



THE STRENGTH OF THE FAMILY MOVEMENT: FROM TORONTO TO NAIROBI

WFSAD Pilots Reason to Hope International Family Training

BY TRISH RUEBOTTOM



With scrap papers and scribbled notes spread out on a table in front of me, I sit at home, trying to put together the story of the trip from Toronto to Nairobi. We went to Nairobi to pilot WFSAD’s new family training program, Reason to Hope, which was generously sponsored by AstraZeneca. The training will officially launch in September at our conference. It was a journey of many new faces, laughter and serious stories, passion fruit and Kenyan coffee. It was a journey to answer the question, what is African mental illness and how is it different from North American mental illness? I say that jokingly, but where there are different lives, there are different needs – how will the Canadian-based program fit into life in East Africa? The training is a new international approach to family self-help: it is structured education and multi-cultural support for families, developed and taught by families. It alternates between facts and feelings, and gives information and tools at the same time as it gathers input and ideas from the group. And from the feedback we received, it was a tremendous success – the biggest criticism being the need for more.

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The group from Day 1 of the recent Reason to Hope workshop in Kenya.

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From left, Bridget Hough (co-instructor of Reason to Hope workshop) with participants Yezab Zafu from Ethiopia and Janet Amegatcher from Ghana.

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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Bridget Hough, co-author and instructor of Reason to Hope, and I arrived in Kenya with a suitcase full of papers and plans, two days worth of jet lag and little idea of what to expect. The next morning we stood in front of a class of smiling faces waiting to hear us say something worth their travels. At that moment, I remembered a friend's words from years ago, when I first left home to travel: "there will be times when you say, 'why am I doing this?' and then there will be times when you say 'this is why'". When I was sitting in the WFSAD office in Toronto trying to book flights for the group, when I was editing the training manual looking for missing punctuation on page 239, and when I was frantically searching for the final funding to pull it all off, I did ask myself, why am I doing this? Standing in front of this room full of strangers as they introduced themselves, I know: this is why.

Day 1: Connecting and Sharing

Instead of a wet, snowy white day, everything is a dry, fragrant green and gold. Bridget and I were introduced to 25 new people; some we were meeting for the first time after months of emails back and forth (thank you Lilian and Elaine for all of your work!). Some had traveled from as far as Nyahururu in the Rift Valley and Chogoria in the Eastern Province. Some had flown in the night before from Uganda, Tanzania, Ethiopia, Sudan, Zimbabwe and Ghana. As we went around the circle, each introducing ourselves and talking about why we were there, I knew, this is why – why we go through the headaches of organizing, the politics of networking and marketing our organizations, and the stress of fundraising. To sit together in one room and tell our stories. To connect and share.

The group was mixed: families coping with mental illness and looking for training, and professionals working with families, who were attending as part of their training to become instructors of the Reason to Hope program. But everyone had their own story to tell – many of the professionals were also family members or con-

Mental Health in Kenya (Mental Health Atlas 2005, World Health Organization):

- Health budget: 7.8% of GDP or USD\$1.26 billion
 - Mental health policy: none, although in 1982, Kenya adopted mental health as one of the essential elements in primary health care provision.
 - National Mental Health Program: formulated in 1996. The main emphasis is on decentralization of mental health services, integration into general health care provision and establishment of community mental health services. Implementation is hindered by lack of resources, especially human resources.
 - Mental Health Legislation: Mental Health Act, 1989
- provides for voluntary and involuntary treatment of people with mental illness and creates a regulatory board to oversee.
- Mental Health financing: 0.01% of the total health budget or USD\$12.57 million (39 cents (USD) per person per year).
 - Psych beds/10K population: 0.4
 - Psychiatrists/100K population: 0.2 or 68 in all of Kenya, half of which are in Nairobi.
 - Psych nurses/100K pop: 2

sumers themselves, who run organizations and work with families because of their own experiences in coping with mental illness.

One of the first things I noticed was a difference in the definition of "allied disorders". In the West, allied disorders are primarily depression, bipolar, and schizo-affective disorder. In the groups we met in Africa, the term allied disorders was used to refer primarily to epilepsy. And the reason is simple: both schizophrenia and epilepsy are brain disorders that carry similar stigma and both are similarly misunderstood and misjudged.

The first day was long: we covered the newest information on schizophrenia, its symptoms and comprehensive treatment; we talked and shared stories, ideas and strategies for coping with day-to-day challenges, medication compliance, preventing relapse, drug abuse, caregiver burnout and self-care, and communication skills. There was so much more to share, but with only one day of training, the time went by quickly.

Afterwards, we were all welcomed to Nairobi at a beautiful outdoor reception. Our group was joined by the Kenyan Ministry of Health's Director of Mental Health, Dr. David Kiima, and the grandfather of African psychiatry, Dr. Samuel Githethuki Gatere. I had a long conversation with Dr. Kiima, who talked about the Ministry's goal to integrate families into the treatment plan. The biggest difficulty he noted, as with all governments, is the inadequate funding dedicated to mental health; in the face of a tight health budget and many competing needs, mental health is often passed over. But Dr. Kiima fights for the attention of the Minister of Health and uses the resources he does have as effectively as possible, including engaging families as a valuable resource.

I talked with Dr. Gatere about our new training and the role of WFSAD in supporting mental health in Africa. "In the West, you learn with your eyes – you read a book to learn", stated the grandfather. "In Africa, we learn with our ears – if we want to get a message across, we put it into a song. How does your training

address this"? This idea would form the basis of most of our second day's discussion, where we explored how to tailor the program to meet the needs of families in Africa.

Day 2: Shaping for African Needs

Where the first day of the program was a structured session with a large group and an even larger amount of information, the second day was completely open-ended, with only a small number of

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How do we as families promote hope in ourselves and our loved ones?

- Solidarity, group support, group therapy.
- Keep up to date with new research, educate ourselves about the illness.
- Hear about positive stories, be sure to tell others of the positive stories.
- Be sure to acknowledge small successes, make positive comments.
- Know relapse triggers and actively work to reduce them.
- Create a supportive home.
- Foster spirituality, attend church, pray, sing.
- Be involved.



“In the West, you learn with your eyes – you read a book to learn. In Africa, we learn with our ears – if we want to get a message across, we put it in a song”.

– Dr. Gatere, grandfather of African psychiatry

Lilian Kanaiya (the famous Lilian!), founder and Executive Director of the Schizophrenia Foundation of Kenya.

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people and no pre-defined content. The group was made up of representatives from the Schizophrenia Foundation of Kenya, the Uganda Schizophrenia Fellowship, the Voluntary Association of Tanzania and Muhimbili

University College of Health Sciences in Tanzania, the Mental Health Society – Ethiopia, the Pan African Network of Users and Survivors of Psychiatry – Ghana, the Sudanese Family Support Initiative, and the Zimbabwe Schizophrenia Fellowship. Each of these representatives would take the program back to their own communities to train families. We started the day with a discussion about day 1: what did not fit with Africa? The answers took us into discussions about active listening between parent and child, the challenges of traditional healers, language barriers and translation, logistics of working in rural communities, and the important role of spirituality in sustaining hope. WFSAD and the group will be working on each of these areas and it will be integrated into the overall program. In the second half of the day, we practiced giving the training. Everyone took turns presenting information and facilitating discussions. Everyone presented with their own style and the program began to develop a more African flavour.

Days 3, 4 and 5: World Psychiatric Association Regional Conference

March 21 to 23 were devoted to the World Psychiatric Association’s Regional Conference, Mental Health in Development. Highlights from the conference were Dr. Norman Sartorius’s plenary speech, “Millennium Goals and Development: Risks, Gains and Tasks for Mental Health Programs”; Basic Needs’ workshop,



Standing from left, Abdelrahman Abudoam, Lilian Kanaiya, Janet Amegatcher, Bridget Hough, Schola Ndonde, Yezab Zafu, Patience Mafunda, Walunguba Thomas, Mufumba Emmanuel and Reverend Ndomo. Front row, Majaliwa Thomas and Trish Ruebottom.



“Strengthening Partnerships Between Consumers and Professionals”, which took a rights-based approach to mental health advocacy; Dr. Mario Maj’s plenary address, “Physical Illness and Access to Medical Services in Persons with Schizophrenia”; and the World Federation for Mental Health’s session, “Building Effective Advocacy for Improved Mental Health Care in Africa”.

Three strong themes emerged from the sessions I attended:

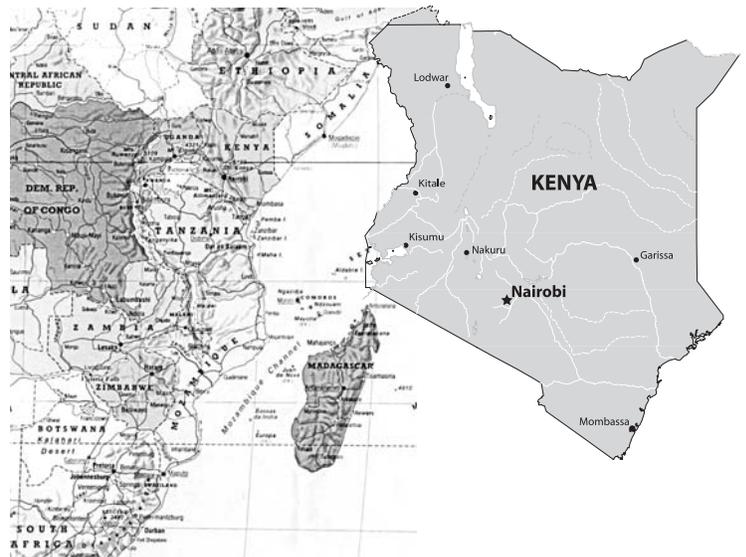
1. Mental health is a human rights issue. Taking a human rights approach to advocacy emphasizes the responsibility and obligation of governments and communities to address mental health needs.
2. Poverty has a huge impact on mental health and quality of life for people with mental illness.
3. The importance of developing and sustaining partnerships between families, consumers and professionals; researchers, policy-makers and practitioners; and the mental health, human rights, development and environmental movements.

On our sixth day, we finally had time to relax. Bridget, Thomas M. and I ventured into downtown Nairobi to explore. We wandered for hours, with no specific destination in mind. In the afternoon we found ourselves browsing for souvenirs in the market. Thomas talked with the shop-owners while Bridget and I browsed. As we went to leave one of the stores, we were called back and asked questions about this psychiatric conference. Thomas explained more about why we were in Kenya. The woman told us that her son had schizophrenia and she didn’t know what to do. We talked for a while: her son is stable on medication, but the doctors say he will never be cured. What about school? His dream of being an engineer? He tried to learn to drive again, but gave up. Will he never recover? The questions everyone has, the questions

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From left, Schola and Thomas M. from Tanzania.



From left, Thomas W. from Uganda, Patience from Zimbabwe and Emmanuel from Uganda.

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with no definitive answers to give, only hope. Bridget talked about her own son's path to recovery, and Thomas told the woman that he himself had schizophrenia and although there is no cure, do not give up hope. Before we left, we gave her the phone number for the Schizophrenia Foundation of Kenya. She had called by the time we returned to the hotel for dinner.

We ended a very satisfying day with a drink on a patio overlooking the busy matatu (bus) station, watching the world go by.

After two days of training, three days surrounded by psychiatrists, and additional adventures involving five lions and one tent, we boarded the plane for home. We left with many souvenirs, 25 new friends, and the beginning of an answer to my original question,

what is African mental illness? The program is now in the hands of Lilian, Reverend Ndomo, Yezab, Thomas W. and Thomas M., Schola, Abdelrahmen, Janet, Emmanuel and Patience. Hopefully, it will be adapted and changed, edited and improved, practiced and, most importantly, disseminated. The challenge will be to keep the momentum going now that we are all home. Talks are already under way with Basic Needs, a British mental health charity, on how to ensure replication of the training and about the possibility of bringing the group together again in the future. Until then, we will be preparing for the official launch of Reason to Hope Family Training at our conference in September. All I can say at this point is that I hope everyone else with us in Kenya learned even half as much as I did. My thanks to all of you for an amazing trip! ■

SFK: Improving Quality of Life for Those Challenged by Schizophrenia and Allied Disorders



The main objective of the Schizophrenia Foundation of Kenya (SFK) is to ensure quality of life to the members of society who are challenged by schizophrenia and allied disorders.

The founders established SFK in keeping with WHO's goal of health for all and believing in the right to health for all human beings regardless of race, creed, gender, age, physical, mental or social status and religion.

OBJECTIVES

- To advocate for persons challenged by mental illness in their endeavours.
- To be self reliant for better conditions and opportunities for those challenged by schizophrenia and allied disorders.
- To be an educational resource for families and the wider community.
- To create support services to those whose lives are challenged by schizophrenia and allied disorders.

FUTURE PLANS

- Conducting family education programs for various Family Support Groups in the country, and translate family education pamphlets from English to Kiswahili.
- Encourage formation of family support groups in various parts of Kenya and neighbouring African countries.
- Seek meaningful working partnership with health professions in various private, public, local government, churches and health institutions. This partnership would ensure quality of care to members of our society challenged by schizophrenia and allied disorders.
- Seek meaningful dialogue with ministries of Labour, Education, Home affairs, as well as judiciary (police and prisons), local authorities, members of parliament through the parliamentary Health Committee, National Constituency Fund and the Chapter of Kenya Human Rights Commission.
- Establish rehabilitation centres and halfway homes in various parts of the country.

"I have never, in my life, felt so much comfort among perfect strangers as I did during the time that I spent the few days with you all in Nairobi. We all came from different countries and different walks of life and yet we became just one family within a few days.

"In the end, I just want to say that I enjoyed meeting you all and may God give us all the strength to struggle and fulfill our objectives. I returned home with more knowledge and wisdom that I took from all of you. It was just an overwhelming experience for me."

Excerpt from email from Yezab, Reason to Hope participant



Interventions to Improve Adherence to Antipsychotic Medications

EXCERPT FROM ARTICLE BY DAWN VELLIGAN, PHD AND PETER WEIDEN, MD, PSYCHIATRIC TIMES, AUGUST 2006

There are two new and promising interventions to improve adherence to medications among individuals with schizophrenia.

The first involves the use of environmental supports and cognitive adaptation training; the second uses cognitive-behavioral therapy.

Read the entire article at www.psychiatristimes.com/showArticle.jhtml?articleId=192202943

- notebooks for recording side effects for discussion with the doctor at the next clinic visit.

A study of individuals with schizophrenia has shown that CAT treatment groups were significantly more likely to be adherent to the end of six months' treatment than were those in the control condition.

Cognitive-behavioral Therapy for Intentional Noncompliance

Environmental Supports and Cognitive Adaptation Training

Cognitive adaptation training (CAT) treatment plans are based on a comprehensive assessment of cognitive functioning, adaptive functioning and the environment.

CAT interventions to improve medication adherence include:

- large calendars with pens attached to track appointments;
- signs;
- medication containers with alarms to prompt the taking of medication;
- labeled single-dose containers to prevent the taking of extra medication doses;
- bus passes to assist patients getting to the clinic for scheduled appointments; and

One of the major challenges in addressing the patient's attitude toward medication is the degree to which patients with schizophrenia avoid acknowledging that they have an illness or need treatment in the first place.

For patients who do not believe they need medication, environmental supports alone will not address the problem, but cognitive-behavioral therapy (CBT) may help. CBT often focuses on:

- recognizing unhelpful, self-defeating, or irrational thoughts;
- challenging them on the basis of evidence from the patient's perspective; and
- developing a plan to replace them with more rational health-promoting thoughts.

Because CBT focuses on changing attitudes, it may be ideally suited to addressing adherence problems in patients who do not believe they are ill. ■

New Dopamine Brain Target Discovered: Potential Breakthrough for Schizophrenia Treatment

EXCERPT FROM CAMH NEWS RELEASE JANUARY 23, 2007

Findings from a recent study by a team of Canadian researchers may have a significant role in understanding and treating schizophrenia. The study, lead by Dr. Susan George and Dr. Brian O'Dowd at the Centre for Addiction and Mental Health (CAMH), discovered a calcium signal that is turned on by stimulating certain dopamine receptors at the same time. Stimulating these dopamine receptors (using dopamine or specific drug) triggers a rise in calcium in the brain. Calcium has a profound effect on almost all brain function. This is the first time that a direct connection between dopamine and calcium signals has been reported.

This data has significant implications for schizophrenia. Research tells us that people with schizophrenia may have disordered calcium signals, and the major treatments for this disease target the dopamine system. Drs. George and O'Dowd state: "our data links these two pieces of evidence, creating better understanding of the disease and opening the door for a new generation of highly specific drugs that may help alleviate the devastating symptoms of schizophrenia".

For more information on this study visit "News and Events" at www.camh.net



Report Warns Against Indiscriminate Use of the Internet

BY PABLO DE SANDOVAL OF EL PAIS (A MADRID NEWSPAPER); TRANSLATED BY GAIL GROSSMAN



An article by Pablo de Sandoval of El Pais, Madrid, reports that many web pages with medical information do not comply with some of the minimal requirements needed, such as the identification of authors, sources, or the simple recommendation that their contents be discussed with the physician.

This is one of the principal conclusions of the Report of the Spanish Society for Health Information: *Lights and Shadows of Medical Information on the Internet*. In the report, professionals and patients try to give the necessary recommendations to manage the mountain of medical data, advice and definitions that are only a click away on your screen.

It is becoming usual that physicians, whenever they make a diagnosis, find that their patients bring them a wad of matter printed from the Internet with opinions and recommendations about their new ailment.

Physicians and pharmacists have no objections to users looking for information by themselves but they warn against the trend to use

it as a substitute for the professional, personal relationship with the patient that doctors and pharmacists offer.

“Physicians consider it positive that the patient takes an active role and comes to the office with their own information”, says Marcial García Rojo, physician of the Pathology Service of the Ciudad Real Hospital and responsible for the exhaustive research presented. But he warns that there are “situations of real danger arising from erroneous information that is published”.

Only five years ago, the only source of information for patients was their doctors. Now they can go to the Internet. The problem is how to determine what information is correct.

Who validates the contents of a web page and with what criteria? “There are some 16 different organizations that certify medical webs”, indicates García Rojo. Some of the most acknowledged

This article summarizes a report by the Spanish Society for Health Information on the advantages and disadvantages of using the Internet to obtain health information:

- The Internet can be a useful tool to stay informed, but it cannot replace the value of a personal medical consultation on a specific condition.
- Obtain health information from reputable websites, particularly those certified by organizations such as the American Medical Association (AMA), the College of Physicians of Barcelona or the Health on the Net (HON) foundation.
- Be very wary of self-prescribing and buying medicines via the Internet.
- The Internet can help patients to connect and provide mutual support to others with the same condition.

would be the American Medical Association (AMA) and the College of Physicians of Barcelona or the Health on the Net (HON) foundation. The latter, endorsed by the UN, created the HON Code in 1996, a quality code based on eight criteria: information offered by a professional, transparency of the signatures and sponsors, source accreditation, confidentiality of email, being clear on financing and up-dating. It must also clearly state that it is no substitute for the physician.

Erik Montesinos, physician at the Valencia Hospital and an HON Advisor, insists on this point: “When something is very specific, HON recommends that patients contact their physician. The information on the Internet must complement but never substitute a medical consultation. It is a step forward that people tend to be more informed. But they must make the effort to assure themselves of the validity of the content. The

physician as a health promoter must recommend his/her patients to be careful”.

Buyer Beware

The complete substitution of medical care can occur when the patient decides to take a drug on his/her own account. Through

the Internet, the risk of fraud or of being cheated is added to that of self-medication. A recommendation is that we must not trust anything that declares that it does not have secondary effects. All pharmaceutical drugs have them. The user must be critical.

The report also warns against what are called cyberquacks. Iñaki Lorente, psychologist of the Diabetics Association of Navarra, and responsible for portraying the point of view of users in the report, recalls cases of patients that went so far as to travel to Mexico, deceived by the Internet for the promise of a miraculous cure for their diabetes.

As a user, Lorente recommends in the report the use of official websites; to trust those supervised by experts; always check with other sources, and above all, always discuss the information with the health team. The risks of accepting the Internet as your physician include: decreasing the frequency of receiving care in person, questioning the professional skill of the physician and accepting false information that affects health.

Of course, "changes in treatment must never be made without consulting with the health team".

The general secretary of the Council of Pharmaceutical Colleges of Spain, Carmen Peña, recognizes that "you just have to open the

Internet to detect pages that offer medicines. The sale of any pharmaceutical drug by Internet is illegal". Peña considers that this practice is "clearly to skip the medical control practiced by pharmacies since we have detected falsified and expired products. Medicines are products that can save as well as kill, and the rule is made to protect the consumer".

"The information on the Internet must complement but never substitute a medical consultation. It is a step forward that people tend to be more informed. But they must make the effort to assure themselves of the validity of the content".

Aside from valuing the professional information in the Net, the Spanish report also recognizes the positive effect of pages written by the patients themselves.

For example, page FENOC, Foundation for Public Education and Training in Cancer, is a reference site for cancer and is addressed to patients. The person in charge, Jorge Estapé,

professor of Oncology, points out that his objective is to "educate and inform people. We help prevent and we give support to the patient with cancer". The most looked for effect is "psychological, as the problem and anxiety are shared with others and experiences are also shared".

Estapé insists that people have to be "educated about which pages are valuable and which are not. In University Webs or Hospital Webs, the information can be good or bad but they do not fool you". And, once more he emphasizes patients should consult a physician. ■



INTERNATIONAL SURVEY

Your Help Needed

HSC NEWS INTERNATIONAL AND QALYITY PROJECT SURVEY

If you're a patient or person with a disability, do you believe that doctors and the healthcare system should do more to improve the quality of your life? If you do, one problem may be that the medical profession, managers, administrators and politicians have little idea what you and others mean when you use the phrase "quality of life".

You can make your voice heard on this subject by responding to a short international questionnaire on quality of life for patients and persons with disabilities. If you would like to participate, please send an email to Louise Oatham at info@patient-view.com. Please write "request for copy of quality of life questionnaire" in the subject line of your email.

The study is being conducted by HSCNews International, an independent publication for health advocates, in collaboration with the QALYity Project, a UK-based alliance of prestigious patient

groups, medical professionals, academics, and journalists. The Project is trying to develop an index that can measure how effective each individual medical treatment (or form of care/support) is at improving the quality of life of people with a long-term medical condition (or a disability) – as determined by the individuals themselves, not by clinicians.

The results of this international survey, and the tools that emerge from it, will be made publicly available, and will also be presented to the National Institute of Health and Clinical Excellence (NICE), a UK-government-funded body that decides which treatments and care should be paid for by the healthcare system in the UK. Many of the actions taken by NICE are relevant to other countries' healthcare systems. ■

For more information, visit www.patient-view.com/qalyity.htm



Better Days Lie Ahead

SCHIZOPHRENIA REVEALED: FROM NEURONS TO SOCIAL INTERACTION

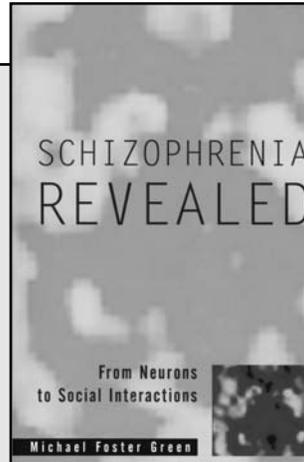
by Michael Foster Green. Published by W.W. Norton, New York, 2003. \$19.95 U.S.

BY DIANE FROGGATT

While this book is not new (first edition 2001), the second edition in paperback adds considerably to lay knowledge by adding chapters on genetics and intervention. Michael Green has written a highly readable book. Science and research, case examples, anecdotes and references to societal experiences such as films and historic events keep readers engaged. Neuroscience-based psychiatry can be difficult to understand, but given a certain threshold of knowledge readers can thoroughly enjoy the text. Green addresses readers on a personal level so that the reader continually feels attracted to the text.

There are seven clearly defined chapters that cover the features of schizophrenia, its development, genetics, neurocognitive deficits, neuroimaging, interventions and outcome. I found myself gravitating to the new chapters, particularly to interventions, always a topic of interest to families who want to understand the actions of medications as well as learn of new developments. The chapter does not disappoint. Beginning with some history on early treatments it proceeds to early and current medications and ponders why the new medications have a better side-effect profile. Green suggests that movement side effects may be fewer because the new medications block the dopamine receptors for a shorter length of time (p.130). Another reason may be the balance of actions between the dopamine and serotonin receptors. Green wonders whether the neurocognitive deficits of schizophrenia – fundamental symptoms – should become targets of treatment themselves. Whereas it has been the effects of medications that researchers have studied to find out why they brought about relief, now neuroscience itself is beginning to provide some of these answers.

The opening chapter is particularly notable for explaining to those who might not be aware that the psychotic manifestations of schizophrenia are not the fundamental symptoms, but the acces-



This second edition of *Schizophrenia Revealed: from Neurons to Social Interaction* gives readers an engaging and informative insight into the causes and treatments of schizophrenia.

Seven chapters cover the features of schizophrenia, its development, genetics, neurocognitive deficits, neuroimaging, interventions and outcome.

Author Michael Foster Green builds the book on “the ‘three pillars’ of schizophrenia: disrupted neural connections, neurocognitive deficits, and functional impairment”.

sory symptoms of the disease. In this belief Green adheres to Eugene Bleuler’s explanation of this illness. So, in his preface he says he has no regrets in building the book on “the ‘three pillars’ of schizophrenia: disrupted neural connections, neurocognitive deficits, and functional impairment”.

Optimum Neurodevelopment: Reduces Risk of Schizophrenia

The risks for developing schizophrenia are described in neurodevelopment terms in chapter two. Green quotes retrospective studies looking at risk for schizophrenia in unborn children. The nervous system is in a critical stage of development early in pregnancy (late first and early second trimester). He uses interesting study examples from war deaths, influenza and famine, which bring the text to life as well as helping the reader to understand the importance of optimum neurodevelopment. In describing the development of neural connections, Green describes the cell migration that happens during the third trimester of pregnancy with a highly understandable metaphor.

“To grasp the importance of disruption in cell migration, imagine a mythical city of brightly colored houses. The city’s furniture factory creates brightly colored items to match the brightly colored houses. The factory receives orders from houses, makes the furniture, packs it in boxes, and then transports it to the correct address. When all is going well, green furniture arrives at a green house, blue furniture arrives at a

blue house, and everything is in place. Now imagine a relatively minor problem – the driver of the truck carrying the furniture has a poor sense of distance and direction. As a result, boxes of furniture are delivered to a neighboring house instead of to the one that ordered it. Green furniture ends up at the red house, blue furniture in a yellow house, and so on... The households are not sure about their identity (do we belong to a green or blue family?), they are not sure what to order next (what colors should the

drapes be?), and they are not sure what to make of their neighbors (which ones do we affiliate with?). Research has shown that something similar happens during neurodevelopment to increase the risk of schizophrenia”.

Genetic Link: Inherit a Risk, Not a Certainty

Finding a gene for schizophrenia has been announced in the press several times over the last several years. The chapter on genetics explains that the genetic component of schizophrenia, as evident as it is, is more complex than linkage with one or several genes. Green is at pains to describe that what one inherits is the risk for schizophrenia, not the certainty of it. Using examples and comparisons he describes the difficulties inherent in linkage and association studies and in finding a phenotype that gives genetic researchers the ability to study it.

The next chapter surveys the key domains of neurocognitive deficits including perception, vigilance, memory, executive functions, sensory gating and social cognition, describing tests that are performed to try and measure these. These tests provide clues to the underlying neural processes. The chapter on neuroimaging describes PET, MRI, Functional MRI – a technique that has high expectations for schizophrenia studies and other technological advances.

This is a really informative and highly readable book that closes with the following positive paragraph:

“...the new generation of antipsychotic medications provide clear advantages compared to earlier medications, including fewer side effects. At the same time, other innovative treatments are popping up like wildflowers. Novel types of pharmacological interventions are being tested that specifically target neurocognitive

deficits and negative symptoms, which are critical aspects of the illness that do not normalize with current treatments. In addition, psychosocial interventions (e.g. social skills training, vocational rehabilitation) are becoming more systematized and more available. These non-pharmacological interventions target the activities of daily living, the skills necessary for re-entry into the

community, and the interpersonal tasks that are deceptively easy for healthy people and exceedingly difficult for patients. A disorder as complex as schizophrenia is unlikely to respond to one type of treatment. Instead, sights should be set on developing a judicious combination of treatments that will manage symptoms, improve neurocognition, and reduce the disability of schizophrenia. Optimism and schizophrenia are rarely mentioned in the same breath. Nonetheless, an impressive amount of light has recently been shed on the world’s most enigmatic disorder, and better days lie ahead”. ■

“Optimism and schizophrenia are rarely mentioned in the same breath. Nonetheless, an impressive amount of light has recently been shed on the world’s most enigmatic disorder, and better days lie ahead”.

The World Fellowship for Schizophrenia and Allied Disorders, the Schizophrenia Society of Canada, and the Schizophrenia Society of Ontario Present

The 2007 International Conference

“Lighting the Path: Hope in Action”



This conference will inspire innovations in the field, bringing together families, consumers, mental health practitioners & community leaders to share ideas, research & stories related to schizophrenia.

Through this innovative conference attendees will:

- Meet top-notch science and research experts from across the globe to share the latest scientific discoveries.
- Participate in plenary sessions and interactive workshops that address family interventions, cultural attitudes, new medications and the role of psychosocial rehabilitation.
- Build ongoing and inclusive networks of information and support.

Join us in Toronto, September 27-30, 2007!
Register at conference.world-schizophrenia.org



Tips: Developing a Crisis Plan

BY TRISH RUEBOTTOM

Having a crisis plan in place can give a person with schizophrenia and family members the assurance of predictability, protection and support if a relapse should occur.

The following article highlights the steps to follow to create a helpful crisis plan.

Dealing with a crisis is never easy. When it is a loved one in crisis, it is even harder – it can be frightening and overwhelming for the family and the person in crisis. For people with schizophrenia, the most common crisis is a return of acute symptoms. Since a relapse can't always be prevented, it helps to be prepared ahead of time. This way you can reduce the ambiguity and indecision of the situation, and also minimize the chance that it will escalate beyond your control. This is where a crisis plan comes into play.

A crisis plan is a road map of what to do, and not do, in a crisis situation. Developing a written plan ahead of time, together with your family members, lets everyone have a say in how the situation can be handled. It makes any intervention more predictable and consensual, while providing immediate protection and support for the ill person and the entire family. It is not always possible for the person in crisis to listen to reason at that very moment, but if the plan is agreed to ahead of time, it can make it easier, knowing that they identified what is helpful and needed and gave consent at a time when they were thinking clearly.

Many people have found it helpful to specify instructions for different levels of crisis, including how to support people, identifying actions to take and to avoid, and suggesting remedial treatments. It is also a good idea to develop a post-crisis plan to help during the transition back to every day life.

The first step in a crisis plan is to identify the signs of an impending crisis:

1. What are the first actions, words or behaviours that indicate the family member is beginning to relapse? What are the triggers in the environment that lead to relapse? Family members or close friends will generally become aware of behaviour that indicates a relapse: sleeplessness and increased anxiety, preoccupation with certain activities, being suspicious, unpredictable outbursts, indications that medication is not being taken, etc.
2. What are the signs of an escalating crisis?
3. At what point is it a full-blown crisis that requires direct intervention?

Next, for each of these three stages, identify the actions, people and treatment that are helpful. Also identify the actions and treatment not to be taken.

1. What actions can be taken to de-escalate the situation?

Some people find it useful to develop a generic day plan for the days when symptoms are difficult to manage and decision-making is difficult, including relaxation and stress reduction techniques,

light exercise and helpful activities to keep busy. What can the family do to help at each stage? Many people with schizophrenia have reported that it helps if those around them remain calm and speak simply, comply with requests that aren't endangering or beyond reason, decrease distractions in the area, and express understanding for what the person is experiencing. Support them in following their day plan and staying on medications.

2. Which family and friends should be contacted?

Write down their names, addresses and contact information and let them know they are part of the crisis plan.

3. Is there anything that is not helpful, that will lead to further agitation?

Sometimes family members will try to argue with the ill person's perception of reality, or become agitated or angry themselves, things that are not helpful for the person in crisis. Sometimes it is good to engage the person in conversation; other times it is best to give space.

4. At what point should the ill person see their doctor? Be taken to hospital? Who should take the family member and how will you get there? At what point should the police be called?

These are particularly tricky questions to answer. No one likes to think that others will need to take responsibility for their care and make decisions for them. But it helps to have answers to these questions that everyone can agree on, especially the person who is ill, so that family members are not trying to guess at what point they should intervene in the midst of the crisis. Take your time answering this part. It might help to have an initial discussion and then come back to it again at the end of the plan.

5. What treatments (medical and psychosocial) are helpful at each stage of the crisis? Which treatments should never be used?

This may include treatments that are currently being used and some that are specific to crisis situations. Some medications may interact with others or have bad side effects – write down all current medications so that doctors will know which ones are safe to give.

6. What details of daily life need to be looked after while the relative is in hospital?

This may include care of children or pets, bills to be paid, employers, healthcare professionals and/or others to be notified.

7. And finally, what are the activities, actions and treatments that are most helpful after a crisis?

One idea is to list routines that can be re-established right away, and other activities that should be put on hold. It might help again, to have a generic day plan.

Once you have created the crisis plan, be sure to share it with the entire health care team and family, so that everyone is aware of the steps to take and their role in handling the crisis. ■



That Ugly Hound

BY GRACE CHERIAN

Grace Cherian is a freelance writer and editor. Her specialty is mental health. You can visit her website at www.gracecherian.com. The following is a first-person account of her struggle and success in living a productive life with bipolar disorder.

I awoke lying in bed, surrounded by an army of men and women in white coats. *Where am I? Why am I here?*

As time went on, I pieced together what had happened. Mom had been phoning me, but got no response. She called my brother David and suggested that Dad check up on me.

Dad knocked on my door. No response. But the door was locked. *Something is wrong.* He knocked on my neighbour's door. Jacqueline had a key to my apartment.

Unlocking my apartment, Dad found me lying unconscious on my bed. He phoned emergency and an ambulance rushed me to hospital.

My kidneys had shut down completely. Doctors in the Intensive Care Unit asked my family to race home and bring back any vials of medication they could find. On my kitchen counter, David found empty bottles of medication which he rushed back to the hospital.

My sister Liz said later, "Twelve doctors monitored the renal dialysis machine for eight consecutive hours to flush out the drug from your body".

By the time Dad found me, I had been unconscious for three days. I remained in a coma for another nine days.

The doctors hooked me to a ventilator; my lungs had stopped functioning. They told my family "She will remain in a vegetative state for life". They recommended "warehousing". *Warehousing?*

My closest friends met and prayed for me.

A few days later, I emerged from my coma. I couldn't do anything for myself. A doctor standing at the foot of my bed told David, "She has undergone three mini strokes and there is internal hemorrhaging in the brain". *Was I involved in a traffic accident?*

Later I remembered what had happened. My doctor had prescribed the medication to treat me for bipolar disorder. But the drugs never got rid of the severe bouts of depression. So I just stopped taking the drugs. They accumulated in the medicine cabinet.

In May 2000, I had said farewell to my friends at graduate school. I was living and working alone. I felt very isolated and depressed. *Each moment feels like an eternity. I cannot bear the thought of living another moment longer.*

I researched the Compendium of Pharmaceuticals and Specialties. How much of my prescription would constitute an overdose? How much would result in a coma? If I took way in excess of what caused a coma, I reasoned, I would die.

I had read the story of the suicide of the writer, Margaret Laurence. She had ground up her drugs and kept gulping them down with glasses of milk. I did the same. When I had taken enough, I lay down on my bed. *This is the end.*

My family has said very little about my suicide attempt. They pretend it never happened. That hasn't helped at all.

My family doctor told me I wouldn't be working for a long time; he filed all the papers necessary for me to receive benefits from a government plan.

As years went by, my self-confidence ebbed. *I will never work again!* I wandered aimlessly through life. Then I learned about the Redirection Through Education program at George Brown College in Toronto, Canada, for psychiatric survivors. I enrolled in the program in January

2004. The slow process of rebuilding my confidence began.

In November 2006, I graduated from BIZ FUTURES (a government-funded Self-Employment Program). This program has taught me the essentials of running my own business. I now engage in my passion – writing and editing!

I've gained insights into bipolar disorder and watch out for its warning signals. During the manic phase, I speak rapidly, go on shopping sprees; start many activities, but don't complete any; over-commit myself; and tend to unleash my creativity. Now I lock up my credit card; avoid shopping malls; and people. Talking tends to stimulate my brain and exacerbates the mania.

I'm also prone to such severe depression that I lie in bed till the afternoon, not wanting to do anything. But taking a shower always helps me feel much better. The battle is getting out of my bed and into the bathroom. I also tend to isolate myself when I'm depressed. This is self-sabotaging. I will try to phone a friend and suggest we meet for coffee. Just knowing that someone cares is important. Walking in the sunshine also helps me feel better.

To stay healthy, I take my medications; maintain a regular regimen; and get proper rest and nutrition. It's also important to shoot for goals. By the end of this year, I aim to become independent of the government benefits. I value my network of supportive friends. But I still feel suicidal sometimes. However I've promised myself I cannot subject my family to that ordeal again. Life is difficult, but it's certainly much more meaningful now. ■

"To stay healthy, I take my medications; maintain a regular regimen; and get proper rest and nutrition. It's also important to shoot for goals".



Update from Martinique

BY LUCIE VOZA

In just under a year, our family support group in Martinique has grown to 130 families and 60 paying members. The group is now called EQUINOXE and was officially established as an association last September.

Recently we have organized several family-to-family groups led by a psychologist, which are appreciated by the families.

Yolène de Vassoigne, the organization's President, is researching all the French and European laws regarding mental health, since Martinique is part of the European Union. One thing we have learned is that as a parent association, the group must have representation at the Hospital's board meetings. Another is that there are funds that are provided for the building of a club and many more interesting advantages that have never been put to use.

Last November, we had a General Assembly to introduce the association. Two hundred people attended, including the Director of the Psychiatric hospital, representatives from two nurses' unions, politicians, psychologists and consumers.

Our projects include:

- **Forming a GEM** (Groupe d'entraide Mutuelle) – or as they are called in North America "Clubs" – where consumers can

come and participate in different cultural, artistic and sports workshops.

- **Creating a special psychiatric emergency team** – currently a person in crisis can go hours, days and weeks before they are taken care of.
- **Establishing a post-hospital center** – a bridge between the hospital and homecoming – where consumers can continue to be followed up to stabilization and have homecare with visiting nurses, if needed.
- **Acting as an advocacy group**, with respect in particular to the law on employment of disabled workers in government enterprises, and the right to housing.
- **Informing and educating**, fighting against stigmatization and discrimination.
- **Training** families, volunteers and consumers.
- **Exchanging information and ideas** by contacting other national and international associations having similar objectives, and accessing practices that have proven beneficial for better psychiatric treatments and follow-ups of consumers. ■

For more information, contact Lucie at lucievoza@wanadoo.fr

News from ACAPEF, Cordoba, Argentina

EXCERPT FROM ARTICLE BY HECTOR PORFILIO. TRANSLATED BY GAIL GROSSMAN

The Cordoba Association for Help for Persons with Schizophrenia and their Families (ACAPEF) (Asociación Cordobesa de Ayuda a la Persona Portadora de Esquizofrenia y su Familia), was created in

Cordoba, Argentina in 1994 after a visit from members of APEF (Asociación Argentina de Ayuda a la Persona que Padece Esquizofrenia y su Familia), the family organization in Buenos Aires.



From left, Edith, Christina, Martha Piatigorsky (WFSAD President-Elect), and Liliana at the ACAPEF bakery.

Later ACAPEF became a member of WFSAD. Since its founding and registration as a charity more than 12 years ago, ACAPEF has grown from strength to strength in providing information and support to persons with schizophrenia and their families.

Dr. Raimundo J. Muscellini first conducted weekly meetings for caregivers in 1994, giving us knowledge about schizophrenia and teaching us how to face the problems that arise at home. There were therapy groups and classroom tasks undertaken, so all the components of the group became interested in the opportunity to organize, and founded what would become ACAPEF. Dr. Muscellini has since become our *pro bono* medical advisor.

Putting the person with schizophrenia first, then the families, our mission was "to clarify so as to contain", and those who would receive our action would always be in this order: first the affected person, then his/her family and then the general public.

Once these lines of action were consolidated we also decided to tackle rehabilitation, and this we have done since 1999 at the Club House "Casa Club Bien Estar", under the direction of Lic. Gabriela Contreras.

Our program was as follows:

- Self-help meetings.
- Group therapy.
- Counseling and consultation.
- Monthly psycho-educational conferences in the city Community Participation Centers and other organizations that request it, for example, groups of psycho-pedagogues.

These last tasks contribute to early detection, since psychologists alerted in primary schools can start prevention.



From left, Marcelo, Sofia and Gisela at ACAPEF bakery.

Combating Stigma and Awakening Skills

All of these actions are also an efficient way to combat the stigma that comes with schizophrenia. The posters we use for promotion of the meetings remain for several weeks and are read by thousands of persons passing by.

In its 12 years of work, ACAPEF has received more than 3,700 families who bring us their difficult experiences, and look for counseling so as to be able to continue to give better care for their loved ones.

The Casa Club Bien Estar (Well being Clubhouse) renews the skills that people might have lost with activities in music, gardening, carpentry, cooking, painting, informatics, literature, radio, corporal expression, movie discussion groups and more. Short trips to the mountains of Cordoba are also enjoyed by our members. Since 2005 an important project in ACAPEF has been the establishment of a small scale bakery (bread and cakes) in a location loaned by the family of one of the members. This enterprise merits a separate article since it involves interaction between the public and the consumers on a busy neighbourhood street. The project is assisted by a therapeutic companion. It is a paid job providing a great stimulus for those working at the shop counters who have daily contact with neighbours and students of a nearby secondary school.

A Casa Club soccer team also competed with another neighborhood team. The Radio Workshop obtained a radio space in the

"FM 88.9 Revés Radio", a dependent of the School of Informatics Sciences of the National University of Cordoba (Facultad de Ciencias de la Información de la Universidad Nacional de Córdoba) and once a week their program with news, comments, interviews and music is aired by user members of the Casa Club Bien Estar.

"An important project in ACAPEF has been the establishment of a small scale bakery in a location loaned by the family of one of the members".

Providing Information

ACAPEF has a small library of books and pamphlets for consumers, families and visitors. We also consider that disseminating news of our activities is as important as the actions themselves since otherwise they remain ignored and do not fulfill any social function such as pre-

vention and de-stigmatization. In this sense we had an interesting experience with a married couple who joined us and immediately placed all their efforts in the bakery and since they owned a chain of supermarkets, they had their plastic bags used for their products printed with the signs and logos of our institution and the pertinent data to contact us. The use of bags in this business is calculated at one million monthly.

Since 1999, ACAPEF has attended Congresses and Symposiums performed in Mar del Plata (four times); Julian Leff's Conference organized by APEF and WFSAD in Buenos Aires, Caracas, Punta del Este; and other meetings with sister associations that have been extremely important to extend and share our knowledge. These gatherings are later commented on and analyzed in massive meetings with all our members. That is why we thank WFSAD for all their efforts and the constancy of their communications. ■



ACHIEVEMENTS

A Success Story from "Mother's Home" in India

Maher, meaning Mother's Home, is an organization that shelters and rehabilitates exploited, destitute women and children in Pune, India. They currently have 43 women with mental illness staying at the shelter, being looked after by a psychiatrist, counselor and most importantly, being treated with love and compassion by the caretakers.

Sister Lucy Kurien was returning from the Maher head office one day, when she saw a woman on the side of the road feeding her small, sick-looking baby. The child was neither able to walk nor speak, though she was old enough. Sister brought them to Vatsalyadham, at Maher. The child was taken to Sassoon hospital for emergency treatment. The social workers visited every day. After only a few weeks, the mother took the child and vanished.

At the shelter everyone felt sad and helpless. The mother was still not stable enough to provide for her child.

A month later, the social workers were going to Sassoon hospital again, when they saw the same woman and child. This time, both mother and child were admitted to Sassoon hospital, the mother in the psychiatric ward and the child in the pediatric ward. Both of them were discharged and brought to Maher after two months of treatment. Both mother and child are doing well. Katputli is now a healthy and active child, mixing well with other children. She is very cheerful, happy and able to walk and talk and even attends Balwadi (kindergarten) with the other children of Maher. Her mother, Kamli, is involved in the program at Vatsalyadham, and is improving every day.

SAMHSA Launches Searchable Database to Help in Prevention and Treatment

Substance Abuse and Mental Health Services Administration (SAMHSA – see www.samhsa.gov) has launched a searchable database of evidence-based practices in prevention and treatment of mental health and substance use disorders. (SAMHSA is an agency of the U.S. Department of Health and Human Services.)

The SAMHSA database is known as the National Registry of

Evidence-based Programs and Practices (NREPP). It greatly expands SAMHSA's efforts to help local organizations make informed decisions about evidence-based interventions for the prevention and treatment of mental health and substance use disorders. ■

For more information please visit www.nrepp.samhsa.gov

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