

World Fellowship for Schizophrenia and Allied Disorders
Third Quarter 2004

Family support through self-help - the family movement's past and future

How do we define self-help through family support and what constitutes success? These are questions that may not have answers that are easy to come by. As the mental health field and the family movement have developed, clear definitions seem to be lacking. A clear goal of helping further the movement, however, is evident.

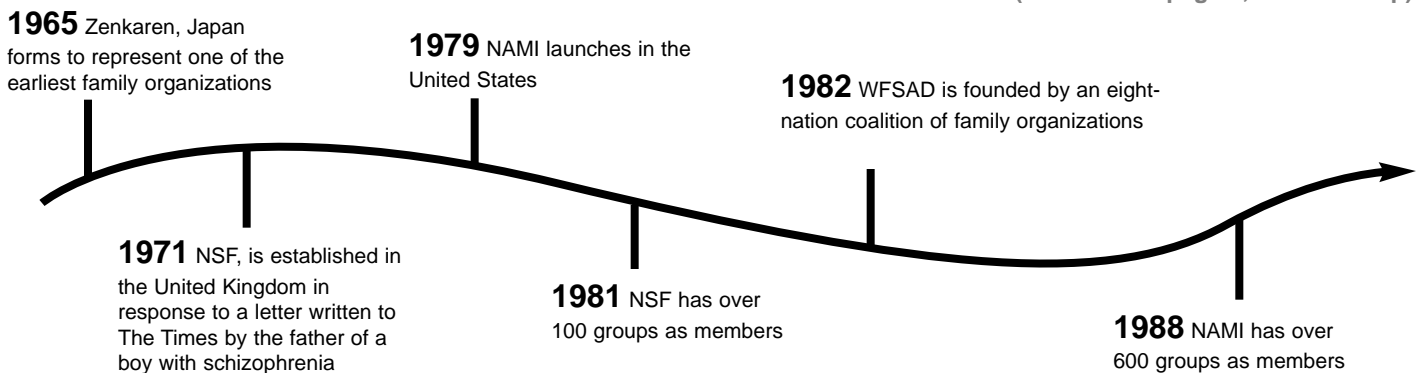
To understand what self-help through family support is, we need to understand its roots and the path it has taken. We have come a long way from the time of the ancient Greeks when all of life's ailments, including mental illness, were caused by an imbalance of the four humours - blood, phlegm, yellow bile and black bile and were treated accordingly. Mental illness was thought to be a direct result of too much black bile. Advances in medicine, etiology and a better understanding of brain

disease brought about relief from symptoms - an amazing step forward for sufferers of mental illness in their battle to become accepted and assimilated into society. In western countries, support ended here and there was a move to return mentally ill people to the community for care. Families became the primary carers and almost always were doing so without established emotional support systems, training or a clear understanding of their relative's illness. In eastern countries, the impetus to form a network of support in the form of family organizations came more from socio-economic conditions and the stigma that far outweighed that of its western neighbours. The results worldwide were the same - no, or little support. There was a gap in the system that needed to be filled.

It is part of human nature to seek out people with whom we share similarities - people that know what our lives are like, what challenges we face and those who will make our lives feel "normal". From this, the family movement was born.

Little is known about the "Family Organization" as a

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EXECUTIVE DIRECTOR'S REPORT



As many of you are aware, the past six months have been a time of change for our organization. As reported in the last issue of our newsletter, Diane Froggatt has stepped down from her role as Executive Director. We have received many messages of support and best wishes and both Diane and I thank everyone for their kind words. I would

like to reassure everyone that Diane has not retired from WFSAD and is still an active part of the organization. She remains on the board of directors and will continue in her new role as Fundraising and Development Officer. This is a new position we have created to focus on two areas that we felt needed special attention. Diane is very happy to take on this role, as she will be able to continue to do the work she enjoys - outreach and development - while lessening the daily burden of running the organization. So to anyone who is worried that Diane has left WFSAD, fear not! You will continue to hear from her and see her in the future.

It is a busy time of year in the WFSAD office. As most of you are aware, this November WFSAD will hold its sixth biennial conference in Chennai, India. If you have not registered yet, be sure to do so soon to confirm your accommodation and to ensure the best travel rates. We encourage you, our members, to take this opportunity to come to Chennai to share what you have learned, what is possible and what you have achieved. If anyone would like to submit an abstract, the deadline has been extended to September 1, 2004.

Our former president, Geraldine Marshall, just returned from a visit to Moscow. We had hoped to hold a more formal event, but unfortunately, we were unable to raise the funds needed in time for the scheduled conference. With thanks to the Heaslip Family Foundation, Geri was able to make the trip and provide some Moscow family groups with a series of presentations, seminars and workshops. A report on this meeting is included in this issue.

Last fall was also a very busy time for WFSAD. With financial support from the Pfizer Foundation, we were able to hold successful workshops for members of the Alianza Latina, during the World Psychiatric Association meeting in Caracas, Venezuela.

As well, the Pfizer Foundation supported cross-border workshops in Nairobi and Kenya which were also very successful. Reports of both meetings appeared in our 4th quarter 2003 issue.

This fall, the Alianza Latina will meet again in Punte del Este, Uruguay, November 17-20th. Although WFSAD will not be providing financial support to Alianza members, Martha Piatigorsky, our Vice-President, and Diane Froggatt are on the organizing committee. We hope that many members will be able to attend and continue building on the strong alliance these countries in Central and South America have formed.

This new role has been quite challenging, but I am learning so much and have had tremendous support from Diane, as well as the rest of our board members. I would like to give my thanks to them, and promise to work hard to continue the exceptional work of Diane Froggatt. Those will be tough shoes to fill!

Patricia Telesnicki
Executive Director



There are three categories of members:

- National Voting Member Family Organization (Annual dues \$100 US or \$150 Canadian)
- Associate Member Family Organization (Annual dues \$50 US or \$75 Canadian)
- Individual Associate Member (Annual dues \$25 US or \$38 Canadian)

Submit the information below along with your payment by US or Canadian cheque or by money order.

Name:
Organization:
Address:
Fax:
Email:



Comings and goings in the WFSAD office - more personnel updates

We would like to take this opportunity to welcome Susan Ford to WFSAD. Susan has assumed the role of Administrative Manager and is working in the office three mornings a week. Susan came to us from the Schizophrenia Society of Ontario - Toronto Chapter offices, where she worked with Diane Froggatt for many years. Susan's experience working with individuals and families with schizophrenia has been a welcome addition to our support service - answering inquiries from our members as well as visitors to our website with kindness and compassion.

At this time, we would also like to introduce Greg Wilson, our Newsletter Editor. Greg has been responsible for the changes to our newsletter, commencing with the 4th quarter 2003 issue. Greg developed a new layout and I am sure our readers will agree that this has been a welcome improvement. We have tried to keep the format consistent, with special features included in each issue.

The last personnel change to report is that Karina Stone, our Project Co-ordinator, made the difficult decision to resign from WFSAD in January. Many of our South American members met Karina in Caracas, Venezuela last October, during the meeting of the Alianza Latina WFSAD. Karina is originally from Caracas, and recently graduated from medical school there. She is in

Canada, studying to receive accreditation to practice medicine here. Unfortunately, the workload was too much and her studies obviously took precedence. We were very sad to see Karina go, as she was such a bright and cheerful addition to the WFSAD office. We wish her the very best in her future.

WFSAD represented in Moscow

Honourary WFSAD Board Member, Geri Marshall recently presented and coordinated workshops for Families and Mental Health - an organization that brings together approximately 150 families and more than 20 mental health professionals in Moscow, Russia. Members of five other public organizations also participated in the one-day workshop.

Geri's presentations, seminars and workshops consisted of new developments in psychosocial rehabilitation and recent research findings. The three sessions included were:

- Partners in Care: The Collaborative Approach to Treatment
- The Importance of Early Intervention
- The History of Care for the Mentally Ill

All presentations were translated into Russian in advance and will be shared with the 40 Family Groups in Moscow and the 89 groups in the Russian regions.

(contined on next page, see Moscow)

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.

World Fellowship for Schizophrenia
and Allied Disorders
124 Merton Street, Suite 507
Toronto, Ontario M4S 2Z2 Canada

Phone
+1.416.961.2855

Fax
+1.416.961.1948

E-mail
info@world-schizophrenia.org

Website
www.world-schizophrenia.org

President
Jim Crowe

President-Elect
Dale Johnson

Vice-President
Martha Piatigorsky

Executive Director
Patricia Telesnicki

Secretary
Public Relations and Development Officer
Diane Froggatt

Treasurer
Stephen McCourt

Past President
Marg Leggatt

Editor
Greg Wilson



WFSAD UPDATES (continued)

Moscow (continued from previous page)

The next day, during a visit to the Center for Informational and Psychosocial Support, Dr. Marshall shared with the patients, their relatives and professionals present, her Canadian experience of using puppets to raise awareness of mental health issues with school children.

In spite of the hardships the majority of people in Russia have experienced, the family groups have flourished. Their growth is

"I was impressed with the positive behaviour and conduct of the patient population. This is due to the stimulating and supportive atmosphere provided by the Moscow medical community. This community is organized by Professor Vassily Yastrebov, psychiatrists Dr. Ella Rytik and Dr. Tatiana Solokhina, plus three psychologists. The cognitive performances of the patient and relative groups was evident which is obviously the result of the education and cohesive affirmative ambience created by the partnership programs"

Gerri Marshall

most remarkable and they have indeed distinguished themselves. Russia now has a national organization created in 2002 called "New Choices". Also available to the groups is a reference manual for patients and relatives written, edited and published by Dr. Yastrebov, Dr. Rytik and Dr. Solokhina.

The Moscow group is extremely grateful to Gerri Marshall for her kindness, good will and effort to spread psychiatric knowledge among families and especially for her wish to help people with mental health problems all over the world.

Many thanks to the Heaslip Foundation in Toronto, Canada for

making this important WFSAD project possible.



Above: Members of a Moscow family group. Opera tunes and melodies were provided after sessions.



Left: Gerri Marshall (left) with Ella Rytik and Tatiana Solokhina.

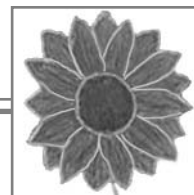
Is it time for a WFSAD Asia-Pacific Council? Jim Crowe, WFSAD President

I believe that the time has come to examine the feasibility of establishing an Asian Regional Council under the umbrella of WFSAD. For some years now and with the support of Eli Lilly (Asian region) we have been the drivers for what is now known as the Asia-Pacific Advocacy Skills Workshop. Lilly has also been very supportive in other ways. With their help, an interactive CD will be available towards the end of this month. This CD will be circulated around Asia and will reflect what is happening in the countries that participated in the Asian workshop. Whilst I was in Hong Kong in February I did a three hour film interview on this initiative, which will be modified for television.

When the Asian Advocacy Skills Workshop was first held in 2002, 25 representatives of family mental health organizations participated. By 2004 the number of participants had grown to 65. They were from China, Taiwan, Korea, Philippines, Hong Kong, Thailand, New Zealand, Australia, Singapore, Japan and Malaysia. Another workshop is presently being planned for 2005, which it is hoped, will be held in Chang Mai, Thailand.

It has already become very apparent that to continue this momentum and cause it to grow we will need to begin planning a process, which will formalize the group. There is tremendous capacity for growth, which in turn will bring much needed benefits to the individuals and their families especially

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NAMI's 2004 Annual Convention

September 8-12, 2004
Washington Hilton Towers, Washington D.C.

The theme for this convention is "Celebrating a Quarter Century of Changing Minds." The subject matter will encapsulate the true spirit and essence of NAMI's grassroots. The conference agenda, currently being developed, will address mental health services, research, forensic issues, housing, employment, consumer-run programs, fundraising and other topics of critical importance to consumers and family members.

For more information:
Web: www.nami.org
Tel: +1 703 524 7600



8th European Clubhouse Conference 2004

September 15-18, 2004
Malmo, Sweden

For more information contact:
International Center for Clubhouse Development
Fontanhuset/Malmo
Tel: +46 40 120013
Email: fontanhuset@zeta.telenordia.se
Web: www.iccd.org



XXIII Congresso APAL 2004

November 17-20, 2004
Punta del Este, Uruguay

For more information contact:
Email: apal2004@montevideo.com.uy



World Psychiatric Association International Congress Treatment in Psychiatry: An Update

November 10-13, 2004
Florence Congress Centre - Florence, Italy

For more information contact:
Organizing Secretariat, Newtours S.p.A.
Tel: +39 055 33611
Email: info@wpa2004florence.org
Web: www.wpa2004florence.org



World Psychiatric Association Regional Congress: Advances in Psychiatry (in collaboration with the Hellenic Psychiatric Association)

March 12-15, 2005
Athens, Greece

For more information contact:
Organizing Secretariat: Era Ltd.
Tel: +30 210 3634944
Email: info@era.gr
Web: www.era.gr/wpa2005athens.htm



XIII World Congress of Psychiatry: 5000 Years of Science and Care

September 10-15, 2005
Cairo International Convention & Exhibition Center, Egypt

Further information can be found at:
Web: www.wpa-cairo2005.com



World Mental Health Day 2004 "The Relationship of Physical and Mental Health: An Overview of Co-occurring Physical and Mental Disorders"

Sign up to receive the 2004 Global Education packet and do your part to help raise awareness and create change in your country!

Further information can be found at:
Web: www.wmhday.net



Send us your events to be included in this section of the WFSAD newsletter.

E-mail: info@world-schizophrenia.org
Phone: +1.416.961.2855





COVER STORY

Self-help (continued from cover)

movement.

Margaret Leggatt, past president of WFSAD, is currently writing a chapter for a book to be edited by Dr. Norman Sartorius and other mental health professionals about the role of the family movement in mental health care. Her research included soliciting feedback from WFSAD voting members about their structure, activities and what they hoped to achieve in the future. Of the 22 voting members of WFSAD, nine replied with the majority not responding due to language barriers. The respondents do, however, represent a cross section of small family groups and large nationally-driven family groups. We will review the outcomes of this publication in a future edition of the WFSAD newsletter when it has been published.

1991 WFSAD helps form the first Mexican family group and shifts its focus to grassroots family empowerment

1992 EUFAMI forms with 23 family groups in 19 European countries

1996 WFSAD helps form the Kenya and Ugandan Schizophrenia Fellowships

1999 Aasha, Chennai celebrates 10 years of successful operation

2002 WFSAD founds Alianza Latina - 16 family organizations from 12 countries in Central and South American

2000 Family representatives from 30 nations meet in Jerusalem for the WFSAD World Conference

The present state of self-help through family support is positive with hopes for a strong future. Incredible steps have been made in the areas of advocacy, education and awareness. From individual groups supporting their members to navigate the mental health system, to classroom education programs all over the world to our members being recognized for the work they are doing, the movement is moving forward and getting stronger every day.

Although the accomplishments of the family movement have been tremendous, the road ahead is riddled with challenges.

Dr. Leggatt's research shows that there are clear lines drawn when it comes to who is involved with family support groups and who is using the services provided.

Anti-professional attitudes are another hurdle the family movement has confronted and continues to face. At present, there

is no, or very little, mandatory training for health care professionals about family support groups and their value as a therapeutic tool. Without a firm understanding of the role family groups and peer support can play, professionals are less likely to refer patients. Some even question the effectiveness of self-help through family organizations altogether. Although the lines between these groups have been reduced, the wall between the "authority" of professionals and the value of intimate knowledge of family members still exists. WFSAD and other organizations worldwide continue to lobby for inclusion.

One very useful method of doing this is to hold "family" symposia during psychiatric conferences to demonstrate to that constituency not only the efficacy of family support, but to show psychiatrists the tools that are used to make self-help efficacious. Most recently this approach was demonstrated at the World Psychiatric Regional Congress in Caracas (2003) where WFSAD Alianza Latina held a symposium and workshops chaired by noted psychiatrist Itzhak Levav.

Another approach to ensure inclusion in the mental health system is to get involved in service provision, to become a player in the mainstream of mental health care and to be a "best practice" player simply because family leaders know, from the inside, what is required. Over many years families involved in the self-help movement have become experts not only in caring but in knowing what the deficits of their systems are and how to remedy these.

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Thousands of housing initiatives across the globe owe their existence to the family movement. And where our organizations have become large and influential some of them have bitten the bullet and gone into large scale service provision, submitting proposals to government to establish so many services that they become a leading agency in mental health service provision.

One notable family organization which has done this is RETHINK in England. RETHINK runs a variety of types of supported housing for approximately 1200 people who are mentally ill. They have 45 significant employment services and have about 500 people on their books at any one time. They also run a number of social enterprises including respite care services and 65 day-care services. In addition they maintain their family self-help and support role throughout the country.

For some of the large family organizations, the choice of service provision has never been a desired option. The vast under funding of mental health systems has signified to them that they should not get bogged down in providing what must necessarily be a minimal amount of the desperately needed service, when they could be a thorn in the side of government urging them to provide the necessary services. To set up and provide appropriate mental health services you need a committed government.

Family organizations everywhere are doing their utmost to persuade governments of their duty to provide comprehensive health care including mental health care. Not least among these is NAMI, the US alliance for the mentally ill, which is spearheading a "Campaign for the Mind of America" to engage non-traditional partners in the fight to provide good mental health care to the nation. NAMI is trying to address, through advocacy, the failure of society to understand how important it is to address mental illness. NAMI is constantly fighting for the attention of the policy makers.

Is there a right choice for all our family organizations in all of this admirable work? For many struggling groups setting such initiatives in motion and maintaining the momentum is an uphill challenge. As a percentage of population, the membership of even the biggest organization is extremely small, estimated at 0.1%. Thus, one of the major questions for family organizations

For many struggling groups setting such initiatives in motion and maintaining the momentum is an uphill challenge. As a percentage of population, the membership of even the biggest organization is extremely small, estimated at 0.1%. Thus, one of the major questions for family organizations unrelated to delivering program is how to build membership in order to have the strength in numbers and in volunteers to make the dreams into reality.

unrelated to delivering program is how to build membership in order to have the strength in numbers and in volunteers to make the dreams into reality. Here is where family education and training may make a difference. For every 10 or so people trained and educated formally by a family organization, one person is willing to give back to this community and assist with the needed programs.

We wrote about the NAMI Family to Family program in a recent newsletter (third quarter, 2003). This program has been enormously successful in raising NAMI's profile with families and in increasing memberships throughout the US. The significant feature of the program from the point of view of increasing

membership is its mandate to enroll trainees from each trained group to become trainers for further programs. The Schizophrenia Society of Canada is just about to launch a similar formal education program for families. These programs do not come without a cost, not only for development but for continued delivery to those seeking education.

So we are led, as inevitably we are, to the need for money to continue to operate and to continue to deliver our programs.

Family organizations are notoriously under funded. Among the 16 newly established family organizations in Latin America only two had made

major attempts to raise money (WFSAD Survey 2003). Yet the evangelical nature of self-help requires that we establish more groups. As Gavin Bird, of the South Queensland Fellowship (Australia) said: "If we accept an application to form a new branch, we have a moral responsibility to make sure the new branch has the resources to service its catchment area."

In this brief article we have attempted to raise issues pertinent to the global family movement and to its members both large and small. The answers to these issues can only be answered satisfactorily at the country, local or grassroots level. We felt it was important that our members know that these issues are not specific to one place but permeate the whole movement. There are other issues bearing on human rights and mental health law that we have not addressed here. These will be addressed on another occasion.



RESOURCES

Solving Problems and Achieving Goals *From Families as Partners in Care: Guide to Professionals Doing* *Family Work in Developing Countries*

SOLVING PROBLEMS & ACHIEVING GOALS

Teaching people to solve problems improves the mental and possibly the physical health of patients and their carers. This enables people to manage problems in their lives with less stress and with some enjoyment.

USING ACTIVE LISTENING

Be clear about our problems and goals. It is not always easy to define what worries us, or what goals we would like to achieve. If we sit down and talk these things over with some good friends or our family they can help us see the problem or goal more clearly. Talking things over together so they become clearer is called active listening. Active listening helps people to make clear, realistic goals, rather than goals that are impossible to achieve.

Clarifying problems and goals with active listening:

- Look at speaker. Look interested in what they are saying.
- Listen carefully to what they say. Reduce distraction from noise, TV, young children.
- Ask questions to make it clear exactly what is the main problem or goal.
- Check that we have understood the point clearly by telling the person what we have thought he or she was saying. Ask if that is correct. For example: "So you would like to make a friend with somebody who likes sport? Have I got that right?" You are upset that you have not got a job at the moment? Is that the main problem?" Now it's time to practice problem-solving and active listening in our resource group:
- Each person suggests a problem or goal they would like to become clearer about.
- For 5 minutes everyone else asks many questions to help to uncover exactly what that problem or goal is.
- Then tell each other what we liked about the way we all used the steps of active listening.
- Once we have done that, we may have time to use the 6-step problem-solving worksheet to solve one of the problems that we have specified very clearly.

Families as Partners in Care is based on research indicating that people with mental illness recover better when their families are part of the treatment team. This program has been adapted by WFSAD from work in developing countries from the work of Ian Falloon, M.D., with his permission.

If you would like to receive a copy of the complete guide, please contact us.

WFSAD's Sixth Biennial Conference

**The Power of the Family Movement:
Sharing the Knowledge**

Final date to register: August 15, 2004

Final date to receive abstracts: September 1, 2004

The final date to register for our conference is fast approaching, and we hope that many of our members will send a representative to India, to share their knowledge with other family organizations. We look forward to seeing participation from family members, family delegates and mental health professionals, as well as government officials and policy makers.

The conference begins November 2nd and continues through November 4th, and is open to anyone from any part of the world. Our host for the meeting will be Aasha, the family organization in Chennai, which is celebrating its 15th anniversary this year.

A significant goal for the conference is to give confidence, strength and ability to family organization leaders and families, in order to build the family movement.

India is a fascinating place to visit. For more information on the conference or to register online, visit our website at www.worldschizophrenia.org. You may also contact us directly by telephone (+1.416.961.2855) or fax (+1.416.961.1948) for more information.

WFSAD would like to thank the following conference sponsors for their generous support:

**The Pfizer Foundation
Eli Lilly, Asia
Novartis Pharma, AG**

Asian Council (continued from page 4)

in the countries already involved. Each time the workshop is convened, representatives must tell the group what their main challenges will be for the coming year. Then the following year each country has to check in and share the progress made.

One of the main issues, which always needs to be looked at, is fundraising. We cannot continue to expect the office in Canada to look for funding to support all the global work WFSAD would wish to do. From experience I believe we have a greater hope of fundraising within the region we hope to work in. This is reflected in the way we are able to positively raise funding for the Asian workshop and support for Asian representation at our conference in Chennai this coming November.

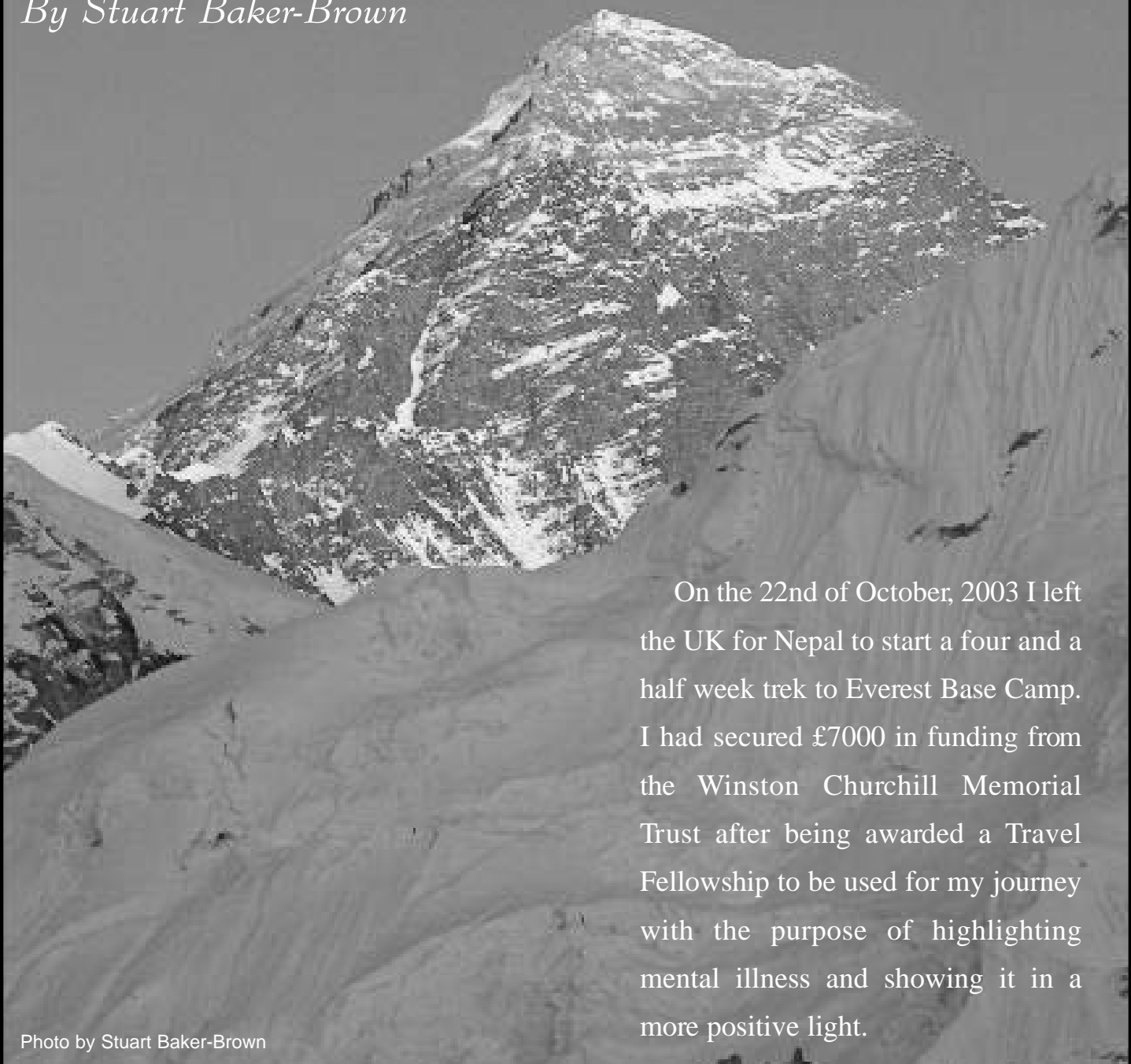
As my time as President now comes to a close I would like members to consider establishing an Asian Regional Council. Over a number of years I have established a strong network throughout the Asian region. I believe that it would be appropriate as the immediate Past President to build on the work already achieved

We have a very real opportunity to consolidate WFSAD work done in the Asian region at this time. There is still a lot of work to be done as we move along this journey, but the calibre of people already involved will greatly assist what needs to be done. Our goal will be to follow the maxim "Asia for Asia" and avoid the idea of the "re-colonization" of Asia. As always, WFSAD encourages the exchange of information rather than the delivery of information.



Mount Schizophrenia to Base Camp Everest

By Stuart Baker-Brown



On the 22nd of October, 2003 I left the UK for Nepal to start a four and a half week trek to Everest Base Camp. I had secured £7000 in funding from the Winston Churchill Memorial Trust after being awarded a Travel Fellowship to be used for my journey with the purpose of highlighting mental illness and showing it in a more positive light.

Photo by Stuart Baker-Brown

In 1996 I was diagnosed with paranoid schizophrenia. At that time my life consisted of sitting on the sofa wishing that angels would come from heaven and take me away. I would spend my days trying to travel in time focussing both on the future and past while trying to pick up positive messages that would help me to cope with and get through the pain and confusion that sufferers of paranoid schizophrenia deal with on a daily basis.

I knew that I could not go on feeling the way I did. I knew when it came to the crunch that I was the only one that could truly do something about improving my life. My illness was destroying me. I chose to fight and change my life. I chose to face my schizophrenia and all that came with it.

It had always been a dream of mine to see Mt. Everest. One day when life was brighter for me, I felt well enough to try and succeed with my dream. I also decided to combine my dream with the desire to help show fellow sufferers and the public that great goals can be achieved whilst living and coping with a severe mental illness such as paranoid schizophrenia. I was ready to start my journey.

When I first began to dream of the possibility of trekking to Everest I weighed 162kg after putting on a massive amount of weight due to unsuitable medication. I often found it hard to walk out my front door and face the world, let alone fly to Nepal and spend nearly five weeks walking the Himalayas.

The physical and mental preparation for the trek was a massive task in itself. On many occasions I wanted to cry because of my paranoia and the difficulty of getting fit. Often when walking alone in the countryside, I had to battle with the feeling that I was going to be abducted by aliens or I would feel panicked just because the wind rustled the leaves of a tree. But I taught myself to cope with my paranoia and, over time, began to feel safe.

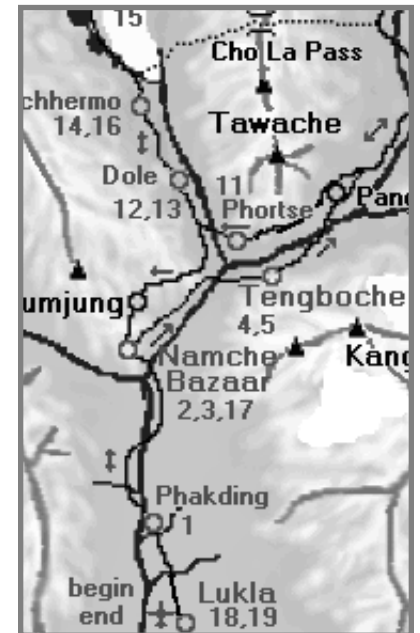
My fight was aided by two lucky breaks in 2001. The first was meeting a carer, Paul Brown, who worked for Rethink UK, a charity that helps people with severe mental illness. Paul helped me to cope with my illness and spent time slowly reintroducing me back to society. The second was finding a medication 'Seroquel' that suited me.

On the 22nd of October, 2003 I left the UK for Nepal to start a four and a half week trek to Everest Base Camp. I had secured £7000 in funding from the Winston Churchill Memorial Trust after being awarded a Travel Fellowship to be used for my journey with the purpose of highlighting mental illness and showing it in a more positive light.

I travelled with a colleague and our Sherpa guide from Lukla (elevation 2800m) through to Namche (elevation 3500m) where I suffered altitude sickness. We then trekked up towards Thame and visited the Buddhist Monastery, which was established around 320 years ago. I was privileged to be able to sit in on a Buddhist meditation ceremony. The chanting was wonderful as was the gentle beating of the drums. I cannot explain the honour I felt by being able to witness this ceremony. It was as though I managed to feel a bit of the belief that these people have and the wisdom and depth of understanding of life and it's meaning, as though I was allowed to touch it for a moment. The whole experience was of inner beauty.

I began to feel a calmness not often felt by someone with a mind that has been full of so much turmoil over the years. Somehow, the feelings from within the Monastery and the magnificence of the surrounding mountains symbolically took away my own mountain of distress and held the harm, felt over the years, within

(continued on next page)



Left: Sherpa Children on route back to Lukla from Namche. Photo by Stuart Baker-Brown
Right: Map of Everest region.

(continued from previous page)

their own walls, away from me and replacing my emotions and fears with peace, serenity and love. I kept this feeling with me as long as I could and can still look back on it now for strength when having to cope with unhappy situations.

A couple of nights during my voyage the temperature dropped to -20 degrees. At times it was very difficult, I was ill and my size was working against me but I was very focussed on reaching my goal of reaching Everest Base Camp. I kept on telling myself that the trek was symbolic of my life with schizophrenia and that's why it was so hard, it couldn't be any different, it had to be that way.

Nepal is a lovely country. I felt at home there and safe amongst the mountains. The Buddhist attitude and way of life helped me to find myself and feel un-judged by its society. I still experienced delusions in Nepal but the images I saw within my mind were a lot calmer and more controllable than the often hectic and forceful images experienced in the UK. I felt unthreatened and managed to watch as Buddhist and Hindu images floated around in my mind.

This reinforced my personal belief that my schizophrenia is fuelled by stresses and expectations of modern UK life.

On 10th of November, 2003 I succeeded in reaching my ultimate goal - I had arrived at Everest Base Camp marking the focal point of my trek and what I hoped would be a turning point in my life.

One of the other memorable moments for me was the experience I had with two Sherpa Children on route back to Lukla. As I was sitting in a lodge writing my diary, two young children were watching me. As I wrote, the boy came and sat next to me and took hold of my pen and started to doodle. I joined in and we both doodled as we talked. It was so nice to be approached without any fear or discrimination. I felt that they were experiencing my true self, the self that is beyond my label of schizophrenic. I was, for a rare moment in life, being treated for the person I am and was approached with confidence and comfort by these kids who knew nothing about my label. It was just a nice, happy and warm situation that I will remember. It was my moment, away from my past, away from my CPN and his shackles, away from the discrimination and the insecurities of life. It was my moment of being me and I felt that it was a moment when some members of the human race felt secure enough to approach me as someone who was warm and approachable and not as a schizophrenic who may be dangerous and could potentially harm. This experience is dear to me.

The whole event from the training to reaching Base Camp was

“I knew the trek to Everest would be long and hard - the tough ascents, the steep descents, the rocky terrain and of course a rather big mountain nearby all symbolized the great struggles I, and others, have to face with a mental illness such as Schizophrenia”

extremely important to me. Finding a positive and worthwhile goal in my life and finding a positive structure in my life has helped my illness immensely and helped me to feel that I have some worth in a society which too easily discriminates against those with severe mental illness - especially schizophrenia.

I have learnt through my experience that it is important for the sufferer to learn about their emotions and their illness and then teach their carers, their wives, husbands or health care professionals and psychiatrists about what is going on inside. It will take time but I believe this is vital to aid recovery. Although the CPN or Psychiatrist can help immensely, they cannot read the sufferers thoughts or truly know their emotions or experiences. I have learned to get to know myself, what's right for me and what's not right for me. Then I can tell others and learn to work with them. I believe that having the right communication is vital for understanding and aiding recovery.

I have learned that each goal is as great as the next, no matter how big or small each seems. To succeed in a fifteen minute walk from A to B, at first, was nearly as great a task mentally and physically for me, as it was to reach Base Camp.

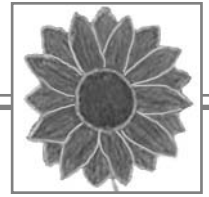
The opportunity that was given to me and the success of my trek has changed my life. I have achieved something very positive that I can now focus on to help me with future goals and challenges. I feel stronger and more positive. Not by just reaching Base Camp, but from the first steps taken by me, to the organization and planning leading up to my trek and my fitness campaign, all has helped me to regain a life that maybe I never really had.

I hope that from my experience, I will help to encourage 'fellow sufferers' to try and live life to the fullest. I hope that my experience will prove that severe mental illness, especially that of Schizophrenia, in time can be overcome and a positive life recovered.

There is so much advice I wish I could give the sufferer. One important piece of advice, which has helped me immensely, is that 'In your weakness you will find your strength' know that it is strength to admit your weakness and with this admittance, may come the start of your recovery.

And finally “never give up”.

Stuart's next challenge is to help other sufferers of schizophrenia and severe mental illness to experience Nepal and all the mountains and the people have to offer through his recently started organization, Nepali Dream Ltd.



Funding boost for community-based mental health service in Ontario

The Ontario Government in Canada recently announced plans to increase its spending on community-based health care by \$185 million over the next four years. The money will be used for expanded case management, better crisis response, early intervention services and the creation of a mental-health registry for the province. The proposed mental-health registry will be a one-stop portal for information about mental health services that can be accessed at any time through a toll-free line, staffed by professionals, as well as on-line. George Smitherman, Minister of Health and Long-Term Care, stated that "for too long mental illness has been an unspoken problem". The Canadian government estimates that as of 1998, over \$8 billion per year is being spent on mental illness across the country with 20 percent of Canadians experiencing mental illness in their lifetime.

"we are making a long-term commitment to community mental health so that people with mental illness can access the care outside of institutions"

George Smitherman
Health and Long-Term Care Minister

source: Government of Ontario web site

Two-Way Communication Check List helps patients address their problems with their health care professionals

For many years I used to take my son to his appointments with the psychiatrist. I often dreaded these appointments almost as much as he did, knowing how unproductive they often were in sorting out any recent symptoms or changes in his life that he should inform the doctor about. Before he got settled with his present psychiatrist who he has been seeing for over ten years, I used to measure the amount of time the psychiatrist spent with him. With one psychiatrist I was not allowed in until after my son had seen the doctor on his own. This did not involve a long wait. Appointments rarely lasted more than five minutes at which time I was invited in and gave any pressing information that I felt the doctor should know. I wondered at the time if the doctor had learned anything in his five minutes alone with my son.

Later I was invited in with my son, but these interviews were always difficult, my son giving a grudging "yes" or "no" to the psychiatrist's questions and me prompting both of them to have

some kind of proper exchange.

Schizophrenia often robs people of their social capabilities. Initiating conversations is one symptom that my son has a great difficulty with. Even when the doctor uses open-ended questions requiring more than a yes or no response, my son used to have difficulty formulating a reply. I am fortunate now that my son goes to his psychiatrist on his own and really does converse with him about what's going on in his life, but there are many who cannot.

That is why it is so encouraging to see that a team of European researchers has developed a means of providing patients with the opportunity to identify and discuss their needs through a short questionnaire in order to better communicate with their health care professionals. Patients answer the questionnaire and then discuss their answers with their doctor.

Results of the study, reported in the British Journal of Psychiatry (2004; 184:79-83), show that the Two-Way Communication Checklist, or 2-COM, has been very useful in helping patients address their problems with their health care professionals.

Many of you may wish to download this questionnaire, discuss it with your relative who is unwell, and/or make a copy of it for your psychiatrist.

The questionnaire can be downloaded from the AstraZeneca Web site at www.psychiatry-in-practice.com in the Assessment Tools section. It is currently available in Danish, Dutch, Finnish, French, German, Spanish, Italian and Turkish

Diane Froggatt

Updates from the World Health Organization - Department of Mental Health and Substance Abuse

The WHO has recently published a report of the Neuroscience of psychoactive substance use and dependence. Of specific interest to WFSAD is the report's focus, in part, on the need for "prevention, treatment and policy approaches that are based on sound scientific evidence, and the development of interventions that do not stigmatize patients, are community based and cost-effective."

The Department of Mental Health and Substance Abuse also recently organized a consultative meeting on the economics of mental health. Two topics covered were the mental health relation to work and the costs (direct and indirect) of mental illness. WHO commissioned reports on both these themes.

source: World Health Organization Information Sheet



KSHEMA offers support to families in Bangalore, India

Family members from AMEND (the Family Association for the Mentally Disabled) have started offering free outreach services for families and guardians of persons affected by mental illness in Bangalore, India. The KSHEMA Outreach Program provides guidance on treatment, rehabilitation, support groups and care centres in Bangalore

The family to family service is provided by members of AMEND who have been trained as KSHEMA volunteers at centres throughout Bangalore. Although the services are offered in a variety of locations, they are standardized by following the KSHEMA Guide Book which was created from experiences in the classroom and by caregivers. It is hoped that the program will help families overcome their grief and develop coping skills to handle day to day problems as well as crisis situations. Legal information about property rights, trusts, and taxation benefits will also be shared with program participants.

In the first three months of the program, three of the six centres have been active and have serviced 32 families with some users also becoming members of AMEND. Extensive publicity and promotion are still needed to inform families that these services are available to them. The services offered at centres with a low number of registered families have been moved into hospitals in order to better reach families while they care for their hospitalized relative - sometimes 24 hours a day.

WFSAD President, Jim Crowe receives College Citation

Jim Crowe, WFSAD President, has recently been awarded a citation by The Royal Australian and New Zealand College of Psychiatrists for his tireless work in the field of mental health for more than 15 years.

The citation highlights Jim's work in Asia and the Pacific, his involvement with the Schizophrenia Fellowship (NZ) and his current position with the World Fellowship for Schizophrenia and Allied Disorders.

The WFSAD Board would like to congratulate Jim on this well-deserved recognition.



The Royal Australian and New Zealand College of Psychiatrists is the principal body representing the medical specialty of psychiatry in Australasia. The College represents more than 2,500 fully qualified psychiatrists in Australia and New Zealand, known as 'Fellows' of the college, and approximately 800 doctors who are training to become psychiatrists.

USF investigates family coping mechanisms

The Uganda Schizophrenia Fellowship (USF) is conducting research on the psychosocial impact of schizophrenia on families using the services of the Butabika Hospital. The hospital provides primary mental health services for the communities around the hospital up to a radius of 30 km.

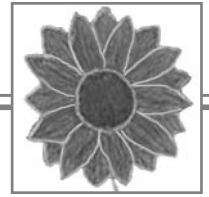
The study will commence in October in the districts of Kampala, Mukono and Wakiso. Thomas Walunguba, Chairman of USF, will be the principal researcher under the supervision of a local psychiatrist. Thomas expects to interview 75 family members about the coping mechanisms they employ.

We hope to report more on the findings in future newsletters.

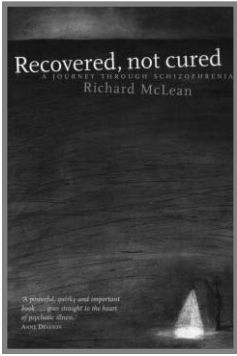
“Jim is a determined advocate for families who are affected by mental illness. He provides practical assistance in running workshops, meeting with families and mental health professionals and assisting with establishing support systems. He continues to strive in all his efforts for improved quality of services for people with mental illness and for the proactive inclusion and participation of people in communities and society so that they can lead fulfilled lives.

In the service of mental health, Jim is indefatigable and inspirational. The College and families around the world have benefited enormously from Jim's contributions over many years”

Quote from Jim Crowe's citation



Recovered, not cured: A journey through Schizophrenia



Author: Richard McLean Published by: Allen & Unwin 2003.
 Fax: 61 2 9906 2218
 Web: www.allenandunwin.com
 Review by: Diane Froggatt

"Years ago I thought people could read my innermost thoughts. In a weird twist I've bared them all in black and white - a bit like psychosis but this time for real."

Richard McLean's book is well represented by this quote. As he recounts the chronological story of the psychotic events in his life, readers will feel his torment and confusion increase. As much as any autobiography on this topic that I have read, McLean is able to put the reader in the place of a young man faced with gruelling experiences including voices, hallucinations and delusions.

Throughout his story McLean never gives up on himself. While believing in the conspiracy that he feels growing around him, many times he challenges his delusions by approaching his friends for a reality check and even confronting those he feels are persecuting him. I was surprised to read that when he challenges these people he is ridiculed, immediately backs down from his beliefs and often questions their reality. The book is liberally interspersed by his drawings. A talented artist, McLean is able to help the reader conjure his mental state at the time of their drawing. Another very powerful addition to the book is the inclusion of emails he has received from other sufferers or their families, some of them very poignant.

Today McLean is well, recovered and continuing to take medication. He was awarded the 2004 Sane Book of the Year award in Australia. This book would be very helpful to those who have had some psychotic experiences and don't know what to make of them. It would also be helpful to families who find that they are not able to believe what is happening to a loved-one.

People Say I'm Crazy

The real-life story of an artist's struggle with schizophrenia

It's a chaotic world filled with paranoia, creativity, fear and desire. A world in which I'm struggling every day, trying to know what is real and what is not.

Ten years ago, after my first psychotic break in college, I started filming myself because I wanted the world to know what it's like to live with labels such as "psychotic," "schizophrenic" and "severely disabled." I filmed everything-from being catatonic to when I had ECT (electroconvulsive therapy).

Finally a new generation of medications came on the market, and they actually began to work. My life became bearable, sometimes even enjoyable. I started to create again-drawing, carving and making woodcuts. If my family and doctor hadn't given me such intense support, I'd probably be dead by now.

John Cadigan

This autobiographical film about John Cadigan's life with schizophrenia reveals a humanized look at mental illness and the



day to day existence of sufferers and their families. The film has been screening at festivals worldwide and was recently a co-winner of Best Documentary Film/Video in the New Jersey International Film Festival. The film has also been included in the program for the NAMI Convention in Washington this November.

For more information about John's film or his artwork:
 Web: www.peoplesayimcrazy.com.



By donating to the World Fellowship for Schizophrenia and Allied Disorders, you will be helping WFSAD to provide:

- Friendship and Support
- Information and Education
- Training and Encouragement

We are the world's voice for the families of the mentally ill. WFSAD offers you sincere thanks for your contribution.

Registered Charity number: 120860911 RRO001

-----USE THIS FORM IF YOU WOULD LIKE TO SEND A DONATION BY MAIL-----

I value the work of WFSAD and submit the following donation:

\$10 \$25 \$50 Other \$ _____

Please debit my credit card. Visa Mastercard

Name on card: _____

Expiry Date: _____

I have enclosed a Money Order in Canadian/U.S. funds.

You can now also donate online at www.world-schizophrenia.org