NEWSLETTER OF THE INTERNATIONAL BUREAU FOR EPILEPSY - CONGRESS ISSUE

INTERNATIONAL Epilepsy News

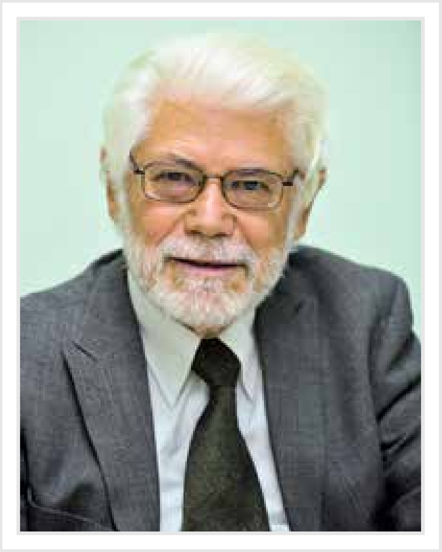
Reporting epilepsy news for 51 years 1963-2014

Focus on IBE in ASIA

10th AOEC

SPECIAL CONGRESS ISSUE

PRESIDENT'S LETTER



Welcome to Singapore

Dear friends - especially our friends from the Asian Region

It gives me great pleasure to prepare this letter of greeting for this special issue of the IBE magazine to celebrate the 10th Asian & Oceanian Epilepsy Congress.

As I write, I am making final preparations for my travel to Singapore to participate at the congress and I feel privileged to be doing so as IBE President. I look forward to meeting representatives from many of IBE's member associations in the region during the congress. Through their budgets, IBE South East Asian and Western Pacific Regional Executive Committees have provided support to the Outstanding Persons with Epilepsy award winners so that they can be with us in Singapore and IBE has also funded bursaries for people to attend the congress who would not otherwise have had the finances to do so.

While I am in Singapore, I also hope to make many new contacts to encourage further membership development in the region. Although IBE has nine Full and Associate Members in the South East Asian Region and 17 in the Western Pacific Region, there are still several gaps to be filled!

The South East Asian and Western Pacific regions, which form the focus of the Asian & Oceanian Epilepsy Congress, covers a huge area with an enormous range of cultural, economic, language and climate differences. This is what makes it such a special region but, of course, there are also problems throughout the region for people with epilepsy. It has often been said, and still remains true that, when it comes to epilepsy every country is a developing nation.

I am greatly impressed at the terrific work that IBE members undertake to improve the quality of life and social conditions of people with epilepsy through the region, sometimes working under difficult conditions where extra efforts are required to overcome the stigma that can have a negative effect on the quality of life of people with epilepsy. Some of our members in the region have provided reports on their recent initiatives to address some of these issues and you can read about them - and perhaps find inspiration for future projects in your own association - within the pages of this magazine.

The IBE Promising Strategies Program, now in its 8th year, has been supporting epilepsy associations since 2007 It is one of our most successful initiatives and the one about which we are most proud. It is good to know that the Bureau has been able to play a role in capacity building and skills training that have impacted positively on people with epilepsy and their families. Although IBE is facing challenging times with regard to future income, we will do our utmost to continue to support and develop this very successful program. In this special magazine you can glimpse the projects that have been previously funded in this region.

I also encourage you to register for, and to attend, the special Epilepsy & Society programme, at the congress, developed for people with epilepsy, their families, and those who care for them.

We must join efforts to promote understanding, reduce the treatment gap, alleviate stigma, and promote and protect human rights of people with epilepsy. Meeting together gives us the opportunity to do so.

See you in Singapore and my best wishes to all!

Athanasios Covanis
President

International Epilepsy News
Singapore Congress Issue

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).

In this special congress issue

Dear Readers

This is a special issue of IE News, specifically created to celebrate the 10th Asian & Oceanian Epilepsy Congress, which takes place in the vibrant modern city of Singapore, with its wonderful historic areas - not to mention the world famous Raffles Hotel.

With the focus on Asia, I invited IBE members in the region to share with us the challenges they face and the successes they achieve in their efforts to support people with epilepsy and their families, and you can read their stories, and perhaps be tempted to borrow from their ideas, in this special edition. I would like to thank those who submitted their stories and photos and, in particular, Denise Chapman who is always a great help in sourcing stories and reports.

There is also the opportunity here to showcase the projects that have been made possible in the region thanks to IBE's Promising Strategies Program. Some of these initiatives have made it possible for people with epilepsy to learn a skill and become self-sufficient. Others have helped increase awareness about epilepsy and thereby dispel the discrimination that can ruin lives.

I would draw your attention to page 5 where you will find details of meetings of interest for IBE members, which take place during the congress, in particular the Epilepsy & Society Symposium.

And, leaving the best until last, we announce the launch of International Epilepsy Day on page 9!

I wish you all a great meeting and, as always, happy reading.

Ann Little
Editor

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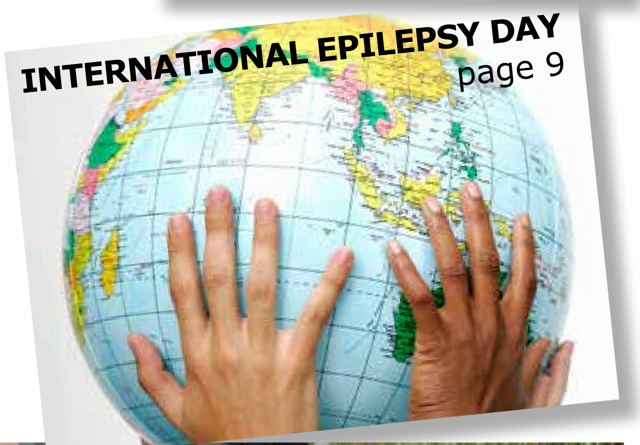

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Message from Dr Man Mohan Mehndiratta

IBE Vice President South East Asia

Dear Friends

Epilepsy is one of the commonest neurological condition affecting all ages, races and social classes. There are an estimated 50 million people with epilepsy in the world of which almost 75% live in low and middle-income countries (LAMIC) with very limited access to diagnostic and therapeutic avenues.

The incidence of epilepsy in LAMIC is much higher 100-190 per 100,000/year as compared to 40-70 per 100,000/year in developed countries. A number of factors are considered to be responsible for this high rate in LAMIC. Low socio-economic status is one of the important reasons for higher risk of developing epilepsy.

This problem is further compounded because of a treatment gap of more than 80% in many low-income countries. Over the years this gap is showing a downward trend. Our IJEP journal will help to report on the research and better education among medical professionals to extend improved care for people with epilepsy (PWE).

The 10th Asian Oceanian Epilepsy Congress (AOEC) is being organized in Singapore from August 7-10, 2014 under the able leadership of the three Scientific Committee co-chairs: Byung-In Lee, Vinod Saxena and Shih Hui Lim. Dr Lim is a veteran organizer. I wish to congratulate all the board members for planning a very rich scientific program for medical professionals and for people with epilepsy and their caregivers.

One of the highpoint for IBE is the Epilepsy & Society Symposium on Saturday 9th August of interest to both individuals living with epilepsy, their care givers and Non-Governmental Organizations engaged in the well-being of people with epilepsy. Some of the highlights of this symposium include the welcome address by IBE President Athanasios Covanis. This will be followed by interaction on topics of interest to PWE such as AED Compliance and considerations, Non-compliance and epilepsy-related injury, Death and SUDEP, AEDs and bone health/pregnancy, Epilepsy and employment, Stigma and epilepsy, Sports and epilepsy, School and epilepsy, Non medication therapies and solutions in epilepsy etc.

I wish you all a great conference.

Dr Man Mohan Mehndiratta
IBE Vice-President South East Asia

Message from Dr Ding Ding

IBE Vice President Western Pacific

Dear colleagues, people with epilepsy and their carers,

Please allow me to warmly welcome you to attend the 10th AOEC in Singapore, especially the "Epilepsy & Society symposium", which will be held on the 9th August. This is an exciting program that will be of great interest to both individuals living with epilepsy and for staff from community organizations supporting people living with epilepsy.

I remember clearly that my first time to attend the "Epilepsy & Society symposium" was in 2007, at the 27th International Epilepsy Congress, also in Singapore. Besides the interesting presentations, what impressed me most was the patient group from the local Singapore association. They looked so full of confidence and happy, and easy to talk with. That experience inspired me to establish a self-help organization of people with epilepsy in Shanghai, which was later to become known as the "Seahorse Club".

During the past seven years, since it was established in 2007, the "Seahorse Club" has organized a large range of activities to help people with epilepsy and their carers to improve their quality of life. In addition, most of the club members attended the "Epilepsy & Society symposium" at the 8th AOEC in Xiamen, China, and four of them were awarded the Outstanding People with Epilepsy award at the 8th and 9th AOEC in Melbourne and Manila.

This time round, it's a great pleasure for me to return again to Singapore. I cannot wait to meet my friends, which I have been missing for a long time. I also hope that the "Epilepsy & Society symposium" will inspire more people, who are interested in patient care, especially those from developing regions where the caring organizations are still lacking.

I wish you all an enjoyable symposium and the congress.

Dr Ding Ding
IBE Vice President Western Pacific

CALLING ALL NEWSHOUNDS!

IBE Editors Network Meeting

Friday 8th August 2014
Time: 12:30 - 14:00
Venue: Oriole Room

Do you edit your association's magazine or newsletter?

Then come along to the Editors Network meeting, chaired by Robert Cole, and take the opportunity to meet publication Editors from IBE member associations around the world.

A great way to find out new ideas on publications and on using social networking to get your message out.

SEE YOU THERE!

JOIN US!

Meeting of the IBE Western Pacific Regional Committee

WPREC
Western Pacific
Regional
Executive
Committee
IBE

Chaired by Denise Chapman, the IBE Western Pacific Regional Committee will meet during the congress. This is a great opportunity to hear about the work of other lay associations across the region, to exchange experiences and to develop contacts.

The meeting is open to representatives of IBE member associations and also welcomes anyone interested in learning more about IBE.

Date: Friday 8th August
Time: 07:30 - 09:00 (note: breakfast will NOT be provided)
Venue: Bluebird Room, Level 4, Grand Waterfront Conference Centre

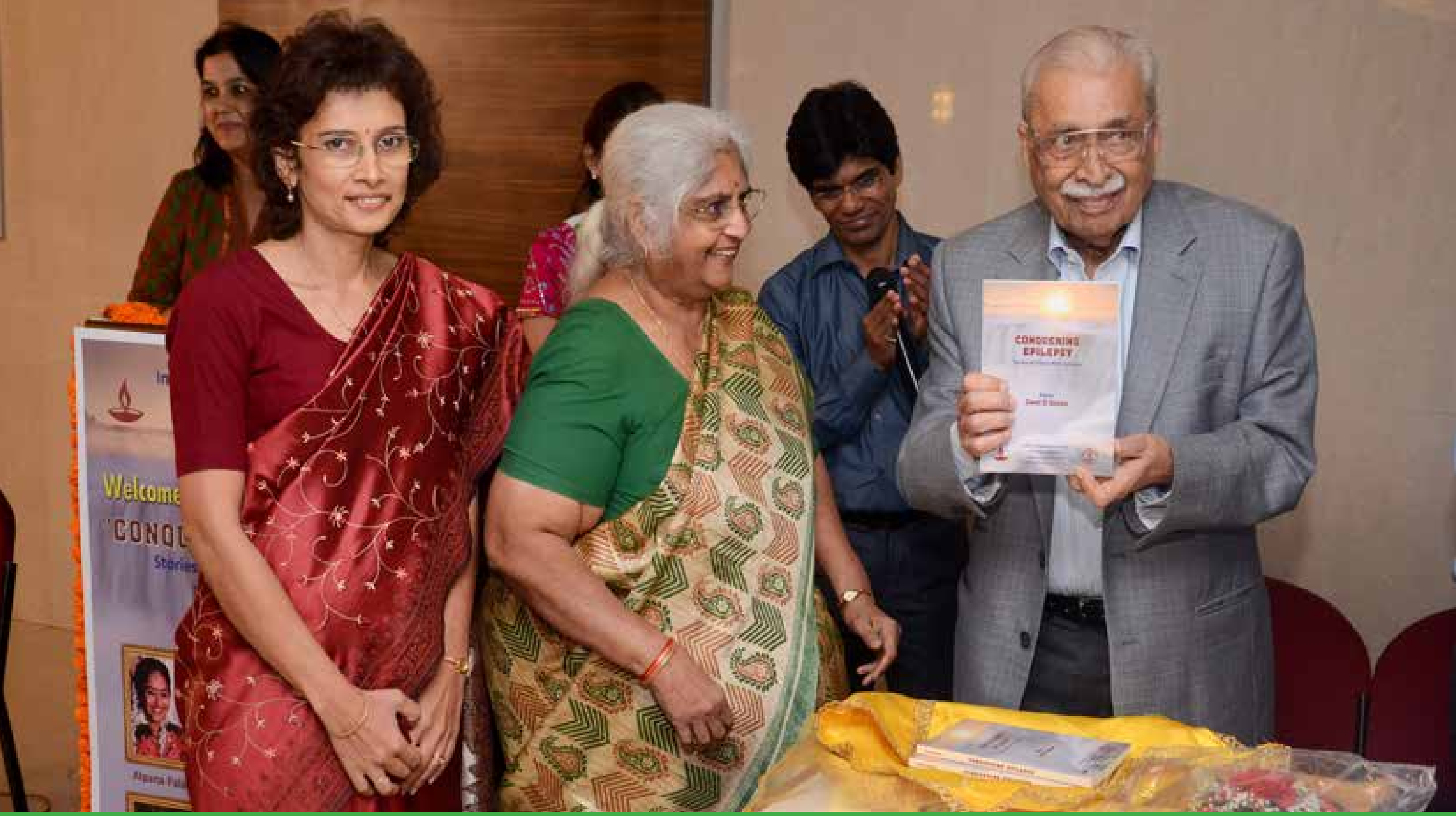
EPILEPSY & SOCIETY SYMPOSIUM

The exciting Epilepsy & Society Symposium will take place on Saturday 9th August from 08:30 to 15:00. This event, which is designed specifically for people with epilepsy, their families and caregivers, focuses on social topics related to epilepsy. It will also be of great interest to educators, nurses and other healthcare providers. Registration for the day is US$50.

Among the thought-provoking topics included in the programme are:

- Be AED smart!
- Living with epilepsy: School, sport and work
- Non medication therapies and solutions in epilepsy

The Outstanding Persons with Epilepsy Award winners will also talk about their experiences, trials and triumphs and a special Mini Fair will offer practical information on first aid, exercise, academic performance and will feature videos, lucky draws and a manicure station!



CONQUERING EPILEPSY

Book Launch and other news from India

Book Launch:

The 2nd edition of the book 'Conquering Epilepsy' edited by Carol D'Souza, was launched on 21st November, 2013 at Hotel Krishna Palace by the eminent neurologist Dr Noshir Wadia. Dr Wadia and the reviewers of the book said it was wonderfully written and would be helpful to all neurologists, their patients and anyone going through a difficult time due to their epilepsy. Dr Wadia lauded the efforts of neurologists Dr Pravina Shah, as well as Dr BS Singhal, in promoting the efforts of Samman members.

Since epilepsy is a hidden disease it is all the more courageous for 27 people with epilepsy to talk about their lives and have it published. Six caregivers who have lost family members who had epilepsy have also given their accounts. At the launch people with epilepsy spoke about how they overcame the disorder with the love and care of their family, friends and the support they have received from Samman.

As the first 1,000 copies of the book were soon sold or were distributed within a few months of the launch of the first edition, it quickly went into reprint. Lupin Limited purchased over a 1,000 copies to distribute to neurologists all over the country and UCB India Ltd purchased 300.

Rural Clinics:

On 1st June 2014 we conducted our 40th rural epilepsy clinic. These clinics, which started in November 2007, were at first conducted every six weeks. In 2011 we had one every eight weeks and since 2012 one every 12 weeks. Three hundred and forty-four (344) people with epilepsy have benefitted so far with medicines (Phenobarbitone, Phenytoin, Carbamazepine, Sodium Valproate, Clobazam, Leviteracetam) being provided to them free of charge or at nominal cost.

We have found that proper documentation, regular follow up, group talks, counseling, educational and vocational guidance, lead to improved compliance and seizure control. There is also a shift in thinking in rural areas, with people coming forward to be investigated and treated. Research, which we undertook, revealed that around 59% had done EEG/CT/MRI. Thirty per cent (30%) had a treatment gap average of 12 years.

Non-affordability, non-availability of medication, long distances to travel, medicine not helping and side effects were reasons given for irregular compliance. Verbal reports suggest that patients seek medical help but do not realize the importance of continuing medication for 2-3 years after seizure freedom.

Main photo from left: Carol D'Souza, Dr Pravina Shah and Dr Wadia at the book launch. Photo above: Dr Shah attends to patients at a Rural Epilepsy Clinic.

SEIZURES IN THE CITY

I'm still a kind kid
A person with special needs
And a learning disability
With a peculiar hyperactivity
The doctors gave me up long ago
The psychologists and psychiatrists are in despair
Yet you pursue a dream, an undying hope
A great sacrifice
To see me the day I receive total healing grace
And attain a new mind.

(Extract from Lydia Says It All, Seizures in the City, 2014)

Sherman Goh, Chief Executive, Epilepsy Care Group Singapore, writes about a special anniversary celebration at the association

The book launch of Epilepsy Care Group's (ECG), `Seizures in the City, which was held in the Arts House on 16 April 2014, saw the gathering of ECG members, caregivers, supporters, friends and interested members of the public. It was a most befitting reunion and celebration of ECG's 21st birthday, a coming of age of the organisation, along with its members.

As the limelight to the event slowly fades, congratulatory words echo in the back of our minds and the photographs are archived in our memory albums, I hope we can really ponder on the significance of the publication of such a great book, if more Singaporeans, and even beyond, can get access to and find the time to read it.

The book has given a voice to many amongst us who would have otherwise been silenced and conveniently 'tucked' in a corner of our society. As I read through the many journeys of our fellow Singaporeans with epilepsy, how their lives have been transformed by their caregivers and ECG, I cannot help but imagine what will happen if these stories are to pass on to many more people.

I see a brave new world, where people believe that experience is not about blind acceptance of what has happened to us. Rather it is what we do with what has and will happen. Like Lydia's mother, she has not given up on loving and teaching Lydia how to pray, despite the world around seems to have given up on them. In doing so, she has taught me a precious lesson on knowing and living by faith, hope and love.

I end this short reflection with a story that I have heard when I was a child:

Five silver stars fell from the sky.

The first is for me for writing these stories down.

The second is for you for reading them.

The third is for all the storytellers from whom I learned these stories.

And the fourth is for all the storytellers who told my storytellers their stories, an ancestry far back into the mists of time.

And the fifth is for all of you who pass on, in your own way, these stories to someone else. When you pass on a story, giving it your stamp, you add to the granting of wishes of those who wish upon the stars.

SANDY'S BIG DAY OUT 2014 at the beach house

A report from Australia

The Epilepsy Centre conducted Sandy's Big Day Out on Saturday 7 June at the Beachhouse, Glenelg, in loving memory of Sandy, who sadly lost his life to epilepsy. This day was dedicated to Sandy's memory.

Sandy's Big Day Out was open to families (direct clients) of The Epilepsy Centre, with children up to 14 years of age. From 10:00 until 12:30 guests enjoyed a "Funcard" which entitled them to waterslides, bumper boats, dodgem cars, mini golf, arcade games, train and carousel rides.

A light lunch and refreshments were provided in the private function room where guests joined as one, and remembered Sandy. The food was excellent!

We had 30 families attend, a total of 126 people, and the majority were children. Although there were some minor medical issues, the children were with their parents and our experienced team. So all was well!

Guests received:

- Plush Sea Turtles for each child
- Children's sized purple silicone wristbands inscribed 'Sandy's Big Day Out'
- Parents received Purple Day wristbands

Paula Alexander Photography attended to capture the day's events. "Trigger the Tiger" entertained the children.

We talked to the group about Sandy MacLachlan's story. The response was fantastic and captured the emotion of the day.

We received some amazingly positive feedback on our Facebook page and some children were so moved to write personal letters of thanks to the MacLachlan family. Young Georgia addressed her letter to Sandy, so I do hope that it reached him!

INTERNATIONAL EPILEPSY DAY is announced!

International Epilepsy Day, a joint initiative of ILAE and IBE will launch on **9th February 2015** and will be celebrated in the **138** countries in which our organisations have member associations.

With IBE and ILAE in official working relations with **WHO**, and IBE on Special Consultative Status on the **UN** Economic and Social Council (ECOSOC), International Epilepsy Day will become the most prestigious epilepsy event in the world.

International Epilepsy Day is set to be a major step in improving epilepsy awareness in every region of the world, and will highlight the urgent need for increased research in epilepsy.

We hope that your association will take advantage of this opportunity to create a special epilepsy awareness day in your country. Please **highlight the date** in your diary for 2015!

PROMISING STRATEGIES 2007-2014

The IBE Promising Strategies Program has been running for 7 years and is one of the most successful of all IBE's initiatives. The aim of the program it to assist Members - particularly those in developing nations - through the provision of financial support for projects whose objective is to improve the quality of life of people with epilepsy. To date, 81 projects in 38 countries have received a total of US$330,000 in funding. Showcased here are the projects supported to date in the IBE South East Asia and Western Pacific Regions.

INDIA

Cell phone repair

In this cell phone repair project, the association helped 5 people with epilepsy to be trained in cellphone repair techniques by qualified engineers for a period of 6 months.

After training they were given materials to establish an outlet in their villages where they can continue with this work, thereby making them independent and self-sufficient.

NEPAL

Video and Poster Production

To raise awareness about epilepsy and its treatment, the Nepal Epilepsy Association recieved funding to produce and disseminate simple and illustrative posters in the Nepali language.
A second project funded by PSP helped develop a documentry films 'A new life for Juneli' which will be shown in Singapore.

CHINA

Web based messaging

China Association Against Epilepsy created a web based system to share resources, provide links to professionals and build up a patient-doctor instant messaging scheme, as well as special interest groups for patients and professionals, such as the Lennox-Gastaut syndrome group.

TIBET

Epilepsy Patient Centre

Set up in the Department of Neurology of the First People's Hospital in Tibet, patients were invited to visit the centre for monthly information talks for people with epilepsy and parents. Using QQ, the popular instant messaging program, an online Tibet Epilepsy Patients Group was set up.

MONGOLIA

Demystifying Epilepsy

In the last few years Mongolia Epilepsy Association has been working with IBE and has organized a series of "Quality of life" programs, thanks to Promising Strategies Program support, in seven rural areas and cities. The association is now ready and eager to go to the remaining 14 provinces to achieve its objective.

CHINA

Caring for Carers

There are approximately 30 million epilepsy carers in China. Caring for a person with epilepsy is often challenging; taking its toll physically, mentally and emotionally. The economic burden is huge, especially for people living in rural areas. The aim of this project is to promote public awareness for epilepsy carers and to improve their quality of life. The project investigated the mental health, quality of life and economic status of carers; and also encouraged carers to communicate and exchange their experiences.

LAO PDR

Tackling a 90% treatment gap

Lao PDR is a low income, multi-ethnic, landlocked country of 6 million inhabitants. Approximately 52,000 people have epilepsy, with a treatment gap of over 90%. Epilepsy awareness is being raised in teachers and pupils in schools in 6 provinces, taking advantage of the training of doctors in the same cities. In this way, it is hoped to trace more people with epilepsy and to help them contact their local trained doctor. Radio spots are translated into three ethnic group languages and sent to all local stations.

INDIA

BAKERY SKILLS

In India, it is difficult for people with epilepsy to find jobs due to discrimination. Through this project, the Indian Epilepsy Association trained a group of people with epilepsy in the craft of baking and bakery management. Training was provided by qualified bakers who are already running successful units. The students were supported in purchasing raw materials and were also trained in management skills.

MALAYSIA

TRAINING CENTRE FOR STUDENTS IN ASD SPECTRUM

Research shows that at least 35% to 40% in the ASD spectrum will develop epilepsy when they reach adolescence. 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).

INDONESIA

Information and Support

Many people with epilepsy are kept at home. Children don't have a proper education and adults become dependent on other people, and no job. PERPEI created a program of education and support with information leaflets and the provision of low cost AEDs.

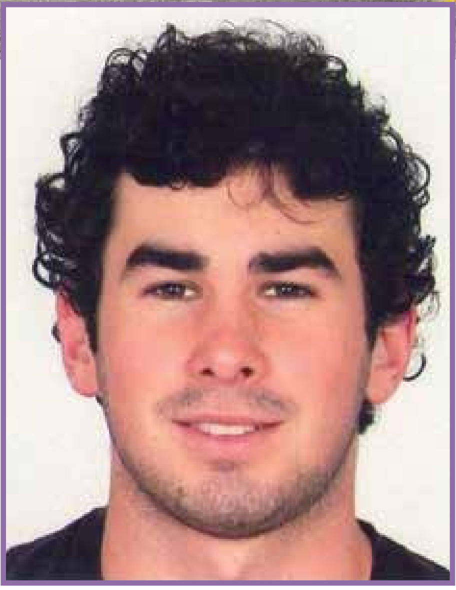
TIBET China

Epilepsy Awareness

In Tibet, due to its special geographical location, there is little public awareness about epilepsy. Unique religious beliefs have increased negative attitudes towards people with epilepsy. Many Tibetans believe seizures are caused by demons and seek out cures through religious rituals. The objective of the project was to promote epilepsy prevention and increase knowledge.

YOUNG AUSSIE TAKES UP SUDEP CHALLENGE

Report by: Denise Chapman, Chair
Joint Epilepsy Council of Australia (JECA)



Cameron O'Brien died at the age of 21 years from SUDEP
He had only ever had two seizures during sleep

Avril Nadin is a remarkable young woman. In her final year of a law and psychology degree, she was awarded the Cameron O'Brien Memorial Bursary to assist with her final year studies.

On receiving her award she learnt of the circumstances behind the bursary. The young man honoured in the award, Cameron O'Brien, himself a law student, had died at the age of 21 from Sudden Unexpected Death in Epilepsy (SUDEP) - the devastating consequence of a condition that he had only been diagnosed with 11 months before.

Cameron was in the 4th year of his commerce law degree at the University of Wollongong, New South Wales and had achieved outstanding results that were to pave the way for the next phase of his life. He had just been accepted in an exchange program at the University of Connecticut in the USA and was excited that all the hard work and sacrifices he'd made had paid off. He was off to the 'States' and all that it had to offer: academic opportunity and ... American sport!

Six weeks before he was due to depart for the US, Cameron died of SUDEP. Cameron had only ever had two seizures during sleep, some eleven months earlier. A diagnosis of epilepsy followed with medication prescribed. Accepting he could be a little forgetful, Cameron used the alarm on his phone to remind him to take his medication. Living at home with mum and dad ensured that he had other reminders as well! He took his epilepsy seriously.

He was a young man with the world at his feet until that fateful day in July 2012. Like many families, Cameron's family had not been made aware of the risk of SUDEP.

Shocked at the discovery that epilepsy can, in rare occurrences, be fatal, Avril decided that she must do something to honour Cameron and increase awareness of SUDEP in the community.

With the support and sponsorship from two businesses – Two Monkeys Cycling and Vitamin King – the *700 for SUDEP: Cameron O'Brien Memorial Ride* became a reality. Planned as a seven-day event, the first stage took place in the Snowy Mountains of New South Wales over a cold and rainy weekend in February with a team

Above: Avril Nadin

Left: hardy cyclists tackle the difficult mountain route

of hardy cyclists tackling the mountainous route. Facing inclement weather, eleven riders in their purple *700 for SUDEP Cameron O'Brien Memorial* jerseys, set off to tame a mountain.

Around the halfway point, a local family who had lost their beloved son to SUDEP in 2011 lined along a section of the road waving banners and cheering the riders along. The gesture was an unbelievable show of support and spurred the team along, knowing that they were riding with a purpose and in memory of Cameron. The two-day ride was exhausting and exhilarating.

As the cyclists climbed their mountain in the memory of a young life cut far too short, Avril set about on her personal fundraising challenge. Both succeeded, brilliantly!

Avril and her team of cyclists raised almost $20,000 for Epilepsy Australia's SUDEP Research & Education Fund.

The *700 for SUDEP Cameron O'Brien Memorial Ride* has now become an annual event, with plans for 2015 already underway.

Congratulations!

IBE honours the Outstanding Persons with Epilepsy, who will receive their awards during the 10th AOEC Opening Ceremony

Robert Wierzbicki
Australia

Shenaz Haveliwala
India

Etsuij Shimokawa
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Serene Low Siew Yin
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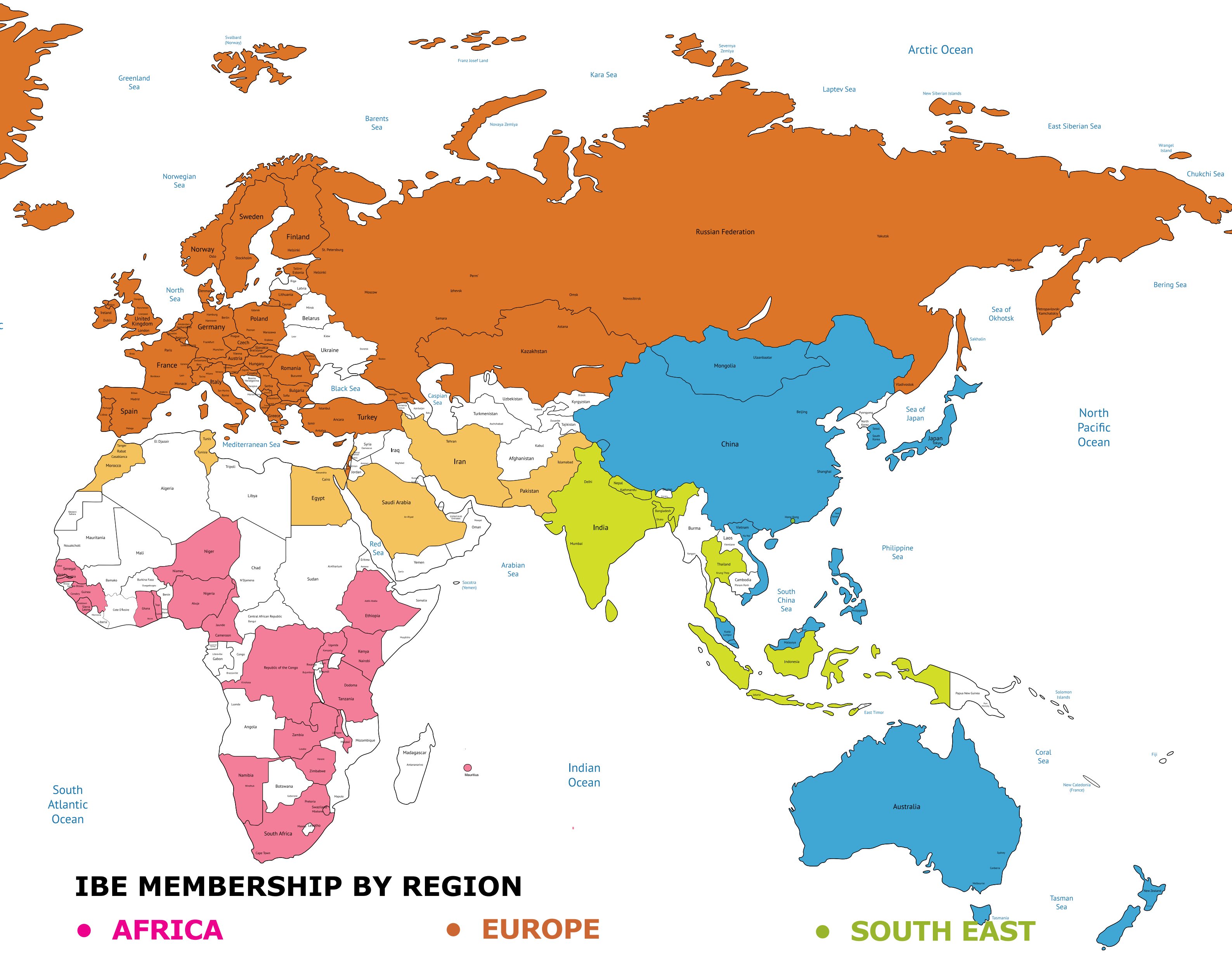

IBE MEMBERSHIP BY REGION

- ● AFRICA
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