



WHO Meeting of NGO's

WFSAD delegate Philip Wilmot reports

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WFSAD took part in the World Health Organization December meeting of non-governmental organizations (NGO's) organized by Dr. Benedetto Saraceno, Director of the Department of Mental Health and Substance Dependence, in Geneva. As past president-elect of WFSAD (1996-2000) I was happy to be our representative at this meeting.

Twenty two NGO's were represented, some 13 of them already in official relations with WHO. The major thrust of the meeting was discussion of the WHO Mental Health Global Action Programme (mhGAP), in which WFSAD has played a significant part through reviewing and suggesting amendments to eleven modules.

The goal of the mhGAP initiative is "to support member

states to enhance their capacity to reduce the risk, stigma and burden of mental disorders and to promote mental health of the population." WHO proposed to provide "leadership to achieve the target in five years through broad consultation and partnership with stakeholder groups, including the World Bank, private industry, academic and research organizations, consumer, family and professional groups, other relevant NGO's, foundations and representatives from donor and recipient Member States." I expressed my uncertainty about whether the five-year period was enough to do more than make a serious start on the problem, given the deficiencies in developing countries and the need for training for so many families in a vast number of countries.

Dr. Saraceno introduced delegates to Project Atlas – Mapping Mental Health Resources throughout the world. This ambitious project begins the task of determining the strengths and weaknesses of mental health systems and services. You may access Project Atlas at <http://mh-atlas.ic.gc.ca>.

I was pleased to meet with WHO personnel and to learn of the likelihood that WFSAD will attain official relations with WHO this year.

In addition it was very valuable to exchange information with representatives from the other NGO's. My full report to the board is available from WFSAD.●

Philip Wilmot (UK)



Kyoto Conference photos on pages 8 & 9

Executive Director's Report

Every week the office at WFSAD answers a number of emails, phone calls and letters on a whole range of issues. It might be a request for statistical or general information about mental illness, but more importantly people trust us to help them help their relative. As our membership expands it is increasingly possible to refer people to self-help family groups in many places. A recent request came from Jamaica and we were able to answer their questions directly and to refer them to a new group there called "Mensana" (mens sana meaning sound mind in Latin). If you would like to send a word of encouragement to Joan and her family group, please do so. Here is their contact information.

Joan Browne,
Mensana,
7 Craig Avenue
Kingston 8, Jamaica
csbrowne@cwjamaica.com

There is also an article on Jamaica on page 4 by Lorraine Barnaby, who we recently got to know through her registration for the Kyoto conference.

In the business of self-help and support for families looking after a loved one, complete solutions are hard to find, but it is clear that people who write to us find our responses supportive. Sometimes our replies give people the strength to continue the caring role. An example is this recent letter of thanks:

I really want to thank you from the bottom of my heart for reading and answering my email. When I read your email I knew everything was possible. This is the first answer that I have received from the emails I have sent. I will continue doing research on my brother's illness and I know that there will be someone that will help me. THANK YOU SO MUCH, READING YOUR EMAIL GAVE ME HOPE. GOD BLESS YOU.

We received a number of compliments from delegates following the 5th Biennial Conference held last October in Kyoto, Japan. You will see some photos from this event on the centre pages of this issue. In this coming month we will begin preparing the proceedings of this meeting.

Very soon after the conference in Kyoto came workshops held by SANE Australia, and sponsored by Eli Lilly Asia, in Taiwan. Many of the delegates who had attended our conference were also present at this meeting and therefore had an



opportunity to widen the family network now forming in the region.

I'd like to thank Philip Wilmot for going to the WHO meeting as our representative. You will have seen a summary of his report on the front page.

At the beginning of February came the 2nd National Indian Carers' Conference. Dr. Radha Shankar, the conference organizer, reported that interest was extremely high. Many more people applied to take part than could be accommodated (registration was limited to 80 persons). All the sessions had enthusiastic participants and India's families, who have had so little help in the past, found the possibility of help, hope and advocacy was now a reality.

In March we will be presenting at the Meriden conference "Working with

families —Giving people their lives back" —see page 15). Dale Johnson and I are preparing for our presentations as this newsletter goes to press.

Plans are also under way for a meeting of the Alianza Latina WFSAD (see last issue for details) during the World Psychiatric Association regional meeting in Caracas, Venezuela. With support from the Pfizer Foundation, we hope to conduct a symposium and several workshops for families and professionals. The goals of the meeting will be several, but the major thrust is to solidify the Alliance, to support individual development among the Alliance's members and to convince Latin American psychiatric professionals of the value of Families as Partners in Care —in other words the value of family psychoeducation and comprehensive care.

This past few months I have been busy drawing up our business plan for the next two years. I have sought input from our members and the response has been encouraging. There will be more details in the next newsletter.

We are now very comfortable in our new offices. Those of you who have not already made a note of it should take down our new mailing address, which you will find on the back page.

May I wish everyone a stress-free 2003.

Diane Froggatt

Africa Training and Exchange, Uganda

Thomas Walunguba, Chairman USF, gives a brief summary of the WFSAD training visit to Uganda last March.

“Father Katende and I greeted WFSAD representatives Margaret Leggatt and Jim Crowe upon their arrival in Uganda. The following day, Margaret and Jim visited the Uganda Schizophrenia Fellowship (USF) headquarters, a small office at Butabika, where they were warmly welcomed by the executive members of the USF, and took part in a brief meeting. I gave some historical background about USF and spoke of its rapid progress. I spoke of the first ever training session for families and caregivers of people with mental illness which we were delighted to conduct in February 2002, with full support from the Holy Cross congregation. USF faces many challenges, which, as for any young organization from the developing world, include lack of transport, limited funds, poor communication and parents not willing to openly join the Fellowship. Margaret encouraged us to contact the Rotary Club for support.

Later our guests and some members of the USF went to make home visits. This gave our members a lot of encouragement. In the afternoon, Margaret and Jim gave a very moving health presentation to members of the USF, mental health workers, staff of Butabika Hospital, some students, as well as the Director of Butabika Hospital, Dr. Fred Kigozi and the patron of the USF, Dr. Basangwa David. The topic was *Understanding Mental Illness*, and it was emphasized that it is important to work with families, and that families in Uganda do not get enough training. Dr. Kigozi commended the work of WFSAD and promised full support to the USF. “I was impressed when this young man, Thomas, talked to me about your visit to this country. I am also interested in destigmatising mental illness,” Dr. Kigozi said.

During the second day the Principal Medical Officer in charge of mental health in the Ministry of Health pointed out that receiving information about mental illness was very important but that funding was limited. “We need to empower the families as they are the permanent resources in the community. Mental health must be a public issue.”

The Jinja branch was the next destination. It was a colourful occasion, with home visits, sightseeing and a traditional lunch in our unfinished building. We visited the Director of Medical Services in Jinja district, who was very impressed with the way USF was educating the public through drama, songs and poems.”●



Making a home visit



Members of the USF who took Integrated Mental Health Care Training last year. Emmanuel Mufumba is in white.

Ed. note: the training referred to by Thomas was conducted by Emmanuel Mufumba, a psychiatric nurse and leader of the USF in Jinja. He conducted the sessions after taking training in Prof. Ian Falloon’s “Integrated Mental Health Care” with other members

Africa Training and Exchange was made possible by generous grants from Nona and Bill Heaslip, the Skoll Community Fund and Janssen-Cilag

Africa Training and Exchange, South Africa

Part of WFSAD’s Africa Training and Exchange last March included a visit to South Africa. To coincide with this visit, the Schizophrenia Foundation of South Africa organized a conference entitled ‘Promoting Family Support Structures in Mental Health in South Africa Today’. One hundred and twenty delegates were registered, but another 100 turned up, causing some excitement. Attendance was largely professional, but with a sizable group of family care givers and some consumers.

This showed just how important this topic was for South African mental health professionals and families alike. WFSAD delegates Jim Crowe and Margaret Leggatt were keynote speakers. It became obvious that working with families and the benefits of in-

cluding them was not a common concept for this audience. Both Jim and Margaret urged the audience to take account of families, and emphasized the benefits to be gained from family participation. They stressed both the needs of families and the value of considering their experiences. Supporting and aiding the formation of family self-help groups was also discussed. Delegates were eager to learn. Brenda Brett, executive director of the Schizophrenia Foundation of South Africa, is considering organizing more training workshops this year.

Visits were made to a mental hospital and radio interviews were given. In each case, WFSAD promoted the message of the need

(Continued on page 13)

News Digest

Pune Newsletter

We are happy to report the publication of a new quarterly newsletter from Pune, India.

We recently received the first issue of The Ekalavya Newsletter, published by Schizophrenia Awareness Association (SAA) in Pune, India. The first issue, available in English, was published in July 2002.

Their hope is that through this newsletter, they will be able to fulfil the objectives of the SAA—to promote restoration of mental health by means of creating an all-round awareness of the illness, and to promote self-help for patients, thereby restoring their confidence, dignity and self-reliance in society.

The newsletter is now available online via their website

www.schizophrenia.org.in
or by contacting

Eklavya Newsletter
C/o Prof. Anil Vartak,
312, A-14 Siddhant Apts. Shaniwar
Peth, Pune 411 030, INDIA. •
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APEF Website

APEF (Asociación Argentina de Ayuda a la Persona que Padece de Esquizofrenia y su Familia), our Voting Member family organization in Argentina, has a new website at <http://www.apef.org.ar>

It came about because a father, searching for help for his son who had been diagnosed with schizophrenia, turned to APEF for assistance. There were such positive changes in the family and his son that this father wanted to show his appreciation.

In addition to working as a cardiologist, the father, Dr. Daru, happened to be in charge of the website for the Association of Cardiologists. He donated his time and expertise to a group of APEF volunteers, and as a result, the website was born. •

Treating Mental Illness in Jamaica

After becoming acquainted as a result of our Kyoto conference, we asked Dr. Loraine Barnaby, from Jamaica, for an update on the state of mental health in Jamaica today. Below are some of her observations.

We have developed a system, from the 19th century, of custodial treatment in a 3,000 bed hospital. This hospital is located in the capital, Kingston and serves the whole island, in the vicinity of the largest prison on the island. Built in the colonial era, it reflected—in architecture and principles—the idea of getting the mad and the bad away from the public's view.

In the early part of the 20th century, Jamaican psychiatrists began to be trained and on their return, attempted reforms. The advent of the phenothiazines created, as elsewhere, the possibility of getting chronic patients out of hospital. This was never easy because of factors such as institutionalization and family resistance, relocation, migration or death.

An effort was made, beginning in the 1960's, to deploy specially trained nurses—mental health officers—to work in the parishes outside Kingston. Four were trained at the outset, and they worked in the rural areas. Patients were admitted to the public general hospital in the relevant parish, treated there and followed up there. Severe cases were still sent to the Bellevue Psychiatric Hospital. More mental health officers were trained, and this created an island-wide network of mental health offi-

cers. Psychiatrists at the consultant level travelled to supervise their work.

However, in line with the trend towards a community approach in the United States and elsewhere, a therapeutic community was started. Multimodal therapy, including occupational psychodrama and cultural therapy, was launched. Several chronic patients were discharged. However, it has been the work of the mental health officers, the use of psychiatric residents in the rural psychiatric clinics, the appointment of regional consultant psychiatrists, and expansion of the cadre of mental health officers, which have all helped to reduce the Bellevue Psychiatric Hospital population significantly, to about 1,000. The move is to further de-emphasize the mental hospital. The university psychiatrists seem to wish to take over the admission of all psychiatric cases. In several respects, including the close working arrangements between the mental health nurses and primary care workers, we are ahead of all other English-speaking Caribbean territories. In the whole island, the Ministry of Health has granted more autonomy to the Regional Health Boards to run all the health services at that level, rather than centrally. This is probably a good step. •

Catesfam Booklet—Esquizofrenia Hoy

CATESFAM (Centro de Atención al Esquizofrénico y su Familia) our Associate Member organization from Venezuela, has sent us a copy of their booklet, *Esquizofrenia Hoy*. This issue is called *Nuestros Logros—Our Successes*.

Attractively coloured, it explains many of the programs of CATESFAM and is full of information as well as personal stories. It will be most useful to families in Venezuela and to members of the Alianza Latina WFSAD.

Regular readers will know that CATESFAM took part in the recent meeting of family organizations in Guatemala.

Planning for a second meeting of the Alianza Latina WFSAD at the **World Psychiatric Association Regional meeting in Caracas, October 1-4** is proceeding. CATESFAM will be the host organization for this meeting.

For more information about CATESFAM, please visit their website at catesfam@cantv.net or write to them at CATESFAM, Calle 79E, Av. La Limpia, sector La Macandona, N° 76-107. Apartado Postal: 10.071 código Postal: 4002, Maracaibo-Edo. Zulia-Venezuela
Tel: 0261-7781898 •

Rethink Battles Inadequate Mental Health Services

In the last issue we reported the launch of the new name of the NSF, UK: Rethink severe mental illness. The article whetted our appetite to have more details of Rethink's current campaign. Liz Nightingale was pleased to respond.

Rethink is the new operating name for the National Schizophrenia Fellowship. The name change is the culmination of a four-year process involving over 5,000 people in numerous forms of consultations and votes. Our new name and identity challenges the widespread stigma and discrimination against people with all forms of severe mental illness.

Throughout the consultations, people living with severe mental illness and carers said that they found our previous name made it difficult for them to come to us for help in the difficult early days when they needed help most. Often they had no diagnosis at that stage, or if they did, found it very difficult to come to accept. They wanted to see us adopt a more welcoming image which would make it easier for people to approach us early on, and also a name which would challenge stigma and public perceptions of severe mental illness.

One way in which people experience stigma is in the services they receive. For too long, mental health service users and carers in the UK have put up with a second-class 'Cinderella' mental health service. We knew that 'postcode prescribing' meant that thousands of people were not getting the best medication because of cost, not health, considerations.

Together with mental health charities Mind and the Manic Depression Fellowship, we sent out 15,000 surveys to find out what people who take medicine for mental health problems think of the services and treatment they receive.

Their answers provided the evidence we presented to the National Institute for Clinical Excellence (NICE), which was asked by the UK government to look into the medicines for schizophrenia. Our evidence played a key role in their final decision and helped secure a landmark victory

for people with schizophrenia. NICE told prescribers in June 2002 to lift bans imposed on modern second generation medicines and offer people real choice in their drug treatments for the first time.

NICE (National Institute for Clinical Excellence—UK) has confirmed what we have been saying all along... drugs are not enough to treat schizophrenia. They recommend a range of other treatments as equally essential, including psychological therapy (cognitive behavioural therapy) and support for families.

Rethink is a membership charity with a network of mutual support groups. An enormous amount of work is already taking place across Rethink that continues a proud tradition of helping carers.

This year, our Supporting Carers campaign will pull together these initiatives into a coherent campaign to:

- Establish how far the UK government's rhetoric of increased support for carers has been translated into reality
- Increase the support Rethink provides to carers through our volunteer service
- Create pathways of information to enable carers to access information and support from Rethink and to

offer mutual support to each other

- Recruit more members

Many of our recent campaigns have focused on getting people the right help at the right time so they have the best chance of recovery. But time and again, our members tell us that their loved ones are forgotten and ignored by mental health services once a crisis has passed. Our Discovered Generation campaign will highlight how recent improvements to mental health services have failed people deemed stable.

The content of this campaign will come from our mass survey, Our Point of View. This survey of service users and carers will help us establish how much of the government's policy commitment on improving mental health services has become reality. This is our biggest and most ambitious piece of research yet, and will influence our work for many years to come.

We have already received over 3,500 responses. Our previous campaigns—such as the NICE ruling—have only been possible because they were based on the direct experiences of service users and carers. The results of the latest survey will allow us to continue to campaign on their behalf for everyone affected by severe mental illness to recover a meaningful quality of life. ●

Contact information:

Liz Nightingale
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Rethink severe mental illness
Working together to help everyone affected by severe mental illness, including schizophrenia, to recover a better quality of life.

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Visit us: www.rethink.org

One Year Since Erwadi

Prof. R. Srinivasa Murthy, who recently was responsible for the WHO 2001 Report on Mental Illness, and has now returned to the National Institute of Mental Health & Neurosciences (NIMHANS), Bangalore, India, provided us with this report on the challenges and opportunities for mental health care in India. The report was written in August 2002, marking the one year anniversary of the Erwadi tragedy, in which many mentally ill people died in a fire in a private facility. It reflected on twenty years since the National Mental Health Programme came into effect. We have taken the liberty of using only the second half of his report in this column. Should you wish the complete article please contact WFSAD.

The two decades from the time of the formulation of the National Mental Health Programme (NMHP) in 1982, and one year after the Erwadi tragedy, the country is coming face to face with the needs of mentally ill persons. India is one of the countries to develop many innovative approaches to mental health care. This leadership should be maintained in the coming years. The advances in the understanding of human behavior and mental disorders justify the optimism of developing meaningful and realistic mental health programs. It is mandatory to bring the fruits of science to the total population of India. The barriers of lack of awareness of the general population, the occurrence of chronicity and disability, the burden of families providing care, the lack of institutional infrastructure can be addressed by following measures:

1. The wide variations across the states of India demands that plans are developed for each of the states and union territories, besides a national plan and programme. It will be ideal to develop district level plans along the lines adapted by Ramanathapuram district, to allow for the strengths and needs of the district, in forming the basis of planning of interventions. There is a need for

central and state level mental health departments in the health ministries.

2. There is an urgent need to develop human resources of specialists as well as non-specialist personnel to provide mental health from the village level to the national level institutions.

The advances in the understanding of human behavior and mental disorders justify the optimism of developing meaningful and realistic mental health programmes.

3. In view of the massive gap between the needs for specialists and the available numbers, innovative short-term programmes for all categories of personnel need to be developed. Such plans should be time bound and standards of training and certification well established.
4. All the psychiatric care facilities should be upgraded in terms of trained personnel, treatment and rehabilitation facilities, living arrangements and community outreach activities. All the medical colleges should have independent departments of psychiatry to ensure adequate undergraduate training in psychiatry.
5. The current amount of training in psychiatry to medical students should be increased to at least two months of training during the clinical period, followed by an independ-

ent examination (this has been implemented by our neighbour Sri Lanka).

6. All the districts should have full mental health teams, as part of the district hospitals and the district health office. There should be at least a 10-bed, separate psychiatry ward in each district hospital. Integration of mental health with primary health care should be achieved to facilitate early identification of patients, regular treatment and reintegration into the community. This can be achieved by training of all the primary health care personnel, provision of essential drugs at all the health facilities, and inclusion of mental health in the regular health information system. All general hospitals should have separate psychiatry wards. National level monitoring of the District Mental Health Programme should be strengthened.
7. All the mass media should be utilized fully for public education about mental disorders.
8. Support from the government for the families of the mentally ill persons, in terms of community-based services, respite care, and help in acute emergencies, financial support for care, formation of self-help groups, should be provided. The full implementation of the Persons with Disabilities Act 1995 and the facilities that are available to physically handicapped (reservation for employment, social benefits, travel facility, etc.) should be available to the persons with mental disorders.
9. Special schemes to support the voluntary agencies, to take initiatives towards treatment and rehabilitation of mentally ill should be initiated. The involvement of education, labor and welfare in the development of

(Continued on page 12)

Sri Lanka and Sahanaya

For a population of approximately 19 million, Sri Lanka has around 3,000 psychiatric beds available. 2,500 are in two large mental hospitals and another old leprosy hospital, situated close to the capital, Colombo. Slightly over 500 beds are available in general hospitals.

More than half the long-stay patients in the mental hospitals are there because they have no place to go.

During the last few decades, there has been a move to develop general hospital inpatient and outpatient facilities, as well as small rehabilitation facilities in the provinces.

There are about 35 psychiatrists, 300 nurses, 15 personal support workers, 15 occupational therapists and a few psychologists. Most are in urban areas. However 40 young doctors have recently been trained to work in smaller hospitals in the provinces.

Now, a full twenty years since its inception, Sahanaya, a major mental health agency in Colombo, has launched one of the most comprehensive and important projects in the field of mental health care in Sri Lanka – it's new Centre for Mental Health and Psychosocial Care to be built at Gorakana amidst the lush and tranquil surroundings of the Bolgoda Lake.

We are planning to extend the present services conducted at the Community Mental Health Centre in Colombo with the objective of meeting some of the emerging mental health needs of the community.

The new centre will focus on the following target groups: those suffering from disabilities associ-

ated with long-term mental illness such as schizophrenia; those suffering from mental health problems associated with trauma, disaster and conflict; those suffering from mental disturbance due to stress; vulnerable groups such as women, children and the elderly; and community groups, professionals and family units.

Furthering the concepts of Sahanaya, the new centre will offer clinical, rehabilitative and psychosocial services designed to restore and improve the quality of life of the person. It will offer training for families, professionals and others in providing mental health care; an advocacy role in the development of psychosocial services; and preventive and promotional programmes. It will also develop ways to raise public awareness concerning mental distress/disability.

In order to complete the building an investment of nearly Rs.70 million is needed. Apart from the building, we need to develop trained staff on professional models, establish management structures and secure equipment and furniture.

From its inception, Sahanaya has been sustained by contributions and support from individual well wishers and public, private sector and social organizations.

If you can help or would like to know more about this project please contact our Project Secretariat, National Council for Mental Health, Kitulwate Road, Colombo 8, Sri Lanka.

Tel: 075-356689 or 075-350819

Fax: 94 750819

Email: sahanaya@panlanka.net •

Nalaka Mendis, Director, Sahanaya.

WFSAD VISIT TO SAHANAYA

WFSAD representatives Radha Shankar and Diane Froggatt attended the Council of Mental Health Conference in Colombo, Sri Lanka, in April, 2002. This meeting was the first major conference in Sri Lanka on community based psychiatry and generated tremendous public, professional and media support. The conference was organized by Nalaka Mendis, Director, and his team from Sahanaya, a major mental health agency in Colombo. Thus, the timing of our visit to introduce ourselves to the local family group was very opportune. Dr. Nalaka Mendis took us to the Sahanaya premises. These are typical tropical buildings with open windows and drop-down blinds. Many of the rooms overlook the Colombo Golf Club. Patient crafts were on display. We were given an official welcome

with betel leaves and the lighting of the ceremonial lamp before conducting the first workshop for the family group. This concerned beginning and developing a stand-alone family self-help organization. To the present the family support group has been under the wing of Sahanaya. We learned that Mr. Sunil Galagadera, a father and leader in the group had drafted, and had approved by the Sahanaya authorities, a constitution for the family self-help group.

Later, during the conference, we gave another afternoon of workshops and were pleased to meet some of the consumers and their families. Most of the families have relatives who attend Sahanaya rehabilitation in this clubhouse-like setting, though there were several families at the workshop whose relatives were not associated. Following the sessions, we left materials with Dr. Fernando and with Mr. Galagadera. WFSAD learned later that members of Sahanaya had translated into Sinhalese the booklet "Rays of Hope" by the Schizophrenia Society of Canada, which we had given them.. •



Radha Shankar and Dr. Nalaka Mendis in the grounds of Sahanaya.

WFSAD Fifth Biennial Conference



KYOTO 2002

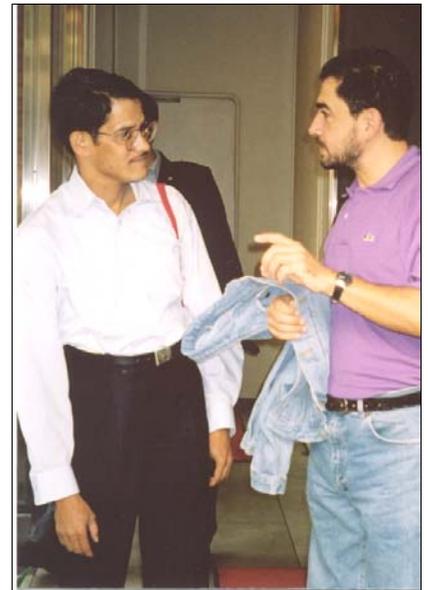


Clockwise from top right:

- Dr. Sean Flynn (*Bill Jefferies Memorial Lecturer*) and Mukul Goswami, Goa, India
- Jim Crowe, WFSAD president, thanking Ken Udagawa, a consumer activist from Japan, for his talk
- Activities at the Kyoto workshop we visited
- Göran Setterberg, who videotaped portions of the proceedings, breakfasting with Lilian Kanaiya, Kenya
- Yoshimori Egami, Executive Director, Zenkaren, centre right, with Tokuo Uemori, interpreter for WFSAD, Dr. Pairat Pruksachatkunakorn, Thailand; and Frank Nicholson, Administrative Manager, WFSAD
- Marg Leggatt and Martha Piatogorsky in the grounds of the Kyoto Conference Hall
- Fred and Penny Frese (left and far right) with Sbeila Ndyabangyi, Uganda; Mukul Goswami, India; Thomas Walunguba, Uganda; and Helen Dabu, Philippines



The Power of the Family Movement : Catalyst for Change



Clockwise from top right:

- Board members of Zenkaren and WFSAD at a dinner held by WFSAD in honour of Zenkaren
- Anil Vartak from Pune, India, talking with Dr. Joseph Vella Baldacchino from Malta
- One of the many craft stalls at the conference, selling crafts made by consumers at the various workshops throughout Japan
- Dale Johnson, Susie Kim, Diane Froggatt, Geraldine Marshall, Radha Shankar and Margaret Leggatt during a break in the WFSAD board meetings
- Masa Kawasaki and Diane Froggatt, joint secretaries for the meeting, meet for the first time in Yokohama prior to the joint conference
- Report from a Thai newspaper showing Tatiana Solokhina, Moscow, with Pairat Pruksachatkunakorn, Thailand and Erkin Toktosunov, Kyrgyz Republic
- Jim Crowe, wearing his traditional Kyrgyz hat, a gift from Erkin Toktosunov, with delegates from the Korean Family Organization

Centre:

- Thomas Walunguba, Uganda, listens intently to Mr. Yoshio Noji, Secretary General of the Kyoto Branch of Zenkaren, as he gives a presentation.



The Face of Family Burden

The following article is based on information sent to us by Sofia Puchelak, President of Family Association: Mental Health, in Krakow, Poland.

Burden has many faces. It may come from fear, anxiety, shame and fear of relapse, or from worsening of the condition.

The biggest fear is that of relapse, and associated with this the fear that the person will stop taking their medicines. Because of this, parents become increasingly protective—who can blame them? They observe the behaviour of the person who is unwell, watching what he is doing and where he is going, to the point that they become exhausted monitoring everything about their relative. It is not that they are trying to control their relative, although it might seem so to others, it is that they want to allay any possibility of relapse or other type of crisis. For the person who is unwell, the parent's behaviour may seem to be distrustful or suspicious and they may react negatively to it. Often parents stop thinking of their own interests, their own desires and become fixated on the unwell person.

If the person stays at home, isolated and inactive, the parent worries again, this time about how to encourage him to be active. The parents worry about too much or too little activity. They may search unstintingly for meaningful activities. In some cases parents provide work activities for their relative through friends. They may work packing groceries, stuffing envelopes, walking dogs, or mowing lawns. Sometimes they undertake more ambitious employment initiatives. All the time the burden remains, for even the responsibility of a job is seen as that of the parent who may have found the job in the first place.

Despite the known fact that people with schizophrenia are of normal intelligence, when it comes to money management, or insight into daily affairs, the illness

robs them of their abilities. Parents may become involved in managing their money and advising them on expenditures, never giving them enough money to compromise their health in any way. If they are living away from the family home, it is very common for parents to pay the rent, help to buy the food, clean the flat and pick up the mail. Without this "overprotective" behaviour, eviction

A nagging question for all families was the unpredictability of the future, whether it would hold any possibilities for their loved one, and what would happen when parents could no longer care.

notices may arrive, cleanliness may be sacrificed, and the person may not eat properly.

The Family Association: Mental Health, in Krakow, Poland, like many family associations before it, carried out an inquiry connected to family burden. Most of the parents responding to the questionnaire had been caring for their relative for an average of seventeen years. The most burdensome things were helplessness, fear, the necessity of changing plans, dreams lost for their son or daughter. During an acute phase, families found the inability to communicate, and symptoms of aggression extremely difficult. A nagging question for all families was the unpredictability of the future,

whether it would hold any possibilities for their loved one, and what would happen when parents could no longer care.

Having established what constituted burden, the Krakow group went on to consider what could be done to alleviate it. First of all the families should be provided with knowledge that would help them to understand the unwell person. Everyone needed hope to sustain them. A great deal of relief could be found by talking to others, the doctor, other family members and especially other families in the same position, and of finding "you are not alone". (One family group in South Africa calls itself YANA.) In meeting together, families begin to recognize that life can go on and that you should not feel guilty about enjoying at least some of your life. It is good for families to learn that to give up all social activities and devote their entire life to the unwell person is not healthy or beneficial. Through family groups family carers get a more balanced view of their situation; accepting advice from other families who see their problems from a more rational perspective.

The Krakow group has been in existence for ten years and works out of the Occupational Therapy Workshops. Their main project is the social firm "Hotel" where 20 mentally disabled persons are employed. They also have a housing project, summer and winter camps, trips and help support a small shop which sells the crafts made by patients. They are active in public awareness and anti-stigma initiatives. ●

Contact information:

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Dopamine and Glutamate System Genes in Schizophrenia

By Livia Martucci M.D. and James L. Kennedy M.D., FRCP(C)

Schizophrenia is a serious mental disorder characterised by peculiar abnormalities of thought, perception and cognition. These manifestations characteristically appear as a heterogeneous constellation of clinical features, such as positive symptoms, which include delusions, hallucinations, and thought disorganisation, and negative symptoms, which refer to the loss of motivation and emotional vibrancy. Disturbances in basic cognitive functions, such as attention, executive functions, and specific forms of memory (particularly working memory), are also observed. Schizophrenia has a 1% lifetime incidence that is fairly consistent across cultures, racial groups, and gender. The onset usually occurs in the late second and third decades of life; rarely before puberty or after the age of 40. Family, twin and adoption studies over the past fifty years have shown genetics to be the most important risk factor for schizophrenia. Recent studies have shown that, if treated properly early in the course of their illness, most patients experience a substantial reduction and even remission of psychotic symptoms following an initial episode, although associated negative and cognitive symptoms can persist. Environmental factors, including exposure to infectious, autoimmune, toxic or traumatic insults and stress during gestation or childhood, also may play a role in the pathogenesis of schizophrenia, perhaps via subtle alterations of neurodevelopment, or by unmasking the genetic vulnerability to schizophrenia.

The dopamine system has been suggested to be involved in schizophrenia. Dopamine is a neurotransmitter, that is, a molecule that works as a messenger between neurons in the Central Nervous System (CNS), and has several kinds of receptors located in different regions of the brain; these receptors are divided in two main families: D1-like and D2-like. D1 family includes D1 and D5 that are protein channels that traverse the cell membrane, allow the passage of ions and can change the electric charge of the cell; these are defined as ionotropic receptors. D2-like receptors are D2, D3 and D4 receptors, and are me-

tabotropic receptors, which transmit a signal from one side to the other of the cell membrane by binding to specific molecules. The observation that antipsychotic agents exert their effect by blockade of dopamine D2 receptors, and that agents that promote dopaminergic activity, such as amphetamines, can induce psychotic symptoms, has led to the hypothesis that dopamine plays a key role in the pathogenesis of schizophrenia.

The clinical syndrome recognised as schizophrenia may be a process with a range of severity and clinical manifestations that vary considerably across individuals

However, it is likely that a more complex biological basis exists and, given the complexity of this disorder, that more than one neurotransmitter system is affected, and that each dysfunction accounts for a specific subset of symptoms.

For several years considerable interest has focused on the possible role of glutamate in schizophrenia. Glutamate is the principal excitatory neurotransmitter in the brain. Glutamate receptors are expressed on interneurons distributed across almost all regions of the CNS; they are subdivided in two main families, metabotropic and ionotropic receptors. Among these is the NMDA receptor, which has very unique features and is involved in essential functions such as learning, memory acquisition and programmed neural cell death.

One reason for the interest in NMDAR in schizophrenia is the discovery that the street drug phencyclidine (PCP), otherwise known as "angel dust", which is a powerful blocker of this receptor, can induce a psychotic condition mimicking schizophrenia, perhaps even more faithfully than the drugs that act on the dopaminergic system, as the symptom range is broader and includes negative symptoms and cognitive deficits as well. This finding may indicate an additional link between the glutamate system and schizophrenia, and it suggests a specific association between glutamatergic dysfunction and negative symptoms.

The clinical syndrome recognised as schizophrenia may be a process with a range of severity and clinical manifestations that vary considerably across individuals, perhaps depending upon the degree to which different brain regions and circuits are involved. Since the glutamatergic system regulates dopaminergic function as well as other neurotransmitter systems, it has been suggested that the dopaminergic hyperactivity that is observed in schizophrenic patients is secondary to glutamatergic dysfunction. To date, the precise mechanism through which these alterations occur is not well known, but several theories have been formulated, based on the biological evidence that have been collected. For instance, it is of primary importance that different neurotransmitter systems in the CNS strongly interact with one another; this finding gives reason to hypothesise that such a complex disorder as schizophrenia may arise from altered interactions between receptors of different neurotransmitter systems. Several studies have been conducted to investigate the nature of these interactions. Some of the most interesting results have been found on the dopamine receptor D1 and NMDAR. The D1 receptor and NMDAR have been shown to interact in numerous brain areas, and have been recently discovered to need a direct

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Dopamine and Glutamate System Genes in Schizophrenia—Continued

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physical interaction in order to perform at least one of their many cell functions. Consequently, we hypothesised that a combined involvement of dopaminergic and glutamatergic systems contributes to the pathogenesis of schizophrenia.

Vulnerability to schizophrenia has been related to genetic factors, and perhaps interacting with environmental and developmental factors. The complexity of these potential interactions clearly complicates research on the underlying disease mechanisms. As noted above, family, twin and adoption studies have demonstrated that the morbid risk of schizophrenia in relatives correlates with the degree of shared genes. In contrast to the 1% incidence of schizophrenia in the general population, the incidence of schizophrenia is ~2% in third degree relatives of an individual with schizophrenia, 2%-6% in second degree relatives, and 6%-17% in first degree relatives. Among twins, the incidence of schizophrenia is ~17% in fraternal twins of affected individuals, and nearly 50% in identical twins. Finally, adoption studies have demonstrated that the risk of schizophrenia is related to the presence of the disorder in biological parents but not in the adoptive family. The manner of genetic transmission within the family is not clearly demonstrated and it is likely that many genes acting together cause the disorder.

The study of genetic contribution to schizophrenia can be approached in different ways. One is the association study strategy, in which the candidate genes are chosen among the genes whose products are thought to have a role in the pathogenetic mechanism of the disorder. We study these genes by comparing the presence of mutations in samples composed of patients and healthy controls (matching for gender, age and ethnic background), or in alternative observing the transmission of mutations from the parents to the patients in a large number of small families (composed of the patients and the parents). As described above, several lines of

evidence have implicated dopaminergic and glutamatergic systems in the pathogenesis of schizophrenia. In this research project we analyse the role played by glutamate system genes in schizophrenia and particularly the response to antipsychotic drugs; DNA samples from schizo-

In contrast to the 1% incidence of schizophrenia in the general population, the incidence of schizophrenia is ~2% in third degree relatives of an individual with schizophrenia, 2%-6% in second degree relatives, and 6%-17% in first degree relatives.

phrenia patients and their parents; and from cases and controls that have been collected at the Neurogenetics Section of the Clarke Site of the Centre for Addiction and Mental Health, Toronto, Canada).

Erwadi—Continued

(Continued from page 6)

mental health programs is valuable. The licensing procedures should be modified to cover the different types of facilities with varying standards (of space, staff, therapy and other facilities) and mechanisms for monitoring their activities should be created.

The very unfortunate tragedy at Erwadi, throwing the spotlight on the needs of the persons with mental disorders, has

Three mutations have been studied so far, two of which are located on the gene coding for the subunit NR1 of the Glutamate Receptor NMDA (GRIN1). The third mutation is located on the gene coding for the subunit NR2B of the same receptor (GRIN2B). We tested our sample for an association of one or more of these mutations with schizophrenia. No association was found, apart from a slight trend in the case-control sample for the GRIN2B mutation. We studied the same mutations on a sample of patients which were administered clinical scales that measure their response to medication of six months treatment, both overall and particularly related to negative symptoms. A slight trend of association was observed for one of the GRIN1 mutations and the overall response to clozapine treatment. Our data are still preliminary, due to the small sample size. Therefore, we are currently enlarging our sample and are planning to test other mutations, in order to obtain more definitive results. Furthermore, we are currently studying three mutations located on the dopamine receptor D1 gene (DRD1), and will soon be able to test our hypothesis of an interaction between NMDAR genes and DRD1.

Overall, the discovery of a genetic factor for schizophrenia would help us understand the mechanism of the illness and aid in the development of new, more specific treatments. ●

initiated a number of activities to bring the best of the available new knowledge, so that the ill individuals and their families can receive the support needed towards a better quality of life. The road is long and calls for continuous effort but it is never too late to start. If not overnight, we can bring about changes over time and prevent tragedies like that at Erwadi. ●

R. Srinivasa Murthy
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Building Membership in Bangladesh

WFSAD provides ongoing support to its worldwide membership through email correspondence. Recently Badrul Mannan, from Daka, Bangladesh, an active family member in her local association, Society for Welfare of the Schizophrenic (SWS), mentioned that her group is having difficulty building membership and involving families. We quote from her recent letter.

“How to call/invite the family members and to remind them of the date and time of the meetings are real problems for us. We do not have free local telephone calls and only a small percentage of our families have telephones. Our only convenient (but not dependable) way is invitation by post. Courier service is depend-

able but is too expensive for us. What we have decided to do is collect enrolment application forms. In one month we will enroll say, 200. We will send them letters of invitation for a family discussion meeting and some other attraction, if possible. The next month there will be a second meeting —arranged in a piecemeal fashion at the beginning, one meeting at a time, until we find a space for routine meetings/gatherings.

“Writing and sending invitations to the increasing number of enlisted persons will soon become a grueling job, but what can be done about that? With sin-

cere words of hope to them (no false promised/hopes), I still do not expect that they will come except when in crisis or becoming fond of the gatherings and resulting renewed energy.” ●

If you have any suggestions for Badrul, please contact her at rajan@bangla.net or write to us at info@world-schizophrenia.org

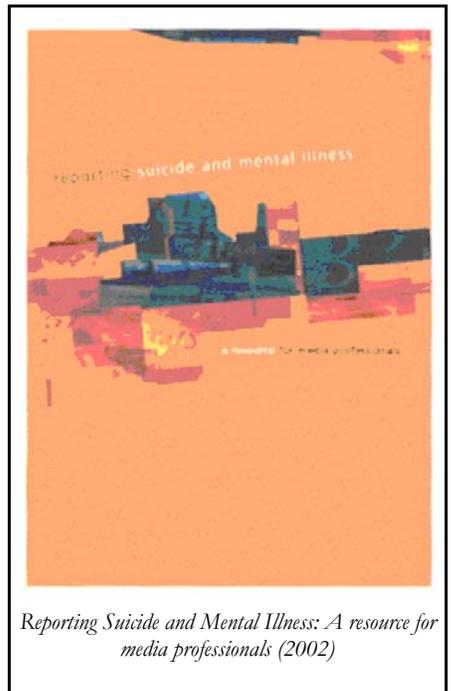
Suicide Watch in Australia

Mindframe is the name of a national strategy (Australia) for promoting responsible and accurate reporting of suicide and mental illness in the media.

The way media reports stories, about suicide in particular and mental illness in general, can influence public and private attitudes to these issues. In fact, debate continues about the reporting of suicide and its possible impact on actual suicide rates.

The Mindframe National Media Strategy aims to establish baseline data on media reporting of mental illness; provide media professionals with information and education to assist with their reporting; and enhance the community’s ability to take action against reporting that stigmatizes mental illness.

For more information, visit the website www.mindframe-media.info or the SANE StigmaWatch program at www.sane.org ●



Reporting Suicide and Mental Illness: A resource for media professionals (2002)

South Africa—continued

(Continued from page 3)

for clinicians to work much more closely with family carers to enhance outcome.

Margaret and Jim had discussions with the family group in Johannesburg and continued on to Cape Town and Durban, where they presented further lectures and seminars to nurses and other mental health professionals. They met with members of Cape Support for Mental Health, a family organization that focuses on service provision as well as ad-

vocacy. Discussions took place on developing family support throughout South Africa and the Cape Support personnel were very enthusiastic. However, success will depend on a far greater number of committed families and family groups from all over the country. Variations in economy and culture and large distances between villages will also make this a very challenging task. ●

Books

The Professor and the Madman by Simon Winchester

Reprinted from a review by Diane Warner, which appeared in the NAMI San Mateo County News, September 2002.

Everyone is familiar with the Oxford English Dictionary, the biggest, most complete dictionary compiled in the 1800s. What you may not know is one of its chief contributors lived in a prison suffering with a mental illness. Simon Winchester's book, *The Professor and the Madman, a Tale of Murder, Insanity and the Making of the Oxford English Dictionary*, tells the complex story in detail. It is fascinating. This is a story as powerful as *A Beautiful Mind* and similar in the fact that William Chester Minor had special privileges and support enabling him to make use of his unique mental abilities.

Learning about this extraordinary individual flames the hope in all of us that persons with mental illness are capable of high achievement. They can be real contributors to society. Again, we see that intelligence is able to coexist with brain dysfunction, an important bit of information that can easily be overlooked if a person is identified as having a disease, and called schizophrenic or manic depressive.

I recommend this book for its readability and style, its wealth of information about the development of a dic-

tionary (e.g. how the average citizen of England was enlisted to contribute through ads run in newspapers) and most of all for its unforgettable portrait of a man with a mental illness, William Minor, who was considered "special" and thereby became a heroic example for others.

I understand the movie rights to the book have been purchased and we can look forward to this story becoming bigger than life. ●

The Professor and the Madman, written by Simon Winchester, published by Harper Collins, 1998.



Chance Place by Frankie Schelly

Chance Place a novel by Frankie Schelly published by FireSign Exclusives, 1854A Hendersonville Rd., PMB 125, Asheville, NC 28803, USA. 2002. ISBN 1-59113-220-7 <http://www.firesignexclusives.com>

Chance Place tells the wrenching story of the difficult lives of Frenchie and Nathan, who meet through being placed in a group home for people with mental illness. The story deals with alcoholism, homosexuality, abuse and mental illness through the eyes of these two men. It

pokes wicked fun at a mental health system that sends people with mental illness out of state (the book is set in the U.S.) to avoid government having to provide support, and it highlights the ridiculous rules that govern social work and the mental health system (the U.S. is not alone in this!).

The reader learns of Nathan's breakdown through his own eyes, experiencing his psychotic reality as his family struggles to help him, then picks up his story much later when the fam-

ily has all but abandoned him from frustration and despair. It is Frenchie, however, who emerges as the major character. A spunky young man who has been robbed of his adolescence from abuse after running away from home, Frenchie comes to terms with his alcoholism and his past through his compassion and understanding of Nathan. He redeems himself by going in search of Nathan, who has absconded from the group home. *Chance Place* will strike a chord with many of our readers. ●

Partnership or Pretence by Janet Meagher AM

Partnership or Pretence by Janet Meagher. 3rd Edition 2002, published by Psychiatric Rehabilitation Association CAN 001 280 628, PO Box 1184, Strawberry Hills, Australia. — \$10USD ISBN 0 9599609 8 8

The book is accurately described as "A

handbook of empowerment and self-advocacy for consumers of psychiatric services and those who provide or plan those services."

Told with common sense and humour, Ms Meagher's book will be really useful for those just embarking on consumer or

family advocacy. Particularly good are the descriptions of the pitfalls of the work, the reasons that some initiatives fail and how to avoid this. ●

Calendar of Upcoming Meetings

**STRATFORD-UPON-AVON,
UNITED KINGDOM, 17-18 March
2003**
Meriden, the West Midlands Family
Programme (UK)
*Working with Families—Giving Peo-
ple Their Lives Back*
See details below.

**REGINA, SASKATCHEWAN,
CANADA, 9 May 2003**
Schizophrenia Society of Saskatche-
wan, Conference and Annual General
Meeting: *I Am Not Sick ... I Don't
Need Help*
Special guest Xavier Amador
Contact: Schizophrenia Society of Sas-
katchewan
Tel (306) 584-2620
Fax (306) 584-0525
Email sssprov@sasktel.net

VIENNA, AUSTRIA, 19-22 June 2003
World Psychiatric Association in col-
laboration with the Austrian Society
of Psychiatry and Psychotherapy
*International Thematic Conference
Diagnosis in Psychiatry: Integrating
the Sciences*
Hofburg Conference Centre
Tel (43 1) 512 80 91 15
Fax (41 1) 512 80 91 80
Email: wpa2003vienna@icos.co.at
Website www.wpa2003vienna.at

NEW YORK, USA, 3-5 August 2003
World Association for Psychosocial
Rehabilitation
*A Better Future For Those With
Mental Illness: Rehabilitation For
Those Without Access* Co-sponsor—
World Psychiatric Association. Contact:
(212) 426 7645 Email: office@wapr.net

**CARACAS, VENEZUELA
1-4 October, 2003**
World Psychiatric Association Re-
gional Congress in conjunction with
APAL
*Alianzas para la Salud Mental Alli-
ances for Mental Health*
Contact Edgar Belfort
Belfort.ed@excite.com

CHENNAI, INDIA, 2004
*World Fellowship for Schizophrenia
and Allied Disorders
Sixth Biennial Conference*
To receive information as it becomes
available, contact WFSAD at
124 Merton St. Suite 507, Toronto,
Ontario, M4S 2Z2, Canada or email us at
info@world-schizophrenia.org

Meriden

'Working with Families—Giving people their lives back'
Conference 17-18 March, 2003
At the Moat House, Stratford-upon-Avon, England

This conference will bring together people from around the world to share their expertise in implementing evidence-based approaches. Whilst there is a central theme of family work, the conference will be of interest to a wide range of people, attempting to implement psychosocial approaches to care within a recovery frame-work and all those involved in promoting, receiving, commissioning and purchasing mental health care.

Topics include—Early psychosis, the integration of different approaches to family work, training and compe-tency of staff to deliver psychosocial interventions, young carers, dual diagnosis.

International Speakers include Prof. Ian Falloon, Italy; Prof. Harriet Lefley, USA; Mr. Cliff Prior, CBE, Re-
think, UK; Dr. Grainne Fadden, Birmingham; Prof. Julian Leff, London; Prof. Charlie Brooker, Sheffield;
Prof. Jose-Miguel Caldas de Almeida, WHO, Washington; and Prof. Dale Johnson, New Mexico, US.

Contact: Conference Line, 5 Leopold Road, Wimbledon, London SW19 7BB
Tel (020) 8944 5050 Fax (020) 8944 0866 Email: families@conferenceline.co.uk

Note: Dale Johnson, WFSAD president-elect, will give a paper and will be part of a workshop with Diane
Froggatt, WFSAD Executive Director.

This newsletter is a
quarterly publication
of the
World Fellowship for
Schizophrenia and
Allied Disorders

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WWW.WORLD-SCHIZOPHRENIA.ORG

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



Sunflower Petal Circle



Join our circle of donors by making a regular gift to WFSAD through your MasterCard or Visa. You may make quarterly donations of \$25, \$50 or an amount of your choice, or a one-time gift for the year. Write to the above address or email us at info@world-schizophrenia.org

Planned Giving

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

I give, devise and bequeath to WFSAD, located at
— 124 Merton Street, Toronto, On M4S 2Z2, Canada the sum of \$ _____ or _____% of (real or personal property herein described), to be used for the general purpose of the organization, at the discretion of its board of directors.

Join our Membership or Become a Donor

Your membership includes a quarterly letter and regular mailings of current information throughout the year. The WFSAD Support Team is also ready to respond to your questions on any topic relating to mental illness.

Annual dues for memberships are as follows:

- National family association
Voting Member: \$100 US (\$158 Canadian)
- Regional/local family association
Associate Member: \$50 US (\$79 Canadian)
- Individual (personal)
Associate Member: \$25 US (\$39 Canadian)

Fill in your Payment Instructions below

- Cheque (US or Cdn funds only)
- Money Order in Cdn Funds

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