

INTERNATIONAL

Epilepsy News

Reporting epilepsy news for 50 years

1963-2013

Special Report:

CHINA

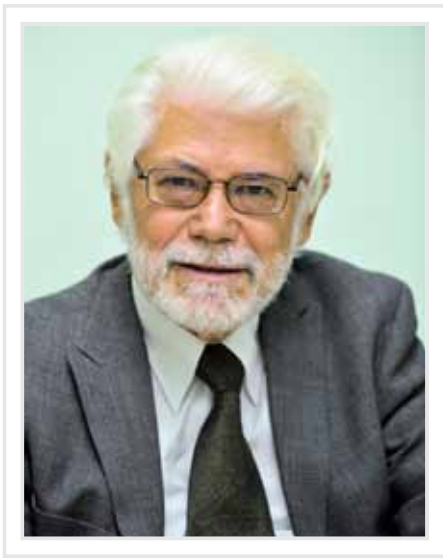
**Montréal
Montage**

**Promising
Strategies
2013**

**EPILEPSY & SOCIETY
IN LJUBLJANA**



PRESIDENT'S LETTER



Dear Friends

A lot has been happening since the term of the new Executive Committee began at the General Assembly in Montreal and, together with my fellow members, we have been settling in to our new positions.

Now, with great pleasure, I write my first President's Letter for IE News to bring you up to date on IBE activities.

Shortly after the Montreal congress, Emilio Perucca and I visited the WHO offices in Geneva as the new co-chairs of the Global Campaign. We had very good discussions and I am pleased to say that the future of the campaign is looking very exciting. In addition, the co-chairs of Global Outreach have also been named: Mary Secco (on behalf of IBE) and Alla Guekht (on behalf of ILAE). Also on the topic of WHO, you will be interested to know that IBE was represented at the recent WHO annual regional committee meetings in Europe, South East Asia and Western Pacific. In the next issue of IE News we will have a lot of information on all of these activities.

The 13th European Conference on Epilepsy & Society took place in Ljubljana, Slovenia, at the end of August and you can read about this meeting in this issue. It was an excellent conference and I would like to thank our Slovenian friends for their great efforts in making sure the conference was a success. In Ljubljana, we had the first meeting of the incoming European Regional Executive Committee (EREC) and also the meeting of all members in Europe - the European Regional Committee. It was very satisfactory to see so many member associations represented and to witness the enthusiasm

Exciting times ahead!

of all. The new EREC is now planning its future activities based on the suggestions and ideas of all members in the region.

On the subject of congresses, you will see from the back cover of this magazine that we have a busy year ahead of us in 2014, with the joint IBE/ILAE regional congresses in Africa, Asia & Oceania and Latin America. There is also the 11th European Congress on Epileptology, in Stockholm in 2014, which is organised by the ILAE Commission on European Affairs.

Epilepsy Advocacy Europe, the joint task force of IBE and ILAE, has also started its new term. I will be co-chairing the task force together with my ILAE colleague Philippe Ryvlin. We met in Ljubljana and are now in the process of finalising a strategic plan together with a plan of action for the coming four years. I hope that we will be able to share more information on this in the next newsletter.

You will have noticed that the newsletter has now become an electronic magazine. There are two important reasons for this - firstly it makes the magazine more easily accessible to everyone as it sits on the IBE website.

The electronic version also gives the opportunity to send out regular E-zines with short information from the magazine. The second reason for our decision was one of finance: printing and circulating the magazine four times each year is a major item in our budget. The savings we will make will allow us to undertake new activities to benefit people with epilepsy.

Finally, I must thank Carlos Acevedo, who has stepped down from his role of IE News Editor after eight years, and introduce you to Ann Little, who assumes the role of Editor beginning with this issue.

With best wishes to all

Athanasios Covanis
President



International Epilepsy News
Issue 2 - 2013

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INTERNATIONAL RELATIONS AND PARTNERSHIPS

WHO

IBE is in official relations with the World Health Organisation (WHO).

ECOSOC

IBE enjoys Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC).

CoNGO

IBE is a member of The Conference of NGOs in Consultative Relationship with the United Nations CoNGO.

EFNA

IBE is a member of the European Federation of Neurological Associations (EFNA).

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In this issue



Dear Readers



Welcome to the latest issue of IE News - the first issue under the wings of the new International Executive Committee and also the first issue for me as Editor. I have big shoes to fill and I hope that I can do justice to what has served as the voice of IBE for the past 50 years.

There is certainly no shortage of news to relate - from the latest projects to be funded under the Promising Strategies Program, to a look back at the 30th International Epilepsy Congress in Montreal and the 13th European Conference on Epilepsy & Society in Ljubljana. In addition, we have the final instalment of Harry Meinardi's history of IBE as seen through IBE's newsletter - which has been a very interesting account of IBE's development.

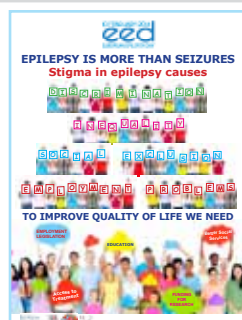
We also bring you a report from the Management Committee's visit to China when we had the opportunity to attend the 5th China International Epilepsy Forum. And there's plenty more, besides, for you to enjoy!

I wish you happy reading.

Ann Little
Editor



Coming in the next issue



PROMISING STRATEGIES 2013



WEB BASED MESSAGING

CHINA ASSOCIATION AGAINST EPILEPSY

Enabling convenient and flexible communication between patients, parents and doctors to improve the long-term prognosis of people with epilepsy.

The China Association Against Epilepsy is creating a website as the core base, to share resources, provide links to professionals and build up a patient-doctor instant messaging system, as well as special interest groups for patients and professionals, such as an infantile spasm group, Lennox-Gastaut syndrome group, tuberous sclerosis group, etc.

Professionals, such as doctors, nurses and rehabilitation experts, will be able to post their teaching course materials on how to use anti-epilepsy drugs, undertake rehabilitation training and many other fields related to epilepsy. Parents can choose a certain topic, about which they are eager to learn, and watch this at home. The resources will be free to download.

There will be a BBS (Bulletin Board System) related to the website with confidentiality of patients' private information guaranteed.

An instant messaging system, such as QQ or Microblog, and other free popular software can be used on smartphones to give reminders which are easily replied to using a wifi or a 3G connection.

Malaysian Society for Epilepsy Training Centre for Students in the ASD Spectrum

Autism is a complex neurological disorder that inhibits the learning process. Apart from struggling with a learning disability many in this spectrum also suffer from epilepsy. Research shows that at least 35% to 40% in the ASD spectrum will develop epilepsy when they reach adolescent.

Due to their learning disability and health conditions, teaching students with autism is challenging requiring highly structured facilities and expertise.

The Special Needs Learning Centre (SNLC) was set up in 2001 to meet the educational and training needs of the increasing number of children diagnosed in the Autism Spectrum Disorder (ASD).

The centre began with an enrolment of 3 pupils and one full-time teacher. Over the last 11 years it has grown to cater for about

22 students, aged between 5 years and 24 years. Many students, who began their schooling at the centre in 2001, are now young adults. Therefore, with the help of the Catholic Church, a vocational training centre for young adults is being set up to:

- Provide the opportunity to learn working skills to enable them to seek employment in structured workplaces.
- Provide an environment to develop leisure and social skills.
- Teach life skills, to enable the students to live as independently as possible
- Allow the students to engage in suitable work to allow them earn a living.

A number of programs are already in place but the centre would like to extend its activities further with support from the Promising Strategies Fund to do so.



POSTER PRODUCTION & CLINICAL EPILEPTOLOGY TRAINING

Two projects, linked through their aim to improve knowledge on epilepsy, submitted by Nepal Epilepsy Association (NEA), are supported this year by the Promising Strategies Program.

Many Nepalese die from diseases that could be easily prevented and easily treated, including epilepsy.

Due to its challenging topography, high levels of poverty and poor communications, lack of electricity and absence of transport options, people living in remote regions of Nepal have little access to the necessary information about diseases. To raise awareness about epilepsy and its treatment, wide dissemination of simple and illustrative posters in the Nepali language will be undertaken by NEA.

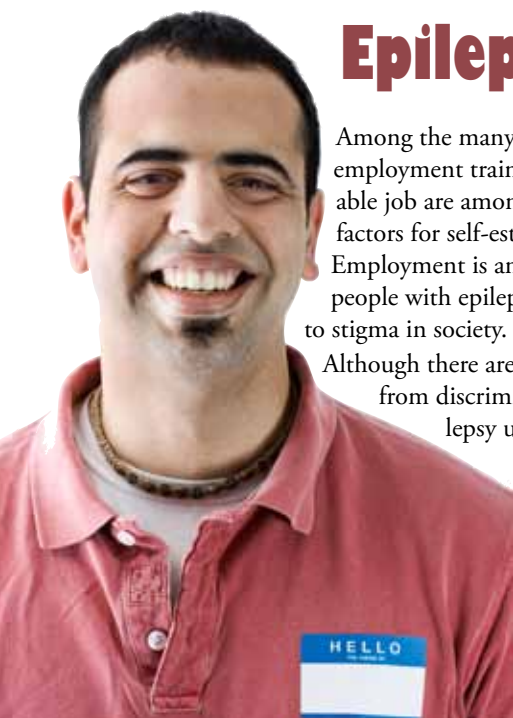
The second project provides training in clinical epileptology for



NEPAL EPILEPSY ASSOCIATION

doctors in remote districts, to arm them with the skills required to provide appropriate diagnosis and treatment in epilepsy.

Epilepsy and Employment Project



Among the many issues involved in QOL, employment training and finding a suitable job are among the most important factors for self-esteem and autonomy. Employment is an important issue for people with epilepsy and is strongly related to stigma in society.

Although there are laws to protect workers from discrimination, people with epilepsy usually avoid taking steps that lead to legal actions, probably in association

PROJECT OF ASOCIACIÓN URUGUA CONTRA LA EPILEPSIA

with felt stigma.

Asociación Uruguaya contra la Epilepsia and Liga Uruguaya contra la Epilepsia, working with an active group of patients, have developed a novel way to fight discrimination of people with epilepsy by teaching employers and the general public about the disease, stating the magnitude and consequences of such discrimination. The first step is a book on Epilepsy and Employment funded by Promising Strategies.

Written mainly by patients, it will contain personal experiences in choosing a profession, finding a job and keeping it, the dilemma of talking about their epilepsy to co-workers and employers and their reactions.

The publication will also include testimonies written by employers of people with epilepsy, serving as a guide for other employers.

It is hoped that the book can be provided free of charge to the general public, workers unions, teachers, and political parties.

In addition, it could be adapted for use in other Latin American countries.

NEUROPSYCHOMOTRICITY

National Center for Epilepsy and the Association of Parents of Children with Epilepsy - ECUADOR

Neuropsychomotricity is an interdisciplinary science that provides guidelines for the harmonic development of the individual. It aspires to a psychophysical, emotional and relationship balance in the individual, and in their relationship with the surrounding environment.

The effectiveness of the project has been evident in the eight years since its introduction by the Ecuador association. During this time, the psychophysical improvement in patients has been accompanied by a considerable decrease in seizures, compliance with treatment, better behaviour in school, improvement in learning, in self-esteem and in relationships. In addition, some patients have been able to

reduce their medication. It is intended to further develop the treatment strategy in deepening scientific knowledge by:

- Establishing scales of assessment for implementation of neuropsychomotricity during the child's development.
- Spreading the programme to schools country-wide, through a partnership agreement between the National Centre for Epilepsy and the Ministry of Education of Ecuador.
- Strengthening working relationships with other countries interested in this proposal.
- Spreading the results of the strategy internationally.





Craft skills training for people with epilepsy

Association of Care of People with Epilepsy, LEBANON

The goals of the association are to train people with epilepsy in manual skills, namely patchwork, stitching, glass painting, macramé, bead-work, wrapping and decorating chocolate produce and preparing them for sale; as well as the execution of social events and activities.

chocolate

Following on from previous successful projects, the association is

planning a new program that will attract more members, earn more income for the association and the team involved, and ensure better and more sustained support to people with epilepsy.

The Association plans to increase output of artwork produce by allotting one room in the Association center for a sewing workshop, increasing the number of women who undertake the work, and introducing an annual event when all the produce will be displayed for sale.

In the absence of special schools for children with special needs and a lack of government support due to the current economic crisis, and as long as people with epilepsy are forced to leave school once they have seizures, and until the Association can stand alone in supporting people with epilepsy on a continuous basis, the association is in need of Promising Strategies support to cover project expenses.

ON THE MOVE

Project of Epilepsy Namibia



Epilepsy Namibia is taking its awareness program nationwide. Through contact with people with epilepsy in the past, and through figures from the latest census, the association has identified four areas in the country where it could reach the highest number of people.

The association will travel 4,000 kilometers, visiting Oshakati in the north, Keetmanshoop in the south, Swakopmund and Walvisbay on the west coast and Gobabis in the east. At each point Epilepsy Namibia will establish contact with the clinic that forms the backbone of care for patients in the region. Public awareness is planned for town centers, with information distribution as well as a DVD presentation.

Special invitations are being extended to people in the area, identified as having epilepsy, for a get together to boost support groups. Translators to local languages are being obtained from the local community.

In the past there has been difficulty in making contact in the North of Namibia where the population density and the prevalence of epilepsy are high, but a neurologist at the State Hospital in Oshakati, who also attended the 1st African Epilepsy Congress in Nairobi in 2012, has become a member of Epilepsy Namibia. She will be a reference point for this awareness campaign. A long standing sponsor, ITCS (Information Technology Consulting Services), will again support the association by providing a vehicle, driver and IT services.

Dairy Farming Project Swaziland Epilepsy Organisation

The organization will train people with epilepsy in dairy farm husbandry, for which the association has already acquired land. Swaziland is presently importing 70% of the milk consumed in the country from

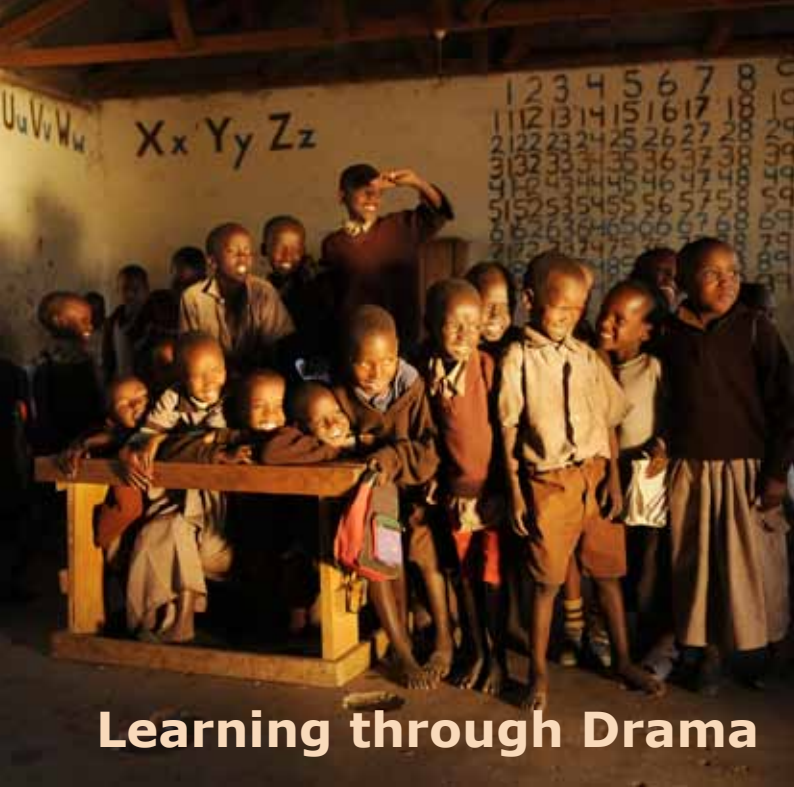
South Africa. This means that the project already has a market in which to sell the produce, as milk is in high demand.

The association plans to begin the project by buying eight dairy cattle - Friesians in particular. Friesians have the advantage of producing larger quantities of milk as compared to the Jersey breed. Each dairy cow can produce milk for ten months annually, with the remaining

two months are for gestation, and has the potential to produce between twenty to thirty-five litres of milk per day.

Through the training, those involved in the project will acquire the means and skills to become self-reliant. This project will not only benefit members but also their families and the community. Once the project is self sustainable, more cows will be produced, thus more income will be generated and this in turn will improve the standard of the community and the family members and ensure continuation of the project. The main aim is to empower people with epilepsy.





Community Drama for Epilepsy Awareness

KAWE, Kenya

With 42 ethnic communities in Kenya, each of which has its own mother tongue, norms and beliefs that can affect attitudes and reactions to epilepsy, KAWE has undertaken many communication campaigns and produced educational materials, but it is very difficult to address the specific myths prevalent in each community through generic messaging. To develop information materials in the local languages is also very expensive.

Although the association has booklets already in circulation in three widely used languages, there are still many who cannot read them due to illiteracy problems.

KAWE has developed a schools and community drama project to depict issues surrounding epilepsy, specific to each community. Through this project the association intends to increase epilepsy awareness, reaching at least 200 public community forums in one year, through filming and recording community dramas for use on local TV and radio, which will allow the programme to reach a wider audience.

Learning through Drama

EDUCATIONAL MATERIALS PRODUCTION UNIT

Epilepsy Association of Zambia

The association is setting up an educational materials production unit to produce brochures and flyers, both in local and English languages, which will be distributed free of charge to association members and to members of the public.

The unit will also produce calendars and seizure diaries, which will be sold at low cost. The diaries will be used by members and clients at other health centres to keep a record of their seizures, appointments and the medication they are taking.

A room at the centre will be converted into a production unit for this work. Some members, who are not involved in other projects, will be trained for this work with

funds raised will be used to expand the project. The association will partner with a local printing company, which will provide guidance to the unit.

Once established, other printing such as T-shirts, banners, and epilepsy education books, will also be considered.

The project will provide employment for people with epilepsy thereby reducing their dependence on their families. The result will be an improvement of life quality, increased awareness



on epilepsy in the general public and the ensuing reduction in stigma associated with epilepsy.

About Promising Strategies

The IBE Promising Strategies Program is now 7 years old and is one of the most successful of all IBE's initiatives. Set up in 2006, as a means of supporting IBE members through the provision of financial support

for projects aimed at improving the quality of life of people with epilepsy, to date, 81 projects in 38 countries have received a total of US\$330,000 in support. A total of 11 new projects, in 10 countries, were selected

by the International Executive Committee for funding this year. Information on all 81 projects, funded to date, can be found on the IBE website, where you can also find further information on funding and selection criteria.

- ARGENTINA
- BANGLADESH
- BRAZIL
- BULGARIA
- CAMEROON
- CHILE
- CHINA
- COLOMBIA
- CZECH REPUBLIC
- ECUADOR

- THE GAMBIA
- GEORGIA
- GUATEMALA
- HAITI
- INDIA
- INDONESIA
- KENYA
- LAOS
- LEBANON
- LITHUANIA

- MAURITIUS
- MALAYSIA
- MONGOLIA
- NAMIBIA
- NEPAL
- THE PHILIPPINES
- ROMANIA
- SIERRA LEONE
- SOUTH AFRICA
- SWAZILAND

- TANZANIA
- TIBET
- TOGO
- UGANDA
- URUGUAY
- WESTERN PACIFIC ISLANDS
- ZAMBIA
- ZIMBABWE



UNMASKING EPILEPSY IN CHINA

Photo: Ann Little

China has a rich and colorful cultural history, and masks have played a major role in Chinese tradition for thousands of years. Depending on their function, Chinese masks were divided into different categories, such as sorcerers' masks, Tibetan masks, shaman masks and theatrical masks.

Today, masks continue to be of great entertainment and artistic value and when representatives of IBE had the opportunity to attend the 5th China International Epilepsy Forum (CIEF), organised by the China Association Against Epilepsy in the city of Chongqing in September, we had the chance to see just how colourful and entertaining mask dancers can be.

The IBE Management Committee was honoured to participate in the Forum, with Athanasios Covanis, President and Robert Cole, Treasurer also invited to speak at the meeting.

"In all sessions, we found that more and more young doctors had the courage to stand up and ask pertinent questions."

Prof Shichuo Li, President CAAE

The Forum was attended more than 700 delegates who had travelled, not only from other parts of China, but also from Taiwan, the US, Italy, UK, Malaysia, Japan and Australia.

Since the first Forum, which was held in Beijing in 2004, the CIEF has taken place biennially, each time in a different Chinese city, and is supported by the International League Against Epilepsy (ILAE), IBE and the WHO. It is now a well known and popular regional event.

Ten internationally recognised neuroscientists and epileptologists from the US, Netherlands, Greece, Italy, Taiwan, Australia, Malaysia, Japan and Australia presented special lectures and seminars, including:

- Sten Grillner, former chairman of the Medical Committee of the Nobel Prize in physiology, who spoke about the modular nervous system;
- ILAE President Emilio Perucca, who reviewed the history of AEDs;
- Athanasios Covanis, who summarised the difficulties and challenges in epilepsy treatment;
- Chief-editor of SEIZURE, Markus Reuber, who reported on his experiences in publishing papers in scientific journals;
- Andrew J Cole from Massachusetts General Hospital, who talked about pre-operative evaluation for epilepsy;
- President of the Taiwan Epilepsy Society, Shang-Yeon Kwan, who reported on recent advances in EEG.

Epileptologists from China also gave lectures on current issues. In addition there were post-main sessions, parallel sessions and video sessions - with many interesting topics presented and with active

Athanasios Covanis presents a crystal candlestick to Shichuo Li as a gift from IBE.



Photo: Ann Little

discussions and debates in an academic atmosphere which, at times, became very animated! Other activities held during the Forum included:

- An epilepsy photography exhibition;
- The inaugural meeting of the CAAE Youth Committee and the first Youth Symposium;
- Educational activities for people with epilepsy;
- An ASEPA training course on psychosocial problems in epilepsy.

"In all sessions, we found that more and more young doctors had the courage to stand up and ask pertinent questions. We were happy with their active thinking and good communication skills", reported Prof Shichuo Li, President of CAAE, who has been instrumental in the creation of the Forum and its continued success.

LI XUANLI - A young Chinese woman with a message

Interview with Sari Tervonen, CEO Finnish Epilepsy Association and IBE Secretary General

Photo: Ann Little



23 year old Li Xuanli from Chengdu in China talked about her personal experiences with epilepsy at the Chongqing conference session targeted at people with epilepsy and their family members. Li has had epilepsy since she was 19 years old, but she is seizure free with the first medication she was prescribed.

Today she works for customer service in a company that sells wedding dresses. She uses the internet a lot, not only because of her work, but also she is involved in many QQ (Chinese Facebook) groups in which the members have epilepsy. There are around 150-200 members in each group she is attending.

"The discussions are also about things other than just epilepsy problems", says Li laughing.

Li was asked to speak about her epilepsy at the meeting. She wants to encourage other people with epilepsy to trust in themselves, so that they can enjoy a better way of life. "Stay confident", emphasizes Li. In addition, she stresses that she speaks up only about her personal experience and that other

people with epilepsy will have different experiences and different stories to tell. She advises people with epilepsy to be active in seeking information from the Internet and to share their thoughts with other persons in similar lifecycles.

IE News asked about her future wishes: "I would like to find a job that would involve the English language somehow" tells Li. For that she is studying English. Maybe you will meet her in an Chinese Embassy one day when you are applying for a visa to travel to China!

IE News would like to thank Li for having the courage to speak about her condition openly, which is something that people do not usually do in China. On the contrary Chinese people and families still hide their epilepsy because of the stigma and ignorance they will face.

It's a long way to a world without prejudice, but every step is important, both in large and smaller countries. Li is one brave hearted person who is taking these steps in China.

Symposium for People with Epilepsy and their Carers

Early on the morning of Thursday 12th September, the meeting room corridor at the Tian Lia Hotel in Chongqing began to hum with the sound of excited voices as more than one hundred people began to arrive to attend the special symposium, organised by Dr Shichuo Li and Dr Ding Ding as a prelude to the official programme of the CIEF.

Delegates covered the full age spectrum from young adults to those in middle-age and older. These were people with epilepsy, their families and healthcare givers, who had come to participate in the excellent half-day event. By the time Dr Li stood to officially open the symposium, and to

welcome the delegates to the symposium, it was standing room only. The programme focussed, in particular, on caring for children with epilepsy, health education, and social support and awareness raising initiatives used by epilepsy associations to provide for a good quality of life for people with epilepsy. In addition to speakers from China, a number of experts from further afield also addressed the delegates.

Following the welcome message from Dr Li, Athanasios Covanis gave a welcoming address as IBE President. He spoke about the work of IBE and initiatives of the Bureau to address the discrimination and stigma so often experienced by people with

epilepsy.

Xuanli Li then spoke about her personal experiences of living with epilepsy, the difficulties she had encountered and overcome, and encouraged others also to be positive in their approach to life. In Li's interview with Sari Tervonen, featured above, you can read more about this motivated young woman.

Dr Yanchun Deng, from Xi'an province, and Dr Jie Zhang, from Hunan province, spoke of their experiences of providing health education for people with epilepsy and supporting parents in caring for their child with epilepsy. A novel initiative being developed is the new website that will

provide links to professionals and build up a patient-doctor instant messaging system. There will be a BBS (Bulletin Board System) related to the website and an instant messaging system that can be used on smartphones to give reminders which are easily replied to using a wifi or a 3G connection. The program is being supported by the IBE Promising Strategies Program and you can read more about the initiative on page 4 of this issue.

Dr Shunglon Lai talked about the very successful bakery business which has been developed by the Taiwan Epilepsy Association and which provides both training and employment for people with epilepsy. The business is run from a commercial unit purchased thanks to successful fundraising efforts.

Dr Yuhua Zhao, from Tibet, described a health education programme being used to inform people with epilepsy and their families about the condition. This programme is also supported by the IBE Promising Strategies Program.

The final presentation was given by IBE Treasurer, Robert Cole, who described initiatives developed in Australia.

Following the formal presentations, there was a lively question and answer session, with young people particularly interested in finding out more about epilepsy. At the end of the event, the doctors attending the symposium gave generously of their time to talk individually with the delegates.

Photos (from top):

1. *Shunglon Lai answers a question posed by one of the delegates*
2. *From left: Robert Cole, Ding Ding, Xuanli Li, Athanasios Covanis and Sari Tervonen*
3. *Question and answer session*
4. *Outside the formal sessions, Dr Li organised a tour to the world famous rock carvings at Dazu.*



GETTING AHEAD OF EPILEPSY

By Megan Howe

First published in Australian Doctor, August 2012

Professor Mark Cook from Australia is quietly optimistic that the 15 million people worldwide whose lives are disabled by uncontrolled epilepsy could have new reason for hope, thanks to developments in neurobionics. For this report on the work of Professor Cook and his colleagues, Megan Howe was the winner of the Print Category award in the 4th Excellence in Journalism awards, which were announced earlier this year. The awards are a joint collaboration of IBE and UCB. The article was first published in Australian Doctor, in 2012.

In May 2012, I was invited to attend the inaugural TEDxUWollongong – an event hosted by the University of Wollongong in NSW to explore how lives are being transformed by medical bionics.

In a series of short, sharp and inspiring talks by experts, the event explored the science and the ethics of medical bionics, ranging from the success of the cochlear ear implant to developments in nanobionics and a talk on whether bionics could lead to the “Holy Grail” for treating epilepsy.

It was this promise for treating uncontrolled epilepsy which I explored in an article for Australian Doctor, a weekly news magazine for Australia’s 20,000 general practitioners.

Professor Mark Cook, Melbourne neurologist and world leader in epilepsy treatment, told the conference that of the one in 100 people worldwide who suffers recurrent seizures throughout their lives, about one-third cannot be adequately treated with available medications or surgical therapies. The condition often prevented them from driving, from working, threatened their safety, and sometimes, cost their life, he said.

Professor Cook explained how groundbreaking Australian research into implantable devices could help people with epilepsy predict when a seizure was going to occur.

Already, 15 Australian patients are trialling one of the first implantable devices – the Seizure Advisory System, developed by US company NeuroVista. The system involves

permanently implanting electrodes on the surface of the brain to monitor electrical activity 24 hours a day. A pacemaker-like device implanted under the clavicle records the information and transmits the records, analyses and real-time ambulatory iEEG data to a small pager-sized device that the patient carries with them.

It has a series of coloured lights: blue indicating a very low risk of seizure, white indicating a medium risk and red a very high risk.

One of the Australian trial participants explained how the device had enabled him to take fast-acting medication when he was at high risk of a seizure. As a result, the seizures that previously dominated his life had stopped completely.

Professor Cook said the potential for such devices went beyond predicting the onset of a seizure: research was now underway into the potential for the devices to control the release of drugs.

Together with Australian nanobionics pioneer Professor Gordon Wallace, he is working on a project to put antiepileptic drugs into electrically-activated polymers which would be implanted. The drugs would be delivered systemically, avoiding the damaging side effects the medication has on the CNS and elsewhere in the body. “Conceivably, we could construct polymer implants, which could not only release the

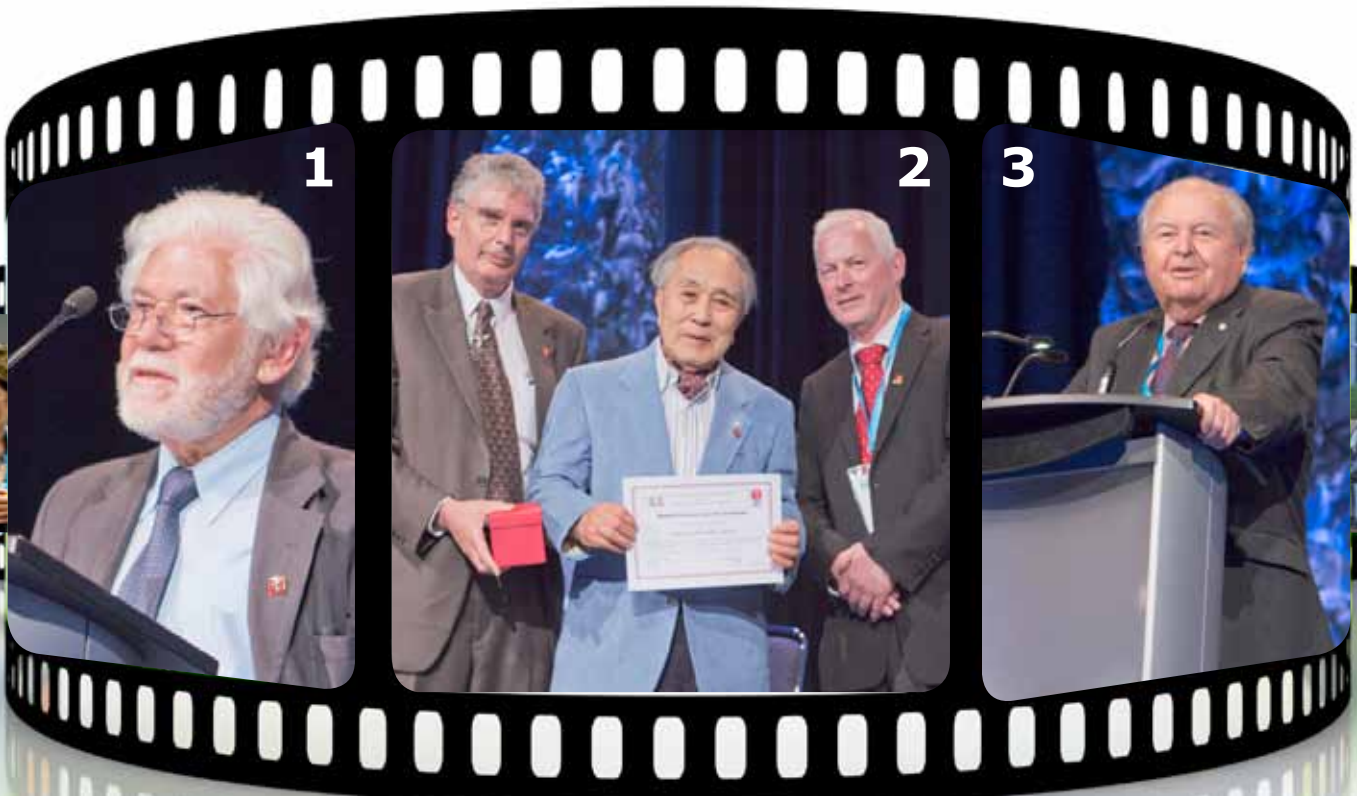
drug, but detect the seizure and use the energy in the seizure itself to release the therapy. This would be remarkable,” Professor Cook said.

In a paper on their research into the drug-infused polymer-based implants, Professor Cook and colleagues stated: “The Holy Grail has so far eluded researchers in the field, however, strong progress is being made.”

He told Australian Doctor he believed developments in medical bionics really could one day prove a therapeutic Holy Grail for epilepsy.

<http://www.australiandoctor.com.au/news/news-review/getting-ahead-of-epilepsy>





THE STATISTICS

We all know that Big Brother is becoming more powerful, with every moment of our lives followed and tracked. Each online purchase, every journey made, what we put in our supermarket trolleys, which films we prefer; nothing is secret. As a result, now almost every website we visit bombards us with advertisements selected just for us - whether we want them or not. And, usually, we don't!

But gathering information can also work to our advantage.

Those who have attended conferences and congresses in recent years will notice how our delegate badges have become a source of great interest for the organisers; scanned as we enter session rooms, they provide valuable feedback allowing the congress organiser to gather information on the best attended sessions; the most popular day of the congress; the average number of sessions attended and, yes, even the tiny number of delegates who picked up their badges but then do not attend any session at all!

Post-congress, these statistics become invaluable in preparing for the next meeting. They indicate, not only the type of session

that delegates like best, but also the size of the hall that would be required to accommodate a similar session in the future. This helps to avoid session halls that are crowded to overflowing or, at the other end of the scale, a hall that is too large for delegate numbers. So, a correct analysis will benefit the delegate with arrangements in place that match the expected delegate numbers and session choices.

Right now, the information gathered in Montreal is being studied as preparations begin for the 31st International Epilepsy Congress in Istanbul in 2015. Because I am sure you are a little curious, here are a few interesting numbers from Montreal:

- A total of 17,614 delegate badge scans at 78 sessions over 5 days
- Delegates came from (exactly) 100 countries
- The top five countries with the highest number of attendees to sessions were: USA, Canada, Japan, China and the UK
- Best attended session: Presidential Symposium: Epilepsy: beyond seizures
- Most popular day: Monday!





THE PHOTOGRAPHS

1. Athanasios Covanis, IBE President Elect, addresses delegates at the congress Welcome Ceremony. The small image to the left shows Rosemary Panelli at the Global Campaign Reception.
2. Prof Juhn Wada, Canada, is presented with the Lifetime Achievement Award by Nico Moshé (left), outgoing ILAE President, and Mike Glynn (right), outgoing IBE President.
3. Prof Frederick Andermann, Canada, Honorary Congress Chair, welcomes delegates to Montreal.
4. Delegates enjoy the warm evening on the open air terrace of the Congress Centre at the Welcome Reception.
5. Mary Secco, Canada, who is now Co Chair of IBE/ILAE Global Outreach, discusses a scientific poster with two colleagues.
6. Hanneke de Boer chats with Nico Moshé during the Global Campaign Reception.
7. At the close of the IBE General Assembly back row, from left: Janet Mifsud VP Europe, Ding Ding VP Western Pacific, Philip Gattone VP North America, Man Mohan Mehndiratta VP South East Asia, Anthony Zimba VP Africa, Najib Kissani VP Eastern Mediterranean. From row from left: Mike Glynn Past President, Lilia Núñez VP Latin America, Athanasios Covanis President, Sari Tervonen Secretary General and Robert Cole Treasurer. Missing from the photo are the three ILAE representatives on the committee - Emilio Perucca, Helen Cross and Sam Wiebe.
8. Carlos Acevedo, outgoing Secretary General and Editor IE News, cuts the celebration cake to mark the 50th anniversary of the newsletter.
9. Karen Harvey, Administrative Assistant, mans the IBE stand in the Exhibition Hall.
10. From left: Josephine Guttierrez, Anthony Zimba, Helen Cross, Sari Tervonen and Lawrence Hirsch.
11. From left: Andy Shih from Autism Speaks; Ann Little, IBE; Sandy Finucane, Epilepsy Foundation (US); and Carlos Acevedo, ANLICHE (Chile) at the *Making the case for IBE's International Advocacy* session. Schihuo Li, China Association Against Epilepsy was a further speaker.

Photos: Karen Harvey, Ann Little and James Dunne





Harry Meinardi

presents his final instalment of IBE's history as reported in its newsletters

The **March 1984** issue has as its frontispiece a picture from an educational video program about epilepsy, made in Sri Lanka by Nimal Senanayake. Furthermore there is his report that in Sri Lanka a particular form of reflex epilepsy, where seizures are evoked by the intake of food, appears to be more frequent than elsewhere. Contributions from Kenya and Nigeria highlight the difficult situation for people with epilepsy in developing countries. As regards “developed countries”, both the EI Chairman and a contribution from Italy point to the fact that

many physicians continue to prescribe conventional antiepileptic drugs that, indeed, prevent seizures but burden the person with epilepsy with side-effects such as drowsiness and slow thinking, which are often, mistakenly, blamed on the epilepsy.

June 1984: Prof Thorbecke reports from Germany that, notwithstanding the repeal in 1977 of all regulations excluding persons with epilepsy from certain “dangerous” occupations, individual assessments remained uncommon. Therefore the German branch of ILAE brought together a group of experts and interested parties to develop guidelines for individual assessment of occupational suitability. These were then published in journals of occupational medicine and in neurological journals.

In their attempt to inform people living behind the, so-called, 'Iron Curtain' about conditions in the West, the BBC prepared a magazine about social and medical care of people with epilepsy in the UK assisted by Jolyon Oxley, medical director of the Chalfont Centre, and Alex Aspinall of the British Epilepsy Association.

September 1984: Dr Najmi from Iran writes about intentions to start a Special Centre for Epilepsy. An attempt, 27 years later, to find out about special centres in Iran failed as neurologists in Iran who recently published about epilepsy

did not respond/receive letters asking for this information. Neither was the Iranian embassy in the Netherlands able to do so. Professor Levy of Zimbabwe discusses the problem that modern AEDs may seem to have less side-effects but that in putting the side-effect of high costs in the balance, when looking at medical and social aspects, makes phenobarb still the best choice in developing countries. The President of the ILAE urges the pharmaceutical industry to see whether increased volume, by opening the African market, would not allow decreased costs.

Prof Mahar Mardjono announces the founding in August 1982 of Perkumpulan Penanggulangan Epilepsi Indonesia, which was abbreviated as PERPEI (Indonesian Society against Epilepsy).

December/January 1985: Eva Andermann reports about genetics and epilepsy - field that has since made giant strides forward.

In Europe a third chair of epileptology has been created in the Netherlands following earlier appointments in Germany and Switzerland.

In *EI Speaks* the IBE and ILAE Presidents announce that, given the fact that the merger of the three organizations had not been achieved, further perpetuation of EI was futile.

IBE and ILAE will continue with separate agendas but certain activities linking the two organizations will be conducted jointly. These include the biennial international congress, certain educational programmes and awards for outstanding achievements in the epilepsy field. EI will terminate on the 6th September 1985 at 2:30 in the afternoon.

March 1985: Van der Linden pleads for the removal of the indiscriminate exclusion of all persons with epilepsy from becoming blood donors. Juul-Jensen reports that excess mortality, due to epilepsy itself and not to its cause, does not exist except in the case of men with primary generalized tonic-clonic seizures (grand mal) who

1984-1985
Collaboration between
IBE and ILAE continues

Look Back with Pride - Part 8

have an excess mortality rate of 1.5 to 3 times the norm.

George and Sylvia Burden have conducted a third survey on entry of people with epilepsy into foreign countries (1984/5; 1973; 1964) and plead for a Handbook for Travellers "which does not just tell people with epilepsy whether they are allowed to go to a country, but what the attitude is, what the opportunities for treatment are, and, most important, who to contact".

June 1985: news comes from four of the five continents. Africa is missing. America tells about the use of Positron Emission Tomography for localizing an epileptic focus in the brain. Asia reports from Sri Lanka on the opening of the first laboratory for determination of AED levels in blood. The Japan Epilepsy Association tells about a nationwide study to see what is available and what is lacking in the provisions to provide up to date assistance to persons with epilepsy. India summarizes a workshop held in Bombay (nowadays Mumbai). Australia describes how the role of practitioners, as regards epilepsy, is to manage the patient within the context of the environment in which he or she lives, rather than just treat the epilepsy. From Europe, Finland describes the work of the

National Epilepsy Centre of Finland and Italy reports on an advertising campaign to fight discrimination of persons with epilepsy and to reduce the fear they have of disclosing that they have epilepsy.

September 1985: the journal has a name change. From now on "*Epilepsy International News*" will be titled "*International Epilepsy News*". Two renowned men contribute to the newsletter - one who had a short life of 45 years; the other who would live to reach his 101st birthday. Bruce Schoenberg (1942-1987) explains the problems in conducting epidemiological studies of epilepsy. Haruo Akimoto (1906-2007, last paper published in 2006!) dismisses the concept of an "epileptic character" as nothing but a superstition.

At the end of 1985 the new IBE executive is in charge. For the second time an editor of the newsletter has been elected as President, (this will happen once more when Hanneke de Boer succeeds Joop Loeber).

December 1985/January 1986: the new President issues a statement about the course for the future now that Epilepsy International has been discontinued. IBE will concentrate on the more non-medical aspects of epilepsy and the social consequences, but collabora-

tion between IBE and ILAE will continue with the Presidents and Secretaries-general being ex-officio members of the respective organizations. Three items of the 1985 EI Symposium are highlighted:

1. The Audiovisual Festival with three Gold Awards for the USA, one for Sri Lanka and one for the UK;
2. The International Publication Seminar dealing with education of teachers, schoolchildren, employers, non-medical professionals including police officers and prison wardens, people with epilepsy themselves and the general public;
3. Self-help for Epilepsy World Wide.

At this point, the author of "Look Back with Pride" moved from the IBE executive to the ILAE executive and so it is appropriate to close this great series, which has given a tremendous insight on developments within IBE as reported by its newsletter that this year celebrates its 50th anniversary.

IBE would like to thank Harry Meinardi most sincerely for his stalwart work, which has provided this excellent and informative series for IE News.

June 1985: news comes from four of the five continents.





Photos (clockwise from top left):

- *Reetta Kälviäinen (Finland), Helen Cross (UK) and her daughter, Charley Cross, enjoying the Welcome Reception.*
- *Terra Folk and Symbolical orchestra players delighted delegates with their eclectic mix of traditional, jazz and blues music that keep feet tapping at the Welcome Ceremony. When they continued to play at the Welcome Reception, some delegates took the opportunity to take to the floor.*
- *Members of društvo Liga proti epilepsiji Slovenije, the IBE and ILAE member association in Slovenia, who played a big role in ensuring a great conference, from left: Matevž Kržan, Jasna Žunko, Ljublica Vrba, Svetlana Simić and Igor Ravnik.*
- *Delegates from Epilepsy Ireland: Mike Glynn (IBE Past President), Eoin Megannety (who took many of the photos shown here) Agnes Mooney, Wendy Crampton and Peter Murphy.*
- *Salla Aatsinki from Finland is interviewed for Slovenian TV about her experiences of living with epilepsy.*
- *The jubilant winning team enjoys a moment of glory at the end of the friendly basketball tournament with the Lipko joining in.*
- *Zoran Janković, Mayor of Ljubljana, welcomes guests to a special reception in the beautiful Town Hall.*
- *Guitarist Miha Ložar and singer Sanja Zupančič, both medical students, entertaining guests at the reception in the Town Hall with traditional melodies. Lipko, the mascot of the Eurobasket 2013 - the European basketball championships that took place in Ljubljana after the conference - meets with IBE President Thanos Covanis.*
- *Matevž Kržan (Slovenia), with Meir Bialer (Israel) and his wife Shoshana, and Thanos Covanis (Greece) and his wife Lynne.*

LJUBLJANA

the perfect setting for a great conference





With a population of less than 300,000, Ljubljana is one of the smallest capital cities in Europe. It is also one of the prettiest and friendliest - as can be confirmed by the 300 delegates who travelled there to attend the 13th European Conference on Epilepsy & Society at the end of August.

The Epilepsy & Society Conferences are the only regional conferences organised solely by IBE and, as such, there is the opportunity to focus in particular, although not exclusively, on social issues affecting people with epilepsy. Ljubljana was no exception, although there were some new activities, introduced for the first time, that provided interesting sessions for professionals such as EEG technicians, epilepsy specialist nurses, paramedics and doctors. The Advocates for Epilepsy Workshop was a new adjunct to the congress programme. This one-day workshop was designed to raise awareness and improve patient care through collaborative practice and was financially supported by the ILAE Commission on European Affairs and IBE. The workshop addressed issues such as seizure observation; acute management of seizures; risk of seizures and safety measures; case reports and achieving better outcomes.

Following of workshop, there was just time to take our places for the Welcome Ceremony and Reception. The Terra Folk and Symbolical orchestras combined forces to provide fantastic musical entertainment that had feet tapping and hands clapping! After a late night, with delegates staying

on late to renew friendships from previous congresses and to make new contacts, it was an early start next morning for the first session. Also a new idea, this was a debate for and against the motion that 'representations of epilepsy in popular culture break down stereotypes'.

The debate was followed by an extended session looking at alternatives to seizure control when drugs fail: - ketogenic diet, vagal nerve stimulation and surgery. Drug adherence and the development of new antiepileptic drugs were also discussed. After lunch, discussion turned to beyond seizures and medication, with presentations on science and superstition, and on cognition. Delegates then broke into two groups for workshops on building networks with other organisations and employment and epilepsy.

With the formal programme of the day complete, it was out to the sunshine for the fun basketball tournament. This was in keeping with the official Eurobasket 2013 competition that was due to take place in Ljubljana following the conference. The tournament mascot Lipko was on hand to bring a smile to every face! A quick change and it was time to let the hair down at the Youth Social Evening.

The second day of the conference was also full of interesting sessions, beginning with the important topic of social media and its place in promoting epilepsy. Always an important topic, the women and epilepsy topic included an excellent presentation by a well-known Slovenian actress, as a woman and mother living with epilepsy.

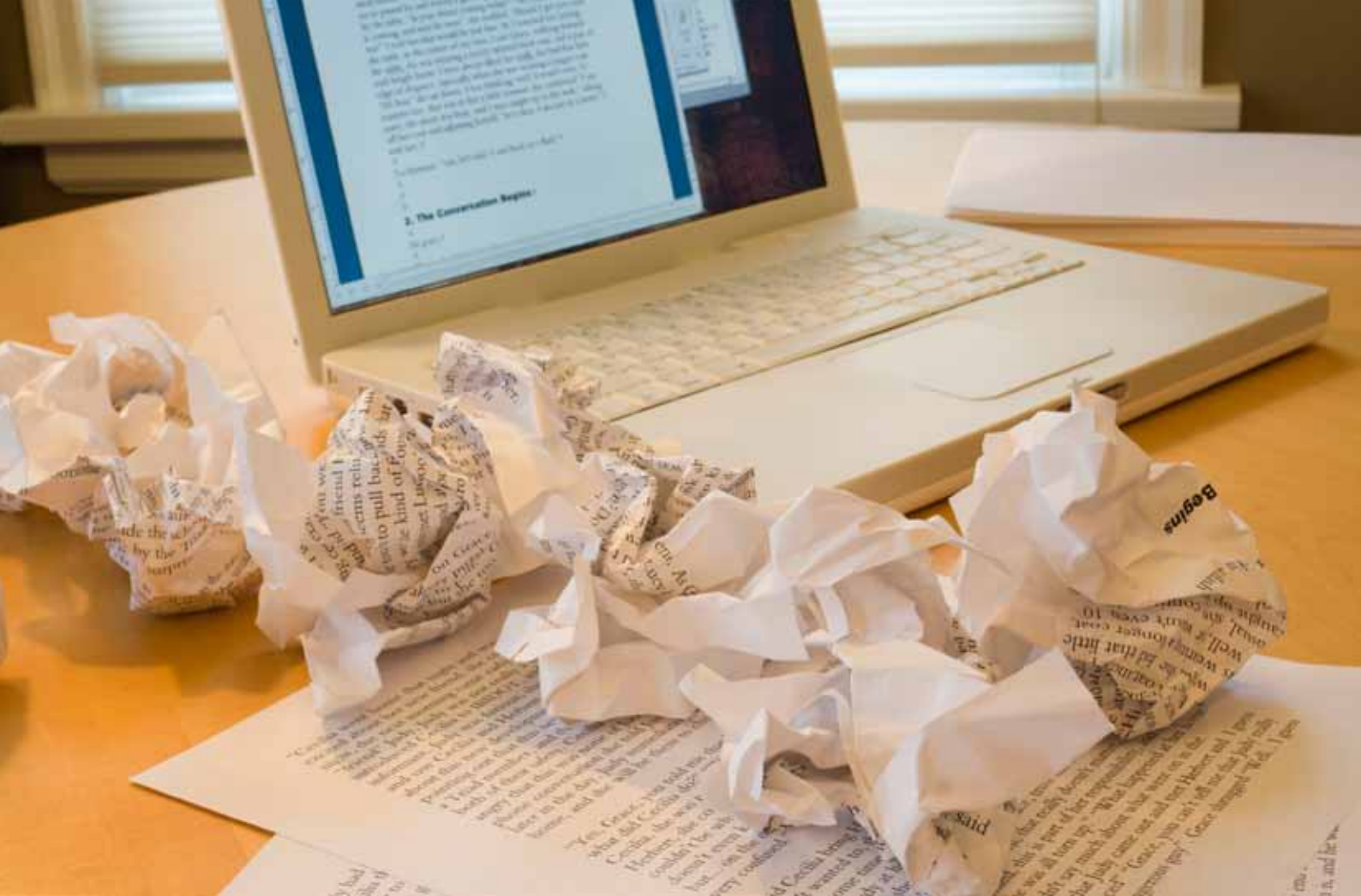
That other perennial worry - switching brands - was another topic that is always interesting to discuss. For this session, also, we had the opportunity to hear about personal experiences.

The final topic of the conference was Epilepsy care in Europe, which was a mixture of medical and social discussion ranging from initiatives for a pan-European study of prevalence and cost; the burden of epilepsy in Central and Eastern Europe; the need for comprehensive care; to the European Written Declaration on Epilepsy and Epilepsy Day. A special addition to this topic was a presentation made by Jelko Kacin MEP (from Slovenia), who addressed the meeting by video. Many of the presentations from the congress are now available on the IBE website for those who could not be with us in Ljubljana.

Outside the main congress programme, there was also a special reception hosted by the Mayor of Ljubljana, Zoran Janković, that took place in the beautiful Town Hall reception room the evening prior to the start of the congress, with musical entertainment provided by two medical students - Miha Ložar and Sanja Zupančič. The media also showed excellent interest in the conference and one of the country's best known news presenters interviewed Salla Aatsinki on her experiences of living with epilepsy and IBE President Thanos Covanis on the problems faced by people with epilepsy and the work of IBE.

Before we knew it, the conference had come to an end and it was time to say our farewells - until the next time!





“Scientjournalist” – A chimera for social transformation

Patrícia Tambourgi, MSc PhD Candidate – Journalist and International Relations Analyst, Student of specialization graduate course Science and Health Communication/Neuroscience of UNICAMP;

Vera Regina Toledo Camargo, PhD – Professor at Labjor of UNICAMP

Li Li Min, MD PhD – Professor of Neurology of Faculty of Medical Sciences of UNICAMP

Prof Li Li Min, who is a member of the IBE Research Task Force, spoke to this paper in a workshop session *Think Global - Act Local* organised by the task force at the 30th International Epilepsy Congress in Montreal in June. The presentation is now available on the IBE website <http://www.ibe-epilepsy.org/research-task-force-act-local-think-global>

Universe of the scientist and journalist

In small circles of conversation with scientists, talking about how to give interviews on their findings, many wrinkle their noses and frown. Some said “What a waste of time!”; others answered “I have no interest in that kind of activity”. Negative impressions like these, concerning the relationship between scientists and journalists, are not rare. And they do not seem to be getting less frequent.

Two problems emerge from this troubled relationship. The first is that the journal-

ist, who seeks scientific information from the scientist in order to write an article, leaves the interview unsatisfied because the scientist does not always have time to explain their findings in an accessible way and often uses technical words, unknown to the journalist. The second is that the flow of information from the researcher to the public ends up being affected. Why does the relationship between scientists and journalists have to be so harsh?

Deconstructing the relationship

If we look at the profile of the journalist and of the scientist, we find many different

things, some diametrically opposite. As far as journalists are concerned, they are restless, seeking aesthetics behind the news, targeting the broadest audience possible, and searching for the popularization of science.

As for scientists, they are methodical, looking for evidence behind a discovery, avoiding the media since their peers are their world, always after gentrification. Despite differences between these professionals, they share a common trait: both of them are extremely curious.

It is evident that the appropriation of

knowledge (by scientists) and its dissemination (by journalists) follow different paths. The challenge, however, is to make them tread a common path by working together. After all, society has the right to know about the state-of-the-art of scientific advances. How can lay people have access to information, if most of the people are not familiar with science intricacies and do not participate in the in academic and scientific meetings?

Let's Change the Rules: The origin

Epilepsy is a highly stigmatizing disease. The mechanism underlying stigma is beyond medical science. ASPE (Assistência à Saúde de Pacientes com Epilepsia -Health Care of Patients with Epilepsy), executor of the Demonstration Project on Epilepsy of ILAE/IBE/WHO in Brazil, demonstrated that media campaigns and appropriate use of language can change the perception of stigma. Thus, the Program CInAPCe (Brand name of Interinstitutional Cooperation for Brain Research), funded by FAPESP, brought together the leading educational institutions and sought an innovative way to publicize epilepsy through actions aimed at the segment of people who work with news, that is, Journalists. The basic idea was that, once sensitized, the journalist becomes a propagator for the cause of epilepsy.

However, we understand the problem in a more complex level, since the other variable is the scientist, who also needs to know the aesthetic as means for effective communication. Moreover, this communion would

be a statement that these two professionals can work together in synergy, bringing something more than journalism and scientific communication, but the science dissemination with capacity for social transformation.

The Laboratory of Journalism of UNICAMP – Labjor – is the arm of the CInAPCe program responsible for deploying a program fostering a graduate course of specialization to bring journalists and scientists to the converging belief of working together as a team for the greater benefit of creating accessible knowledge to lay people.

Labjor, in partnership with the Department of Neurology of the Faculty of Medical Sciences of UNICAMP, offered the first specialization graduate course *Science and Health Communication/Neuroscience* from 2009 to 2010. There were 26 candidates shortlisted after the first phase of examinations; 22 were approved; and 15 people concluded the course. The participating students were from different backgrounds – journalists and scientists –, which fulfilled the criterion of having both professionals in the same environment.

Currently, we are in our second edition (2012-2013). The number of people interested has increased: we shortlisted 47 people after the first examination, and approved 26 students, with a good balance between scientists and journalists.

The program has 12 mandatory courses,

which entail both science and journalism content, in a total of 360 hours distributed over three semesters. The course is free of charge. The aim of the program is to prepare professionals with a global vision of sharing scientific knowledge in health sciences, with a special focus on neurosciences and its relation with science and technology systems.

And Results?

This sort of endeavor aims to long term results. In the future, we hope to have a society with cultural knowledge derived from the best scientific evidence to deal with fast paced future challenges. For the time being, in our micro-environment, we are sending the message that scientists and journalists can work together as a team to “translate” scientific findings into accessible and meaningful information.

This type of exercise creates a full circle of communication process among all stakeholders: at one end, the scientist; at the other, lay people, who are also taxpayers having the right to know about their investment and to pitch demands for scientific community.

It is high time that Science serves human beings for emancipation instead of being an instrument of destruction. As for now, products on epilepsy have been developed: books, e-books, podcasts, informative booklets, blogs, websites, social networks (Facebook, Twitter), several articles in magazines, talk-shows, TV-programs, interviews, media-desks. All these products have been used in local campaigns to raise awareness on epilepsy. This action is a good example of standing up for epilepsy.

Together we can make it happen!



FUTURE CONGRESSES



2nd AFRICAN EPILEPSY CONGRESS
CAPE TOWN, SOUTH AFRICA
22nd – 24th May 2014



11th European Congress on Epileptology
STOCKHOLM
29th June - 3rd July 2014

ILAE-CEA



10TH ASIAN & OCEANIAN
Epilepsy
CONGRESS



SINGAPORE 2014
7 - 10 AUGUST



17-20 Setiembre 2014
BUENOS-AIRES
VIII CONGRESO LATINOAMERICANO DE EPILEPSIA



31st International
Epilepsy Congress
06-10 September 2015

Istanbul 2015

