to the notice of the chief psychiatrists in the regions; they were sent information about the main goals and activities of the Council, together with information about the heads of various committees that had been formed. Particular emphasis was given to the need to think about programs for Mental Health Day. The secretary of the Public Council is Galina Tumenkova; coordinator - Tatjana Zmushko. Galina's email address is tumenkova@serbsky.ru.

The development of the "Public Council on Mental Health Problems" marks an important milestone in the history of Russian psychiatry.

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

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## Progress of Family and Mental Health

After this talk by Professor Yastrebov, staff, patients and family members at the psychiatric hospital provided us with information about the progress of Family and Mental Health, a charitable public organization. This organization in Moscow was founded by researchers from the National Mental Health Research Centre and officially registered on June 6, 2002 after six years of experience in providing social, psychological and informational support to people with mental illness and their family carers.

Psychiatrists Tatiana Solokhina and Ella Rytik gave a presentation of the aims, goals, current programs and future plans of Family and Mental Health. Members of the organization include family carers, people with mental illness and professionals – psychiatrists, psychologists, social workers, a lawyer, and a general practitioner.

The aims of the organization are to:

- Improve the quality of life of the mentally ill and their families by providing psycho-social rehabilitation;
- Change community attitudes towards the mentally ill and to psychiatry; and
- Provide education for professionals in social and psychological approaches to treatment and care of the mentally ill.

The organization realizes its aims through:

- Involving patients, relatives and professionals in interactive activities that provide mutual support to each other;
- Understanding the complexity of family rehabilitation processes;
- Providing ongoing programs;
- Satisfying the needs of each group – patients, relatives and professionals; and
- Developing a professional team that is well-educated and able to make relevant, reliable and responsible decisions.

## Comprehensive Program of Activities

The activities of Family and Mental Health include:

### For patients:

The Club, which addresses the needs of patients, and includes a handicraft workshop, a studio providing art, music and folklore and art therapy.

A Rehabilitation Centre for patients that involves training in the development of communication skills, psycho-education, group psychotherapy and computer courses.

### For relatives:

Psycho-social education; individual and family counselling; and training in how to manage emotional reactions ("lowering of expressed emotion").

### For the family:

A leisure program of excursions mainly in the summer. Families are also given clinical, genetic and diagnostic information.



## What Can We Learn from Russia's Progress?

Russia's success attests to its use of the following tried-and-true principles of building strong groups:

- Attract and develop consensus among key stakeholders. One person can't do it alone.
- Be sure to include:
  - Decision-makers from relevant organizations,
  - Patient representatives, and
  - Carer representatives.
  - In Russia, they also included clinical representation.
- Some recent research also suggests inviting people who are "known obstructers" when working to create change. This allows the organization to consider and address all points of views as it grows, increasing ownership and support for the new direction. It also reduces the possibility of critics outside the organization acting as barriers to progress.

The Family and Mental Health organization also published an educational manual in 2003 for persons with mental health problems and their families, based on what had been learned from their experiences in recent years. Two detailed publications have also been distributed – "Our Journal" describing the activities of the organization, one for 2005, and another for 2006. These publications have been put together by the psychiatrists.

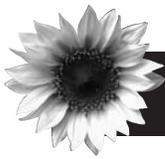
### Hospital Creates Home Environment

After this presentation we visited wards in the hospital and learned how some patients were now housed in small 6-10 bed units – very different from some of the huge wards that Jim Crowe and I have seen in visits to other countries. Credit goes to the staff for creating a home environment. Two other things really impressed me. Families are given a lot of help from staff, and patients are able to stay for as long as they feel they need treatment and care. I was very sincere when I congratulated the Director of the hospital on the challenges he must have faced to bring about these excellent results.

Then we were given a wonderful afternoon tea and musical entertainment from one of the patients. The occasion ended with staff, family members and patients quietly and tunefully singing that beautiful Russian song "Moscow Nights".

The entire afternoon was a very moving occasion. ■

*Various pamphlets about schizophrenia, the role of families and stigma have been translated into Russian and are available on our web site at [www.world-schizophrenia.org/publications/index.html](http://www.world-schizophrenia.org/publications/index.html)*



# Investigating the Genetics of Schizophrenia and Bipolar Disorder The Maudsley Family Psychosis Study

BY CHRIS CHADDOCK AND PROFESSOR ROBIN MURRAY

At the Institute of Psychiatry in London, U.K., the Maudsley Family Psychosis Study is being carried out. The aim of the Family Study is to discover markers for schizophrenia and bipolar disorder, which can be used to detect the predisposing genes and environmental factors that influence the development of these disorders. This article summarizes some of the major findings that have directly come from our study. These findings would not have been possible without the fantastic support that we have received from 190 families who have at least one person affected with schizophrenia or bipolar disorder; many have come via Rethink.

Both schizophrenia and bipolar disorder are to some extent hereditary. This means that understanding the genetics of these disorders is of key importance. Illnesses like schizophrenia and bipolar disorder are not thought to result from the action of a single gene, but rather from the impact of many (maybe even hundreds) of genes, with each one having a small effect. Recent evidence suggests that some of these susceptibility genes may be associated with both schizophrenia and bipolar disorders, providing an explanation for why it is sometimes difficult to distinguish one from the other. Whilst each gene's individual impact is too small to predict who will

go on to develop symptoms, understanding the effects of each gene is already proving important in identifying the causes and development of the illnesses.

Within the Maudsley Family Study, we use a number of techniques to investigate the biological markers of psychosis including neuropsychological tests, Event Related Potential (ERPs) and MRI scans.

This article summarizes investigations into the genetics of schizophrenia and bipolar disorder, which are to some extent hereditary. Some of the key findings include:

- People with schizophrenia and their closest genetically related relatives tend to have better verbal abilities than visual-motor skills.
- The speed that information travels in the brain tends to be lower in people with schizophrenia and bipolar disorder and their relatives. The study also identified a gene that seems to modulate this speed.
- Certain structures of the brain known as Grey matter and White matter

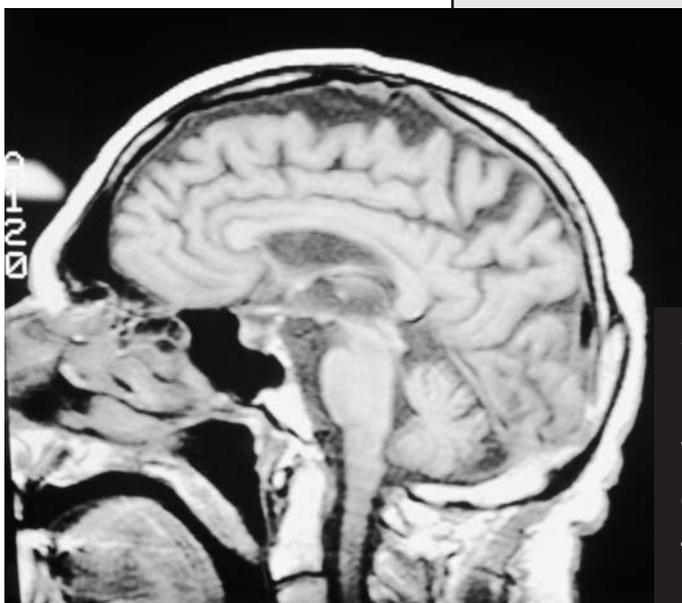
appear to be specifically altered in schizophrenia and bipolar disorder, impacting the processing of information and coordination of different parts of the brain.

## Comparing Verbal Abilities to Visual-Motor Skills

*Neuropsychological tests* allow us to look at an individual's strengths and weaknesses over a number of different cognitive (thinking) domains. For example, we have identified that people with schizophrenia have better verbal abilities than visual-motor skills. They may be more efficient, for instance, at defining words than manipulating cubes rapidly to construct geometrical designs. We have recently tested a large group of relatives of individuals with schizophrenia. We found that those relatives who were more closely genetically related to a person with schizophrenia also tended to show better verbal than visual-motor skills.

## Looking at How the Brain Works

*Evoked Response Potentials (ERPs)* are a way of looking at how the brain works. The test involves placing leads on the scalp which then record information about how the brain is functioning. One particular test that has proven very useful is the P300, which is a brief



**“The aim of the Family Study is to discover markers for schizophrenia and bipolar disorder, which can be used to detect the predisposing genes and environmental factors that influence the development of these disorders”.**

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electrical wave in the brain. The P300 wave measures how the brain pays attention and distinguishes between potentially important and non-important stimuli. One particular component of the P300 wave is the time it takes from the sound, to the time of the maximum amplitude of the wave, which is called latency. This latency has been found to be longer in both people with schizophrenia and their relatives, and also in people with bipolar disorder and their relatives. We found a significant association between a particular susceptibility gene for schizophrenia (Neuregulin) and the latency of the P300 wave. This finding may prove very important as it has identified a gene which seems to modulate the speed that information can travel within the brain.

### Identifying Alterations in Brain Structures

*Magnetic resonance imaging (or MRI)* is a way of creating images of the inside of the body and brain. We have used MRI scans to investigate whether there are particular structures within the brain that appear to be specifically altered in schizophrenia and bipolar disorder.

We investigated two major constituent parts of the brain: Grey matter, which is comprised of brain cells where the processing of information is completed; and White matter, which is made up of fibres, like electrical wires, that connect different parts of the brain together so that the brain can function in a controlled and co-ordinated fashion.

People with schizophrenia and those relatives who were most closely related to somebody with schizophrenia had slightly smaller volumes of Grey matter in areas involved in planning, organizing and remembering things – patients with schizophrenia often complain of problems with these processes. People with genetic liability to bipolar disorder did not have brain changes in the same regions, but in areas of the brain that have a role in regulating

mood. Importantly, people with a genetic liability to schizophrenia and also those with a genetic liability to bipolar disorder both showed an alteration in the volume of White matter in similar areas of the brain. This finding suggests that alterations in how different parts of the brain communicate may be similarly affected in both schizophrenia and bipolar disorder. ■

## HOW CAN I HELP? Families and Twins Wanted

The Maudsley Family Study is currently inviting families who have a member diagnosed with schizophrenia, or schizo-affective disorder, to take part in the study. We are also interested in seeing twins, where either one or both have a diagnosis of schizophrenia, schizo-affective disorder, or bipolar disorder. We would be very happy to hear from anybody with one of these diagnoses, and also from their relatives.

### If you would like to know more...

If you would like to find out more about the Maudsley Family Study (and Twin Study) please email, [madiha.shaikh@iop.kcl.ac.uk](mailto:madiha.shaikh@iop.kcl.ac.uk) or telephone and leave a message on 020 7848 0541.

Alternatively please write to: Madiha Shaikh, PO63, General Psychiatry, Division of Psychological Medicine, Institute of Psychiatry, De Crespigny Park, London, SE5 8AF (United Kingdom)

We will be able to send to you more information about the study including a newsletter detailing our research findings.



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## PSYCHIATRY ALONE CANNOT CURE MENTAL ILLNESS: WHO Official

Speaking at the second annual International Conference on Schizophrenia in Chennai, India in October 2006, B. Saraceno, Director, Mental Health Division, WHO, noted the following:

*“Mere psychiatry is insufficient to handle mental illness; it necessitates the involvement of non-medical sectors and the community, in addition to medical professionals.*

*“We are used to thinking that doctors and nurses represent the health sector and that patients and their families are the ‘objects’ of their work. But patients and their families are a resource not properly used”.*

He stressed that families and patients should be made partners in building quality mental health systems. Another important contributor would be the private sector non-governmental organizations (NGOs).

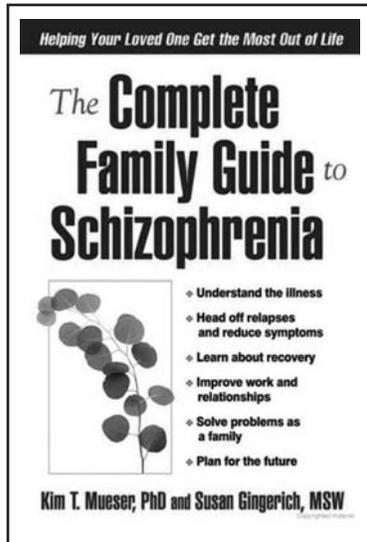


# SCHIZOPHRENIA: Help and Hope for Families

Help Your Loved One Get the Most Out of Life – The Complete Family Guide to Schizophrenia  
by Kim T. Mueser PhD, and Susan Gingerich, MSW. Published by Guildford Press (www.guilfordpress.com) 2006.

BY DIANE FROGGATT

This is not the first collaboration between Mueser and Gingerich on this topic. Some 12 years ago they wrote their first guide for families. Now a new publication on the topic comes on the scene and demonstrates that they have surpassed themselves and others in the field of educating and supporting families. Thirty chapters and 480 pages long, it is full of valuable, readable information set out in a logical and spacious way (no cramped text!). It is almost an encyclopedia on all aspects of schizophrenia from the views of both the patient and family. Each chapter is followed by a resource list, be it books, videotapes, websites or the like, as well as worksheets and checklists. After reading a chapter that interests you, you may be invited to visit a resource such as “Ian Chovil’s personal website”, or watch “The Bonnie Tapes” or other chapter-related resource. The book is intended for American families and though some of the references are United States specific, particularly the chapter on community resources, most of the information is useful for anyone anywhere.



*To the extent that you can control the factors that contribute to it, medical recovery is certainly a goal worth pursuing. But many people with schizophrenia and their relatives would argue that it’s preferable and more helpful to think of recovery as a process rather than as a single outcome. That’s because medical recovery can span decades, even a lifetime. It’s difficult for many families to keep going with their eyes on such a distant, often elusive, goal. Recovery as a process, on the other hand, keeps your eyes trained on shorter term achievements that may actually bring more meaning to everyone’s life than recovery in the strictly medical sense.*

This passage reminds me of earlier days in my family when, after the trauma of the initial experience of schizophrenia, we learned to measure improvements in our son’s condition in what we

used to call “millimetres” – and we celebrated these millimetres as though we had all conquered Everest!

Because this handbook is so large and comprehensive it might have been a bit daunting for a family reading about schizophrenia for the first time. However, Chapter 4 – Comprehensive Treatment – which follows the general framework of the stress-vulnerability model in guiding treatment, constantly refers readers to other chapters or sections of the book where they may read about particular matters in more detail.

Part Two focuses on the relationship between the person who is unwell and family members. Each person – be they parents, siblings, spouses, partners or offspring – can find a chapter devoted to emotional reactions, strategies and coping tools.

Part Three – Preventing Relapses – begins with a comprehensive chapter on medications, not just describing what they do and what they do not do, but giving practical help in order to maintain medication therapy.

Notable throughout is the subtle encouragement given to family caregivers to continue their work and become more active to ensure optimum treatment for their unwell relative. The section continues with stress management techniques, relapse prevention and reduction, and crisis management, including guidelines for helping prevent suicide.

Families who have been coping with schizophrenia for a long time will recognize many of the techniques and helpful advice included in Part IV – Creating a Supportive Environment – in which family

**“Notable throughout is the subtle encouragement given to family caregivers to continue their work and become more active to ensure optimum treatment for their unwell relative”.**

A really new feature is the chapter (Chapter 3) on recovery, and the authors’ efforts to explain and instill in the reader a “Vision of Recovery”. It is a gentle and sensitive chapter that leads the reader through an understanding of what the idea of recovery now means for all the stakeholders in schizophrenia treatment and care. It is not, as one previously expected, recovery from an illness as one might expect from a bout of pneumonia. It is a process in which a person can find his own path: in fact, the description is of a “process of recovering” rather than the traditional notion of “recovery”. Numerous examples from consumer literature on the subject are quoted so that by chapter’s end not only does the reader understand the “process” of recovery, he has an idea of how he might help his loved one to achieve it. Early in the chapter the authors say:

relationships are discussed in connection with communicating, solving problems and establishing rules and responsibilities.

Part V – Coping with Specific Problems – gives practical help on issues such as persistent psychotic symptoms, cognitive difficulties, anxiety, depression, alcohol and drug problems, as well as anger, violence and lack of insight. The section is a serious attempt to assist with these problems with many suggestions that will be helpful. Of particular value is the section on alcohol and drug abuse that describes the process through which people can change behaviours. Useful ways of approaching this and similar challenges occur throughout the section.

## WHEN A PARENT IS MENTALLY ILL: Focusing on a Teen's Perspective

*I'm Not Alone: A Teen's Guide to Living with a Parent Who Has a Mental Illness*

by Michelle D. Sherman, Ph.D. and DeAnne M. Sherman. Seeds of Hope Books by Beaver Pond Press, Inc. Edina, MN, 2006.

BY TRISH RUEBOTTOM

**About the Authors:** *Michelle D. Sherman, Ph.D., is a clinical psychologist and Director of the Family Mental Health Program at the Oklahoma City Veterans Affairs Medical Center, where she works extensively with families. She is co-chair of the Family Studies Team of the South Central Mental Illness Research, Education and Clinical Center (MIRECC). She is also a clinical associate professor*

*in the Department of Psychiatry and Behavioral Sciences at the University of Oklahoma. DeAnne Sherman, who is Michelle's mother, is a French teacher, trained dancer, and choreographer. In addition to being an experienced public speaker, DeAnne also volunteers her time teaching and mentoring junior high and high school students in the performing arts. The collaboration of psychologist and teacher, daughter and mother, brought true synergy to this project. The authors drew from and pooled their personal and professional life experiences in creating this book.*

This is an excellent book for early teens, 12 to 14 years old, a group that is often very isolated and

The book is a fountain of information and a great reference book for families and patients alike, to be read a chapter or so at a time and accessed time and time again as a great support and resource for all.

The last book that I remember greeting with such enthusiasm was Dr. E. Fuller Torrey's *Surviving Schizophrenia: A Manual for Families, Consumers and Providers* (Fourth Edition). Mueser and Gingerich's book has all the information and style of Torrey's book coupled with a definite "how to" theme and current information for the early twenty-first century.

**By the end of the book, youth will have read about others going through the same things, but will also have written their own thoughts and feelings about their situation, learning more about their own family and themselves.**

left out; it is a quick, easy-to-read, personal and interactive workbook that's main message is in the title: "I'm not alone".

The book is full of stories and examples from other youth, talking about common situations and reassuring the reader that all of the things they are feeling are ok and actually fairly common. It gives statistics on mental illness that emphasize just how common it is. And most importantly, the workbook gives room for the youth to explore questions about their own situation and feelings throughout the book, and to develop strategies and action plans for themselves. The focus is always on the teen, even when providing information about – and the perspective of – the family member with a mental illness.

Beginning with an overview of mental illness, the book focuses in the first section on definitions, types and causes of mental illness (specifically talking about schizophrenia, depression and bipolar disorder) as well as addictions issues, and treatment. The next section focuses on the teen: common feelings, remembering to take care of yourself, coping strategies, how to tell people, and how to deal with crises.

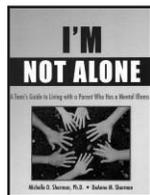
The book ends with some commonly asked questions, resources and glossary of terms based on the authors' many years of experience. It is very practical and actionable, and gives the reader hope "because there are things you can do to make things better" (introduction, p.v). ■

### SUGGESTION FROM "I'M NOT ALONE":

#### Express Your Feelings in Writing

Mom/Dad:

- I really want you to know that...
- I thank you for...
- I want you to understand that...
- I admire you for...
- I miss how our relationship used to be. I miss (share the things you used to do together – or describe how it used to be)...
- When you..., I feel...
- I wish that we could (share how you'd like your relationship to be now or what you'd like to do together)...





# Birds of a Psychic Feather

This article provides excerpts from a compelling first-person account of mental illness and describes how the narrator ultimately achieved relief from her worst symptoms through the help of a therapist, medication and through her close relationships with others.

The difficulty is to write clearly about an unbelievable something that occurred 10 years ago. It is recalled in my mind as unrelated images and imaginings, like a half remembered dream. Ten years ago, apparently, I was way out of my mind, yet until recently I had no idea that was the case.

I experienced a second mental breakdown two years ago, and have since been examining my emotional history and redefining the first episode that occurred. The description is how those events appear to me now.

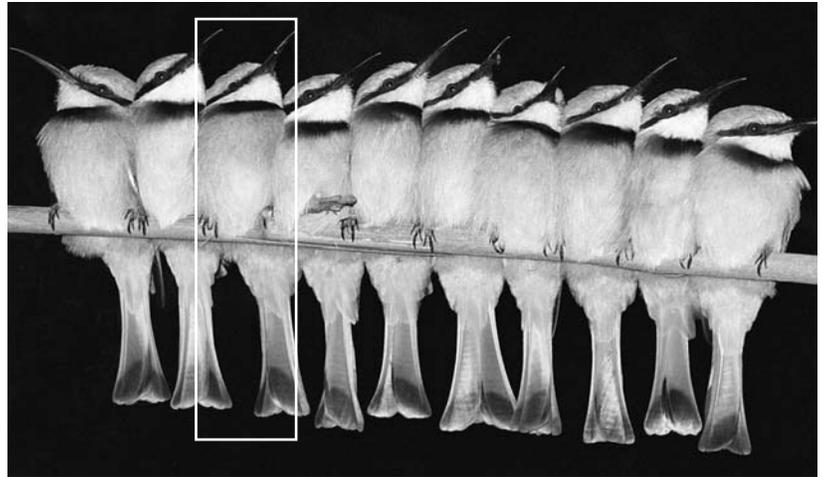
It is 1979, I am almost 20 years old. I have just left my alcoholic husband and am driving 600 miles south to a high-security specialized medical school. Because my husband drove us into debt and my military pay records have been lost, I have no money. One thousand miles west, my mother is nursing my 55-year-old grandmother who is dying of cancer.

During my drive, I notice that I am “seeing” things that are not there. Rabbits, cats and bugs appear and disappear. I also see people from my past, who I know to be dead or hundreds of miles away, driving the vehicles on the highway next to me. I believe that the FBI is following me because I notice that black cars with no license plates are taking turns driving behind me.

I am not alarmed. I attribute the sights to fatigue, and it makes sense that the FBI is tailing me since I am going to a high-security school, and the officers told me I would be closely watched. I am also too excited about the new life I am entering to think much about these events.

Once I arrive I settle into my room, meet my roommate and begin the school routine that will soon become familiar. I do well at the self paced, though rigorous program, and in my limited spare time I write news articles for the base publication.

After nearly a month I become fearful of my roommate. She seems inhuman to me – robot like. I notice that many of the students are this way. They don’t seem to have emotions. I conclude that the school is brainwashing all of the students through intercom speakers and the documents we are required to read. I find a fellow student who is also suspicious and she and I spend time running, drinking and discussing the propaganda to which we feel we are being subjected ...



...I meet another student in the hallway. “You look most attractive in your uniform”, he says. I am intrigued by his bold statement and I see that he is a tall, dark handsome man with an air of mystery about him.

I realize that this man is special because he appeared on my 20th birthday as I begin Phase II of my program. It happens in fact that we come to spend a lot of time together.

That night I first experience the dream. The images, colours and sounds are of amazing clarity. I am in an Egyptian Temple and before me on a platform stands a princess in a robe and head-dress. She speaks to me in a foreign tongue, very fast but I understand her meaning. She talks to me of my special role in life. This dream comes to me almost every night for the next three months.

Some nights the princess gives me a riddle ... I pondered the meaning of these riddles and finally confided in my mysterious man friend about them. He was not surprised. In fact he told me he knew about the dreams and the princess. He told me some things that indicated he was having similar dreams and then said that he felt I was ready for new knowledge that he had been sent to teach me. He was, he said, a prince looking for his lost kingdom. From then on he spoke entirely in riddles and told me things he had learned from the moon.

One wonders why I didn’t tell him he was obviously on drugs or crazy. I was confused and bewildered by the dreams and illusions I was experiencing, and mistrustful of this man who said he had them too. But I withheld judgment, tested him with questions and finally believing that he was authentic became something like his apprentice. Each week we had long conversations about things we felt were immediately meaningful. During these talks the prince, as I came to think of him, would tutor and quiz me ....

I began to think of myself as two people. One I referred to as “she”. “She” was the Egyptian princess – a constant voice in my head telling me what to do to help the prince find his kingdom.

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One day she told me that I was to have a special part in his future and that I should brand myself to make this clear. I used a hot iron to burn a scar into my arm that happened to resemble a lightening bolt. I knew this was the right thing to do because the burn did not hurt. Shortly after this I became pregnant. I told the prince and he said that this baby would be a king.

But now I became fearful of the prince, seeing great anger in his eyes on occasion and sensing in him a ghostly monster. I remember I once touched him and saw my hand go right through his arm. About then, the prince went to his home town to consult with his father. When he returned he announced that his father wished him to shun me and the baby. He did not explain why. That day I got a call saying my grandmother had died and against the wishes of the prince I got on a plane to go to her funeral. While in the sky I looked out and saw the giant head of the prince in the clouds forbidding me to go. Then the captain announced that the plane would be unable to land due to ice formations on the Chicago runway. I knew then the prince was all powerful.

I went to the officers of the school and complained of fatigue and anxiety. They gave me some pills that I did not take, fearful of their effect. Instead I talked with an officer in charge of the newspaper I'd been writing for and told him a small part of my dilemma. He felt that I was being drugged.

This had not occurred to me. But I reasoned that my thinking patterns resembled those I had experienced during my teenage use of drugs. I also noticed that the prince was particular about his food and never left it unguarded. I came to believe that he was drugging me through our daily meals together. I avoided him from then on. Interestingly I did begin to recover ...

Eight years later, I found myself in another extremely stressful situation. I'd earned my Master's degree in Communication and had been developing and teaching public relations writing seminars on a national level. By accident I discovered co-workers were cheating me. I'd recently broken an engagement to a talented music critic I loved very much and learned my stepfather was dying of cancer. I became quite depressed. I found it hard to do my work, to get out of bed, or to be with my friends. I'd started therapy to help get me through the ending of my engagement, but outside events seemed to be overwhelming. Again I saw rabbits and cats, but again attributed it to fatigue. I didn't even mention it to my therapist.

Then while home alone during a three-day snowstorm, I slowly receded from the outside world and was drawn inside to a place of many voices. A constant blur of conversation ran in the background, as if I were in a busy restaurant or airport. In the foreground, two or three voices argued, sang, rhymed words and spoke nonsense.

Looking around my room, I found that things had lost their emotional meaning. They were larger than life, tense and suspenseful. They were flat and coloured as if in artificial light. I felt my body to be first giant, then miniscule. My arms seemed to be several inches longer than before and did not feel as though they belonged to me.

This time I had help. I reached up and up the wall to a tiny little phone and called my therapist. I told him what was happening. He arranged for me to see a psycho-pharmacologist. This doctor took my history and explained that I was experiencing an imbalance of brain chemicals and put me on medication.

That was two and a half years ago. Since then I have remained on medication. First Haldol, but I gained too much weight, so we tried Moban. Now my symptoms vary in kind and intensity, but I am able to perform my job. I no longer travel or do much teaching since I need abundant rest, but I am able to relate to co-workers and do my work as a newsletter editor.

Some of my friends stopped speaking to me after the breakdown. A few have stuck with me and have been incredibly supportive. I have altered my lifestyle dramatically to allow for therapy twice a week, a lot of rest, careful eating habits and avoidance of crowded or loud places. My work ambitions are considerably different (once I would have said "lowered" but I no longer think that way). I have slowed myself down considerably and changed my values so that my relationships have become very important. I am also a more actively compassionate person. I attend 12-step meetings regularly for support and guidance and I have learned how to avoid worsening my symptoms.

Becoming too cold, too hot, tired or overwhelmed by noise or crowds will bring on symptoms such as elongated arms and unclear thinking, "seeing" little animals or a sense that my head is full of cotton. This happens also if I work hard at a steady pace without rest or adequate food. The emotional stress of therapy will sometimes cause me to go away or dissociate as will other types of emotional trauma.

Every so often I decide to go off my medication. I realize from experience that this makes no sense but it seems I have to try it now and then. Within from two days to one week, the symptoms return or intensify. This is painful and scary so I go back on. Then it takes me from one to three weeks to get back on an even keel. While this is a negative experience, it is my way of testing the possibility that I am well. I have trouble accepting that my illness is long term. I keep thinking I will stop the medication and wake up one morning and the illness will be gone.

I am coming to believe that the best way to accept my illness is to make it useful. To do that, I am cautiously sharing information about it with others. I am writing letters to people whom I see promoting the stigma of the mentally ill. I am writing stories about myself and others who are ill to help educate the mentally well. I would like them to understand what it feels like, and I would like to clarify for myself through my writing that this illness is really happening to me. I also benefit greatly from reading what other ill people write so I hope that I say something that helps someone else. Recently I told my mother of my illness. She said, "Well it's the furthest thing I would have ever imagined for you". I recognize in her words disappointment and sadness. And I hear my own silent echo of those words. It is the furthest thing I think that any of us imagine for ourselves. ■

*These excerpts are taken from a first-person account that appeared in the Schizophrenia Bulletin, Volume 16, No. 1, 1990.*



## Keeping Care Complete

BY DIANE FROGGATT

In the last issue of the WFSAD newsletter (2006-4, p. 4), we briefly reported on a study of caregivers of individuals with bipolar disorder, schizophrenia and schizoaffective disorder. The following is a more comprehensive report on the study.

This survey, for which there were over 900 respondents in eight developed countries, was conducted by the World Federation for Mental Health (WFMH) and Eli Lilly and Company. It sheds light on experiences and insights of family caregivers of individuals with bipolar disorder, schizophrenia and schizoaffective disorder. The goals of the project were to:

- Learn about the perspectives of family members – an untapped reservoir of insight;
- Raise international awareness of the impact of mental illness treatment and relapse on individuals and their families; and
- Complement clinical trial data that highlights the consequences of treatment discontinuation.

Of the respondents, one third were parents, a quarter were offspring and one fifth each spouses and siblings. Three quarters were female. Nearly all had a high level of involvement with their family member. Results have been provided by country as well as an overview of the combined results across countries.

It is no surprise to WFSAD that among the key findings were the following:

- Caregivers view effective medication as a top treatment priority and as contributing substantially to quality of life.

- This survey of family caregivers points to the importance of the correct medication, family support and reducing stigma and discrimination to help people with mental illness stay well.
- It also suggests a variety of reasons why consumers stop taking medication, and that more than “stabilization” is often the goal of treatment.
- The challenge now for organizations is to interpret findings from this valuable study in light of actions considered.

- Finding a medication that is effective can be a difficult and lengthy task, but it is worthwhile in order to provide the foundation for stabilization and wellness planning.
- Stopping medication and subsequent relapse can have harsh financial, physical and emotional consequences for the person and his family.
- Changes in medication should be treated with utmost care to avoid the possibility of relapse.
- The goal of treatment should be to maintain wellness, both physical and mental.
- Three quarters of caregivers listed family support as a key factor in keeping their family member well.
- It was the opinion of 84% of carers that stigma and discrimination make it harder for their family member to stay well.

### Why Do Relatives Stop Taking Medication?

One question asks caregivers why, in their opinion, their relative stops taking medication. This is particularly interesting, given the recent CATIE study (reported in WFSAD Newsletters 2006-1 p11; 2005-4 p10) in which non-adherence to a treatment regimen was a common result. In the Canadian result (used because detailed analysis was not publicly available for the combined report), the majority of caregivers attributed this to the patient feeling well and thinking he does not need medication. Fifteen percent said it was the side effects; 8% said the patient saw no improvement in his condition, but surprisingly, no one reported forgetting to take the medication as a reason for stopping.

Even after stabilization a number of families report that changes were made to medication regimens. In the past “stabilization” was the goal of treatment. The family response indicates that this may no longer be a sufficient enough goal.

Half the respondents (in the Canadian section) reported that family support played a major part in keeping their relative well. Other suggested methods such as talk therapy, social support, doing volunteer work, were not considered anywhere near as effective, but given that few of these methods are generally available it would be reasonable that these would not score highly.

The raw data is now widely available, especially in the participating countries. The results can be read at the WFMH website ([www.wfmh.org](http://www.wfmh.org)) and can also be requested from Eli Lilly and Company. A more challenging job still will be interpreting the opinions given in the light of actions to be considered. The survey is a valuable tool for use by family organizations in their advocacy work. We congratulate the authors. ■



## REGIONAL NEWS

### UPCOMING MEETING:

#### Growth Factors and Psychiatric Disorders

The Royal Society of Medicine is holding a conference on “Growth Factors and Psychiatric Disorders” on March 23, 2007 in London, UK. Topics on the agenda include:

- Pharmacological treatments of schizophrenia
- Schizophrenia genes
- Trophic factor actions on hippocampal plasticity
- Genetic variations in affective disorders
- Growth factors and inflammation in psychiatric disorders
- Molecular mechanisms of depression and mood disorders
- Genetic approaches to the study of anxiety

Find registration information at [www.rsm.ac.uk/academ/gfpd.htm](http://www.rsm.ac.uk/academ/gfpd.htm)



# The Legacy of Mr. Graham Louw

Graham Louw was a staunch supporter of WFSAD. Our most recent meeting was at a mental health conference in British Columbia where he discussed his plans for the future and his interest in rural programs in South Africa. He had the same fire and determination as always, even though he was already in his 80s. He served the cause of mental health well. The following tribute to Graham has been provided by Comcare Trust.

### Tribute from Comcare Trust

On June 16, 2006 our founder, champion and friend, Mr. Graham Louw, passed away suddenly. For many people, both locally and internationally Graham Louw was Comcare Trust.

When a family learns that their loved child has a psychiatric disorder, it is so overwhelming that each day becomes an unbearable challenge. Graham Louw believed that a diagnosis was not the end of the road or the end of a life, rather just a different path to take. Seldom was he daunted by the challenge of this new path. Instead he remained committed throughout to helping people and families struggling with psychiatric disorders to appreciate that quality of life and happiness was possible in spite of psychiatric disorders, and that people with psychiatric disorders needed opportunities to realize this.

Against all odds, popular practice and advice, Graham Louw and another family bought a home for adults with psychiatric disorders in 1984. Soon he realized that this group home afforded people with psychiatric disabilities both independence and the chance to celebrate life in the community. He spent the next 22 years of his retirement extending this service and creating an

organization and structure that would out-live him. Testimony to the success of his efforts occurred on Monday, June 19, 2006 – when the Comcare office reopened after his sudden passing, it was business as usual.

Many founders of organizations do not have the foresight to prepare for when they are no longer around to oversee the operation of the organization they had the vision and drive to start. Comcare Trust was blessed to have a truly wise founder who considered this inevitability long ahead of its actual realization and for this we will remain ever inspired and thankful for Mr. Graham Louw.

Today Comcare Trust provides eight supported accommodation services for 60 residents and a day centre for adults with psychiatric disorders. We have sound financial, administration and management systems and structures. We strive to offer a quality service that uniquely accommodates the challenges and difficulties our mental health care users encounter. We regularly evaluate our services and remain focused on sustainability and development for the future. This is the Legacy of Mr. Graham Louw.

# Dr. James Miles: Visionary and Agent for Change

BY GERALDINE MARSHALL, PAST PRESIDENT, WFSAD

Psychiatry has lost one of its great heroes. Dr. James Edward Miles passed away peacefully in North Vancouver, British Columbia (B.C.), Canada, on October 29, 2006.

Jim completed his medical training at McGill University in Montreal. He returned to Vancouver to practice family medicine for a few years before pursuing his interest in psychiatry. He completed his training at Maudsley Hospital in England.

Jim had a long, successful and distinguished career in his new field. He was a full Professor at the University of British Columbia. In 1976 he developed his first Affective Disorder Clinic in Canada (now called Mood Disorder Clinic).

For five years he was the Chief of the Department of Psychiatry at the University of British Columbia. In 1985 he established the first Schizophrenia Research Unit in Canada and he also established a research Chair at the university. He was mentor to many of the young psychiatrists now practicing in B.C. A very successful out-

reach program to the interior and outer limits of B.C. was also started by Jim.

Jim was a visionary and an agent for change. His leadership brought families and consumers and psychiatrists together in the new concept of "Partnership in Care" for the mentally ill. This created the opportunity for WFSAD and several similar NGOs to reach out nationally and internationally to teach, guide and support families with a mentally ill member.

Jim was a trusted advisor and friend to me during the many years I traveled to various parts of the world. The changes he made to psychiatry are the most positive of our time. He touched many lives and lived his life with much love, grace, charm, intellect, creativity and great humour.

He will be sadly missed by his family, his many friends, colleagues and patients. ■



## REGIONAL NEWS

### “Exploring Madness” Film Wins Award

Two Indian films on mental illness were shown at the Third International Video Journalism Awards last November in Berlin, and one of them – *Sentenced for a Lifetime* – was ultimately rated the second best film in the festival. The two films were part of “*Exploring Madness*”, a series of six short films that look at mental illness in India from a social perspective. The films were directed by Dr. Parvez Imam of f-20 Communications.

If you would like more information about this series or to purchase any of the films, please contact f-20 Communications by email at [f2ofilms@yahoo.com](mailto:f2ofilms@yahoo.com) or by writing to:

f-20 Communications; 1-National Park;  
Lajpat Nagar – IV; New Delhi – 110024;  
India.

### “One-Stop” Shop to Mental Health

Professionals, caregivers and people with experience of mental disorders, can now access a wealth of mental health publications and products with the launch of “Mental Health Shop”, at [www.mentalhealthshop.org](http://www.mentalhealthshop.org). The online resource features an array of books, leaflets, DVDs and videos on a range of

mental health topics including recovery, treatment and discrimination.

The Mental Health Shop was created by two leading mental health charities in the UK — Rethink and Mental Health Media.

Rethink aims to help everyone affected by severe mental illness recover a better quality of life. Mental Health Media works to reduce discrimination by promoting the diversity, visibility and expertise of people with experience of mental distress. ■



## WFSAD NEWS

### Introducing A Reason to Hope Family Training

A Reason to Hope, a new WFSAD instructional tool for families, will be piloted in Nairobi, Kenya, on March 19-20, 2007, prior to the World Psychiatric Association’s Regional Conference, and will then be officially launched at WFSAD’s own conference in September, 2007 in Toronto, Canada. At the end of the two-day training, family leaders will be qualified to provide the training in their own communities. The course includes:

DAY 1 – provides information to families about schizophrenia, symptoms and treatments, how to care for a family member with a mental illness and how to take care of yourself along the way.

DAY 2 — explains training aspects of delivering the course for leaders of family support organizations.

A Reason to Hope training is an internationally applicable course for families, adapted from the Schizophrenia Society of Canada’s “Strengthening Families Together” program (2006) and WFSAD’s Strengthening Families Through Empowerment Program (2001). A Reason to Hope provides information, support and skills-training to help families cope with the confusion, pain, guilt and stress of living with a mental illness in the family. It is a brand new instructional tool that takes into account cultural norms and values, treatment beliefs and economic situations in which people live, in order to serve the wider global population.

This project is supported by educational grants from Astra Zeneca UK and Canada. ■

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

Please help to maintain our programs:

- Training and Education
- Advocacy
- Social Research
- Family Organization Development

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