

INTERNATIONAL

Epilepsy News

Reporting epilepsy news for 54 years

1963-2017

Meet the new Committees

Report from Pakistan

School Project in Brazil

Tibet Promising Strategy



PRESIDENT'S LETTER

End of a busy term of office



Dear IBE Chapters, Dear Friends

This is my last President's Letter before I pass the baton to the incoming President Martin Brodie and his team. So, this is a good opportunity to look back and reflect. The greatest highlight is the WHA/WHO Resolution on Epilepsy, approved by the World Health Assembly in May 2015, with 43 countries making statements in favour and 19 countries co-sponsoring the resolution. The resolution calls on Member States to prioritise epilepsy care in a coordinated fashion, placing equal weight on both the medical care and social aspects of the disease, recognising the importance of all stakeholders, including people with epilepsy and their carers. The other major international activity was International Epilepsy Day, first celebrated on Monday 9th February 2015, with events taking place around the world as well as in the European Parliament. Great advances were made by the IBE/ILAE joint task force Epilepsy Alliance Europe (EAE). Co-chaired by Philippe Ryvlin and me, EAE celebrates International Epilepsy Day and is involved in a number of projects: E-PILEPSY, ESBACE, EpiCARE, European Brain Council Value of Treatment project, EPITARGET and RADAR-CNS. In addition, membership of the European Advocates for Epilepsy MEP group in the Parliament grew to 55 MEPs. This group is responsible for hosting the epilepsy workshops, meetings and receptions that we hold in the parliament. A Global Research Initiative on Epilepsy was formed in 2016 and a meeting took place February 2017 in Brussels with all stakeholders involved to view joint European, North American

and Asian research programs. A very successful meeting with action plans to be accomplished in the future.

In the last four years, IBE/ILAE congresses were held in Ljubljana, Dubai, Hong Kong, Singapore, Istanbul, Buenos Aires, Cancun, Cape Town, Dakar and Prague. Now it is the turn of Barcelona, which is expected to be one of the most successful international epilepsy congresses since Rome 2011.

Internally, the IBE Strategic Plan 2016-2019, was approved by the chapters and is now our roadmap to 2019, and a revision of the Constitution & Bylaws was approved by the General Assembly in 2015, with one of the major changes being a return to the title of 'chapters' for our members.

International Epilepsy News, first published in 1961, is published quarterly; the IBE website was redesigned in 2014; a new website epilepsy.org to promote International Epilepsy Day activities and to share personal stories of people living with epilepsy. We use Social Media, especially Facebook and Twitter, to give us instant access to people with an interest in epilepsy. We continue to expand our partnerships - official working relations with WHO, and members of European Patients Forum, the European Federation of Neurological Associations, and observers at the European Medicines Agency - in addition to our very close working relations with ILAE.

IBE now has Chapters in 104 countries; with new members in Lebanon, Guyana, Luxembourg, Pakistan, Spain, Costa Rica, Moldova, Italy, UK and Paraguay. During my term as President, it has been my great pleasure to visit IBE chapters and speak at meetings around the world. I travelled to 30 countries and would like to thank all those who invited me for their generous hospitality. IBE has Chapters in 104 countries. As IBE President, it has been my great pleasure to visit chapters and speak at meetings. I thank all those who invited me for their generous hospitality. It has been a privilege to serve you all; what will remain with me is seeing, at first hand, the tremendous work of our chapters to make a difference to the lives of people living with epilepsy and those who care for them.

With best wishes

Athanasios Covanis, President



International Epilepsy News Issue 3- 2017

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- ⊙ P Satishchandra (South East Asia)
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- ⊙ Sam Wiebe

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).

EPF

IBE is a member of the European Patients' Forum (EPF)

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In this issue



Dear Readers

With IBE membership continuing to grow, with more chapters due for ratification at the IBE General Assembly in Barcelona, the expertise, knowledge and diversity that the 140 chapters in 104 countries around the world bring to IBE is awe inspiring.

This came to mind as I considered what might be suitable as an image for the cover

of this special congress issue of IE News. When I look at this aerial view of Barcelona, the colourful Gaudi mosaic in the foreground symbolises to me how the diverse talents within the IBE membership can come together to form a breathtaking cohesive form. The horizon out at sea in the distance symbolises IBE's future, which offers such potential, provided we can harness it to best serve people with epilepsy.

IBE has now reached its next crossroads and it is incredible to realise that, already, four years have passed since the now outgoing International Executive Committee began its term of office during the 30th International Epilepsy Congress in Montreal. However, when we consider all the activities that have been introduced and followed through since then, we can see that much has been achieved in the intervening period and much positive progress has been made.

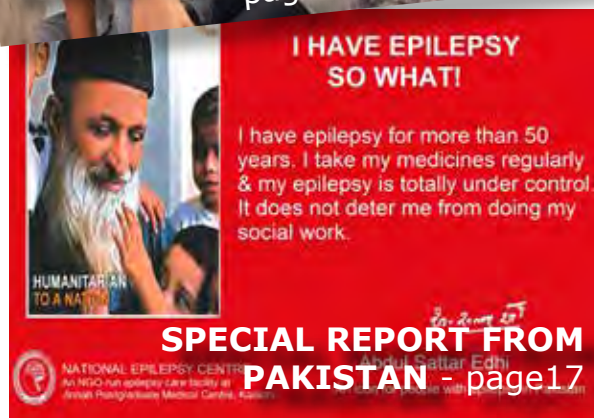
This issue of IE News gives us the opportunity to set the scene for the next four years with introductions to the new committees and a stock-take on membership. You will also see a snapshot of one of the new activities planned by the incoming President and directed at young adults - EpilepsyNext.

There are also three important reports featured - from Ecuador, Brazil and Pakistan and, as promised, the second of the Promising Strategies Projects, chosen for funding by the current International Executive Committee, is presented to you.

In the next issue of IE News there will be more information on plans for the coming term, including introductions to the new Commissions and plans for International Epilepsy Day 2018.

Until next time - good reading,

Ann Little
Editor





GENERAL ASSEMBLY

Venue: Meeting Rooms E3/E4/E5
Date: Tuesday 5th September
Time: 15:30 to 18:30

AGENDA

1. Opening Address - *Outgoing President, Athanasios Covanis*
2. Minutes & Matters Arising
3. Officer Reports
4. Executive Director's Report
5. Regional Reports
6. Task Force Reports
7. Joint Projects with ILAE
8. Presentations to new Chapters and outgoing Committee Members
9. Introduction of incoming Committee
10. Closing Address: *Incoming President, Martin Brodie*
11. Adjournment

Representatives of IBE chapters, Regional Committee Members, Task Force Members and representatives of associations interested in IBE membership are welcome to attend. The assembly will be followed by a Cocktail Reception for those attending.





INTERNATIONAL EXECUTIVE COMMITTEE 2017-2021

The President, Secretary General and Treasurer form the IBE Management Committee, which is authorised to make decisions in the name of the International Executive Committee between meetings of the full committee, provided these are in accord with existing IBE policy. The seven Regional Vice Presidents (VPs), who have been elected for a two-year term (2017-2019), are also the elected Chairs of their Regional Executive Committee.



Mary Secco, Canada
Secretary General



Martin Brodie, Scotland
President



Anthony Zimba, Zambia
Treasurer



Athanasios Covanis
Greece, Past President



Jacob Mugumbate
Uganda, VP Africa



Hassan Hosny, Egypt,
VP Eastern Mediterranean



Caroline Morton,
Netherlands, VP Europe



Tomás Mesa, Chile
VP Latin America



Phil Gattone, USA
VP North America



Satish Jain, India
VP South East Asia



Ding Ding, China
VP Western Pacific



Samuel Wiebe, Canada
ILAE President



Edward Bertram, USA
ILAE Secretary General



Helen Cross, UK
ILAE Treasurer

The President, Secretary General and Treasurer of the International League Against Epilepsy are ex-officio voting members of the IBE International Executive Committee

African Regional Committee



Jacob Mugumbate, Zimbabwe
Chair



Youssouf Noormamode
Mauritius, Vice Chair



Betty Nsachilwa, Zambia
Secretary

Eastern Mediterranean Regional Committee



Hassan Hosny, Egypt
Chair

The positions of Vice Chair and Secretary on the Eastern Mediterranean Committee are currently vacant. They will be filled by nominees of the President-elect in liaison with the Regional Committee, once the new term begins.

European Regional Committee



Caroline Morton-Gallagher
Netherlands, Chair



Natela Okujava, Georgia
Vice Chair



Shirley Maxwell, Scotland
Secretary



Francesca Sofia, Italy
Member



Ljubica Vrba, Slovenia
Member

In addition to a Chair, Vice Chair and Secretary, the European Regional Executive Committee, due to its size, also has two elected Members

Latin American Regional Committee



Tomás Mesa, Chile
Chair



Alicia Bogacz, Uruguay
Vice Chair



Mauricio Olave, Colombia
Secretary

North American Regional Committee



Phil Gattone, USA
Chair



Angela Ostrom, USA
Vice Chair



Susan Pietsch-Escueta, USA
Secretary

South East Asian Regional Committee



Satish Jain, India
Chair



Man Mohan Mehndiratta
Vice Chair

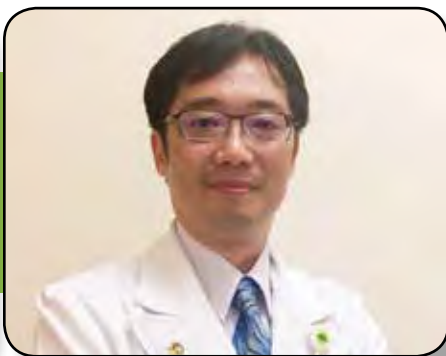


Muzharul Mannan
Bangladesh, Secretary

WESTERN PACIFIC REGIONAL COMMITTEE



Ding Ding, China
Chair



Yuan-fu Tseng, Taiwan
Chair

The position of Secretary, which is currently vacant, will be filled by a nominee of the President-elect in liaison with the Regional Committee, once the new term begins.

EPILEPSY EDUCATION AND TREATMENT PROGRAM IN TIBET



A PROMISING STRATEGIES PROJECT

Set up in 2006, as a way of supporting IBE chapters 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.

For centuries Kangding has served as the last outpost before the wild Tibetan mountains and passes of the Chengdu-Lhasa highway. It has been acting as the bridge between Han and Tibetan cultures and as a major trading port on the Tea Horse Road.

Our team members are from Chengdu and Kangding and, once again, we want to act as a bridge of knowledge exchange, and proper epilepsy management, with the help of IBE.





The Tibet region is on the Qinghai-Tibetan plateau, which is about 4,000 metres above sea level. Over 3 million Tibetan people live in an extremely harsh natural environment on this high plateau. Few qualified neurologists work in the area. Our previous study showed the prevalence rate of active epilepsy to be 2.4 (95% CI = 1.7–3.3) per 1,000 in the Tibet Autonomous Region. And 97% of patients with active epilepsy did not receive antiepileptic therapy [1,2]. As a result, medical, educational and financial support is urgently needed to bridge the treatment gap in Tibet.

The Ganzi Tibetan Autonomous Prefecture is part of the Tibet area and Kham Tibetan dialect is the primary language.

ORGANIZATION

Ganzi People's Hospital is located in the city of Kangding, Sichuan Province, in a valley of the Tibetan Plateau, about 210 kilometers west-southwest of Chengdu.

Since 2014, each year West China Hospital has sent a neurologist to Kangding, to live and work with the local doctors for twelve months. A neurologist, nurse and Kham Tibetan dialect translator from West China Hospital and Ganzi People's Hospital work together on the project. With the staff, we plan an epilepsy education and treatment program in Kangding city. We have already provided services such as:

1. Continuous training for local primary

medical workers.

2. Education in local communities.
3. Treatment, data collection and analysis, and follow-up.

With the help of CDC and the government, a network for education, control, and screening of Hydatidosis (Echinococcosis) and other chronic diseases has already been built and has worked well in Ganzi's villages and counties [3]. By using the already existing network, after the start of the project, we want to provide those services and epilepsy screening in all 18 counties of Ganzi.

Members of our team have helped in setting up a management network, based on the primary health care system in rural areas of Sichuan Province, and have carried out door to door epilepsy screening in Tibet[1,4]. We believe those experiences will be helpful in this Tibetan project.

Medical resources are very insufficient in the Ganzi Tibetan Autonomous Prefecture. At county-level, hospitals have only 3 to 5 doctors, and only one with a practitioner's license. People living in Tibet have the shortest life expectancy and highest

illiteracy rate in China. Our previous study showed the epilepsy treatment gap to be as high as 97%. And 60% of people will choose traditional Tibetan medicine [1,2].

TARGETED POPULATION

General doctors and patients are the targeted population. There is an urgent need to train the local general doctors in proper epilepsy control; to educate people with epilepsy to adhere to appropriate treatment; and increase public awareness of epilepsy.

One million people live in Ganzi. Our previous study showed the prevalence rate of active epilepsy to be 2.4 (95% CI = 1.7–3.3) per 1,000 in Tibet Autonomous Region. So there would be 2,400 people with epilepsy and 90 (18x5) general doctors in county hospitals.



Photo of our staff in front of Ganzi People's Hospital with the project manager, Jiani Chen (back row, second from left), The road in the background is part of the ancient Tea Horse Road, and the mountain in this photo is the gateway to Tibet.



ANTICIPATED IMPACT OF THE PROGRAM

1. Provide information on prevalence, knowledge level, and treatment gap of epilepsy in the population of Ganzi for further studies.
2. Through the training program, improve diagnosis and treatment in county-level hospitals of Ganzi.
3. Promote better understanding and management of epilepsy in people with epilepsy for long-term epilepsy control.

POTENTIAL OBSTACLES

1. Transportation: driving on the highest plateau on earth could be a challenge, but Ganzi hospital would assist our team with their experienced local drivers.
2. Cooperation of the local hospital, CDC and the government: a network for education, control and screening of hydatidosis and other chronic diseases has already been built and worked well in Ganzi[3]. Doctors from Ganzi People's Hospital regularly go to counties and villages to undertake chronic illness control. Thus we could use this network.
3. Continuous participation of local doctors: In our previous rural area project in Sichuan province, we found that it would be a problem to make the local doctors perform continuous recording and follow-up of people with epilepsy, thus in this project. We plan to offer them a small bonus as an incentive.

OBJECTIVES AND BUDGET

The objectives of this project are three-fold.

1. Continuous training for local primary medical workers to enhance diagnosis. During 2017, the doctors from West China Hospital and Ganzi People's Hospital will visit regularly all 18 counties in Ganzi to provide training

in epilepsy screening, diagnosis and treatment for local primary health workers.

2. Treatment, follow-up, and patient education for better epilepsy control. As Ganzi People's Hospital is the only hospital has neurologists, MRI and EEG in this area, a referral system between local hospitals and Ganzi People's Hospital will be set up. Follow-up will be carried out by local health workers. They help patients learn more about epilepsy and explain the rationale and potential benefits of treatment, which might enhance compliance. Epilepsy patient data will be recorded using our online database.
3. Providing education in local communities to promote a better understanding of epilepsy. We will translate epilepsy handbooks into Kham Tibetan dialect and promote general awareness of epilepsy in local communities.

ASSESSING EFFECTIVENESS

The effectiveness of this education and control program would be measured by pre-post knowledge changes.

The questionnaire used to measure education effectiveness is the KAP questionnaire [5] for PWEs and locales, and the epilepsy knowledge questionnaire for doctors[6]. All these questionnaires were translated into Chinese.

The questionnaire would be gathered before and after lectures to see the changes in epilepsy knowledge.

OUTCOME MEASURES

The project will be measured by

1. The numbers of local health care physicians trained.
2. The numbers of epilepsy patients screened and educated.
3. Prevalence of epilepsy in Ganzi Tibet area. Calculation formula: number of PWE/population size × 100%

4. Treatment Gap. Calculation formula: proper management rate = proper management of the number of PWEs / the number of PWE × 100%. Treatment Gap=1- proper management rate

PROJECT SUSTAINABILITY

There is a rural areas education and control project for epilepsy in Sichuan province. Each year that project will provide support to 7-8 counties in Sichuan and will last for 2-3 years then shift support to other counties.

This project will be continued by support from the project for rural areas after it finishes supporting other counties[4].

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IBE FOCUS ON YOUTH

An exciting new initiative to help young people grow in independence and develop the skills and qualities necessary for a happy and productive life.

The initiative also challenges them to use these attributes for the betterment of themselves and the global epilepsy family. More information coming soon!

4 PROGRAMME MODULES:

1. **The TEA Room:** a safe online environment for teenagers with epilepsy to meet and discuss issues of relevance to them.
2. **Young Adult Summits:** a coming together of young adults to share their experiences, identify challenges that prevent them from participating fully their community and develop projects to address these challenges.
3. **Leadership Training Programme:** offering tailored high-quality support to young adults (18-30 years), who have the motivation to learn about advocacy and maximise their leadership potential.
4. **My story:** Many people have powerful personal narratives that can inspire and inform about living with epilepsy. My story supports them in sharing their story in their own voice without stereotyping or victimising. These stories will let us, and the world, know that a person is more than their illness.

More information coming soon!





EPILEPSY AT SCHOOL

Educational Project of the Brazilian Association of Epilepsy (ABE)



The Brazilian Association of Epilepsy is launching a new program to guide and support teachers and staff of public schools in the state of São Paulo, Brazil to deal with children and adolescents who have epilepsy.

In São Paulo in May of this year, it was with great satisfaction that the Brazilian Association of Epilepsy (ABE) announced the start of the project “Program of Social Inclusion of Children and Adolescents with Epilepsy in School Environment”, that will educate principals, coordinators, teachers, mediators, inspectors and students from 92 public schools of São Paulo about the disease. The expectation is that more than 100,000 students will have been impacted by the project by the end of the year.

The program will enable school principals and coordinators, teachers and supporting staff to understand, in a basic way, what epilepsy is, so that they can provide the necessary care to students affected by the disease. Thereby, the education professionals can combine concepts with correct at-

titudes, contributing to fighting prejudice, stigma, bullying and exclusion.

Divided into three stages, the project began on 29th March, when 150 school teaching coordinators and health care educators, attended the first meeting. The second stage is dedicated to the class teach-

What makes the difference? Testimonies!

ers and school supporting staff. The third stage is directed at school students. ABE's plan to begin this phase by August 17th.

Among the topics discussed are the clinical and the psychosocial aspects, ranging from the basic concepts of epilepsy, dealing with stigma, prejudice and the difficulties faced by the student at school and the role of the teacher in this context.

Based on this, the participants of the first meeting conveyed the knowledge obtained to the classroom teachers from 1st to 9th grades and high school. To assist in the understanding of the content by both teachers and students, booklets and explanatory folders are being distributed.

To enable training, there are video lessons on both clinical and psychosocial axis and an "Epilepsy Rap," was also produced by ABE. For the videos with seizure types a partnership with the Portuguese League Against Epilepsy was formed and, for the material for children, the Chilean League Against Epilepsy that kindly authorized the translation of "Juanito's Story". ABE is very grateful to both.

This initiative is a way to bring up to date information to important stakeholders in society. In addition, the introduction of an effective training program promotes conditions for educators to act with greater security in the personal and social context of the child and adolescent with epilepsy.

Embrace this cause too: education multiplies concepts and consolidates the acceptance of diversity among people.

Translational Medicine and Education

Laura Guilhoto – Project Coordinator of the Clinical Axis

"Whenever contact with different sources of expertise takes place, such as neurology and education, the main subjects, i.e. the students, are empowered by what they learn in avoiding prejudice, helping early diagnosis and, consequently, by improving their quality of life. Epilepsy has been, since remote ages, a great cause of stigma and bullying which can be prevented if discussed appropriately in social groups such as the school environment."

The importance of talking about epilepsy

Regina Alves de Lima – Project Coordinator of the Psychosocial Axis.

"Epilepsy is a disease that requires prior knowledge by school authorities in order to be detected, so that people affected by it receive the care and the necessary acceptance, to ensure that neither physical nor emotional, or even moral problems, hurt them."

The key role of educators

*Bruno Araújo Torres
President of the Brazilian Association of Epilepsy -
Project Coordinator*

"Whenever teachers have a solid knowledge about epilepsy, they can have an effective and transformative impact on the social achievements of students and the school and, as a result, in the professional life and social engagement by society of these students when they become adults."



Photos:

Teachers from school participating in the project, attending training workshop. Teachers are also provided with materials and information leaflets free of charge for distribution in their schools.



- North American Regional Committee**
- Canada
 - Jamaica
 - USA

- Latin American Regional Committee**
- Argentina
 - Brazil
 - Chile
 - Colombia
 - Costa Rica
 - Cuba
 - Dominican Republic
 - Ecuador
 - Guatemala
 - Guyana
 - Honduras
 - Mexico
 - Panama
 - Paraguay
 - Peru
 - Uruguay
 - Venezuela

- European Regional Committee**
- Albania
 - Austria
 - Belgium
 - Bulgaria
 - Croatia
 - Cyprus
 - Czech Republic
 - Denmark
 - Estonia
 - Finland
 - France
 - Georgia
 - Germany
 - Greece
 - Hungary
 - Iceland
 - Ireland
 - Israel
 - Italy
 - Kazakhstan
 - Lithuania
 - Luxembourg
 - Malta
 - Moldova
 - Netherlands
 - Norway
 - Poland
 - Portugal
 - Romania
 - Russian Federation
 - Scotland
 - Serbia
 - Slovakia
 - Slovenia
 - Spain
 - Sweden
 - Switzerland
 - Turkey
 - UK

- African Regional Committee**
- Cameroon
 - Congo, DR
 - Ethiopia
 - Gambia
 - Ghana
 - Kenya
 - Malawi
 - Mauritius
 - Namibia
 - Niger
 - Nigeria
 - Senegal
 - Sierra Leone
 - South Africa
 - Swaziland
 - Tanzania
 - Togo
 - Uganda
 - Zambia
 - Zimbabwe

- Eastern Mediterranean Regional Committee**
- Egypt
 - Iran
 - Lebanon
 - Morocco
 - Tunisia

With chapters in 104 countries around the world, IBE is the largest epilepsy association that is focussed primarily on the social aspects of epilepsy. As an IBE Chapter, an epilepsy association gains access to a large and impressive network that spans the globe.

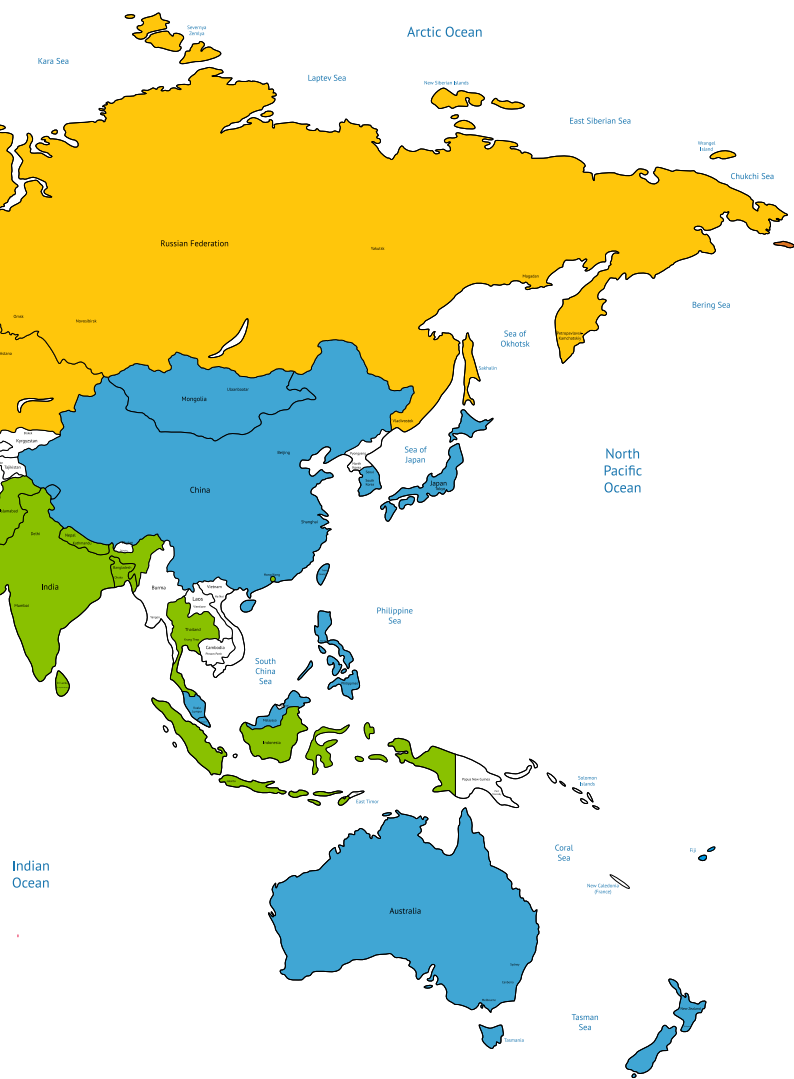
The IBE is represented in every region of the world and its membership is richly diverse.

As an international organisation with strong and important links to international agencies, including WHO, UN ECOSOC, the European Patients Forum, European Federation of Neurological Associations and ILAE, the IBE is held in high regard and has an impressive international reputation.

IBE's network forms a strong and impressive body that facilitates the sharing of information, news and experiences, thereby assisting its members to develop new and improved methods in order to achieve its goals.

In order to support our stakeholders it is essential to harness the voice of the millions of people with epilepsy across the world who are affected by epilepsy. IBE is uniquely placed to act as a dynamic force for collaboration between the diverse group of epilepsy patient associations that make up our network.

Our membership continues to grow and, in the past four years, we welcomed the following associations as new IBE chapters:



IBE

membership around the world

South East Asian Regional Committee

Bangladesh
Hong Kong
India
Indonesia
Nepal
Pakistan
Sri Lanka
Thailand

Western Pacific Regional Committee

Australia
China
Fiji
Japan
Korea
Malaysia
Mongolia
New Zealand
Philippines
Singapore
Taiwan

FULL (Voting) CHAPTERS

- *Costa Rica - Asociación Internacional Bureau For Epilepsy Capítulo Costa Rica
- Fiji – Epilepsy Fiji
- *Guyana - Epilepsy Foundation of Guyana
- Luxembourg - Association d'Aide aux Personnes Epileptiques
- Moldova – Association Supporting Children with Special Needs
- *Pakistan - Epilepsy Support Pakistan
- *Paraguay - Asociación Paraguaya de Lucha Contra la Epilepsia (ASOPALEP)

ASSOCIATE CHAPTERS

- Georgia - Georgian Society of Young Epileptologists
- Italy- Federazione Italiana Epilessie - FIE
- *Lebanon - Avance Association of People with Epilepsy and Special Needs
- *SPAIN - Epilepsia España
- *SPAIN - Asociación Nacional de Personas con Epilepsia - APNE
- UK – SUDEP Action

Associations marked with an asterisk (*) are currently regarded as Provisional Chapters pending final ratification by the General Assembly on 5th September 2017.

A TIME TO CELEBRATE!

APNE marks its 30th Anniversary

Galo Pesantez, President of the Ecuador chapter of IBE, shares photos and text



The Association of Parents of Children with Epilepsy (APNE), IBE's chapter in Ecuador since 1991, this year celebrates its 30th Anniversary. Founded in 1987, as a

self-help entity to help improve the lives of children living with epilepsy and their families, the association has grown in its function and membership over the years.

Initially it was the parents who sought refuge in the hope of finding a helping hand and voice of encouragement; and in doing so, would find solidarity with those in a similar situation so that they could help and strengthen each other in their efforts.

Since the first early days, the efforts of those involved from the beginning have been achieved as far as possible. But, of course, there is still work to be done and we must always hope for utopia. Nevertheless, there have been many achievements for people with epilepsy and their parents to date:

- The Ecuador National Centre for Epilepsy was created
- APNE has been able to provide free medication for patients with epilepsy who have low economic resources
- The School for Parents of Children with Epilepsy was established
- Neuropsychomotricity services - an aid in the treatment of children with epilepsy - were introduced
- A group for Parents of Children with Refractory Epilepsy was developed
- Use of Cannabidiol in refractory epilepsy was legalised

In order to create access to information that allow us to provide comprehensive and positive management of epilepsy, the "CREATING NETWORKS" Project was established, which, using the facilities that social networks provide, will establish timely and reliable communication for all those involved in the care and treatment of the patient.

For the implementation of this project an initial cooperation agreement was established between the Association of Parents of Children with Epilepsy, the School of Developmental Neurology and Psychomotricity and the National Epilepsy Center.

TREATMENT GAP AND STIGMA REDUCTION IN PAKISTAN

A tested public awareness model. Report sent by Zarine Mogul

Globally, the reduction in the epilepsy treatment gap and in stigma are major issues that need the attention of the epilepsy community; even more so in developing countries where epilepsy is not a health priority of the government and where civil society organizations barely exist. Realizing such handicaps, a group of volunteers, mostly from the medical community, along with some concerned citizens in Pakistan (population approximately 200 million) have attempted to address these issues with gratifying results that we would like to share.

In this effort, through trial and error, we have been able to produce a workable model, within our constraints and the prevailing health-care system. Initially, from city level it evolved to district, province and, eventually, to country level. The interim results, based on two parameters - indirect and direct - indicate a fair degree of success.

In the indirect method, total country AED sale figures (provided by IMS, a well reputed marketing statistics firm operating in more than 80 countries) show a rise by almost 2,000% (Compound Average Growth 20%) in the last 16 years.

In the direct method, a repeat population-

based prevalence study, using the same protocol and the same urban sample, shows a decrease in the treatment gap from 80% to 20%. It needs to be reiterated that all other variables have remained constant and this success can only be claimed by the public awareness campaign of this small volunteer group.

Historically, it all began in 1987 when a population-based epilepsy prevalence study along with Knowledge, Attitude and Practice survey was undertaken by our core group, results of which have been published in three Epilepsia articles.

The treatment gap results were an eye opener for us. A meager 2% of people with epilepsy in rural areas and 20% of people with epilepsy in the urban population were taking an anticonvulsant at the time of the survey. Another stumbling block was the negligible number of specialists, which necessitated efforts to increase human resource too.

This dismal situation worked as a stimulus for us to ponder and plan some intervention. Epilepsy awareness was initiated through print and electronic media in tandem with epilepsy teaching to the medical community. Sustained efforts on many fronts enabled us to formally launch, in

2001, a Comprehensive Epilepsy Control Programme (CECP) along with Friends of Epilepsy group (now Epilepsy Support Pakistan). Under the banner of CECP, the dedicated volunteers, along with some Friends of Epilepsy, have been able to initiate and continue an ongoing epilepsy care program in the country.

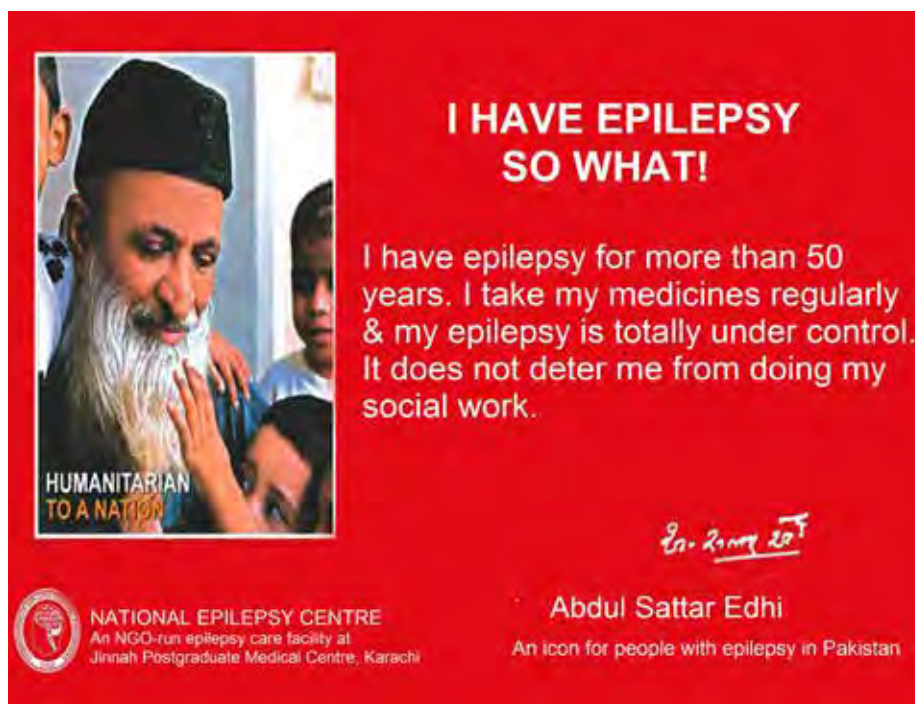
Among its many dimensions, maximum focus has been on public awareness raising through different indigenously developed projects. It has gradually evolved, having reached its crescendo where it is being attempted to change the nation's mind-set about epilepsy through a regular 'paid for' telecast of a short comprehensive television documentary covering all aspects of epilepsy, including the disorder, its treatment, first-aid of seizures and addressing psychosocial issues.

We have proven not only to have reduced the epilepsy treatment gap significantly, but are also seeing satisfactory results indicating reduction in stigma which, in our view, is the most difficult to achieve. The reduction of stigma in epilepsy is palpable as more and more people are openly talking about their condition and seeking treatment for their condition.

Our greatest breakthrough came in 2003, when Pakistan's most honoured, saintly humanitarian social worker, in the league of Mother Teresa but with far more extensive and diversified social works, came out of the shadows and announced that he had epilepsy. This gave a tremendous boost to our epilepsy awareness campaign. The late Mr. Abdul Sattar Edhi is known to every person in Pakistan for his diversified social services and holds a Guinness Book of Records for the largest free ambulance service in the world.

His saintly status is revered, not only by the people of Pakistan, but, in around 32 other countries where he was known to reach the site of major natural or man-made disasters with supplies and volunteers and help.

His contribution to epilepsy in Pakistan is also unmatched. He allowed us to display public awareness stickers and posters on his countrywide fleet of Edhi Ambulances



I HAVE EPILEPSY SO WHAT!

I have epilepsy for more than 50 years. I take my medicines regularly & my epilepsy is totally under control. It does not deter me from doing my social work.

Abdul Sattar Edhi

Abdul Sattar Edhi
An icon for people with epilepsy in Pakistan

NATIONAL EPILEPSY CENTRE
An NGO-run epilepsy care facility at
Jinnah Postgraduate Medical Centre, Karachi



Welfare Funds such as CECF, NEC and Friends of Epilepsy (now Epilepsy Support Pakistan, IBE's Pakistan Chapter). The activities are listed in the order of evolution:

1. A short message was coined to be used for all awareness activities; "Epilepsy is a treatable medical disorder. It is not caused by evil spirits, djinns, witchcraft or any other such causes. For diagnosis and treatment contact your doctor."

2. Tens of thousands of Epilepsy Awareness Stickers with the message were pasted onto the nationwide fleet of Edhi ambulances, intercity buses and cargo trucks, oil tankers and other vehicles. Each sticker had a display life of about 6 months. The message reached far off corners of the country.
3. Miscellaneous activities bearing the awareness message included graffiti, billboards, roadside banners, distribution of handbills and slogan-engraved ballpoint pens as souvenirs.
4. Detailed awareness through print and electronic media and information read or heard by millions. National dailies and magazines covered epilepsy related articles; the national television carried interviews with specialists and meet-the-press sessions of experts helped disseminate awareness by media coverage.
5. School Awareness Workshops for teachers and senior students were conducted grass root level. These workshops were conducted in large schools (with 2,000+ students) in Karachi. This activity was human-resource dependent, not time or cost effective and limited to a small local group and was thus replaced with Epilepsy Awareness Posters.
6. 45,130 specially designed coloured pictorial Epilepsy Awareness Posters with information on epilepsy, first aid for seizures and stigma-reducing matter were affixed at all major schools throughout the country, especially in no-go areas of two provinces with

poor law and order conditions. These posters were also affixed in public places such as railway station, intercity bus depots, GP waiting rooms and outpatient departments of public sector hospitals. Display life of each poster was more than 6 months.

7. District-wide intensive epilepsy awareness was done, followed by Free Epilepsy Camps. This was a major activity with maximum yield. In every pre-chosen district, a 6-day intensive public awareness campaign covering the total population was done. Every nook and corner was covered through banners and loudspeakers mounted on rickshaws disseminating continuous information about epilepsy. The objective was to create enough noise to get every person talking about it. A free epilepsy treatment camp was held by volunteer doctors on the weekend. Also family physicians of the district were invited for an epilepsy update workshop. A total of 46 were held in almost all districts of Pakistan (barring a few in no-go areas); 2,100 Primary Care Physicians, 800 Female Health Workers and 750 Final Year Medical Students were trained. This very fruitful activity had to be discontinued due to security issues in the country.
8. Celebrating international events like International Epilepsy Day, Purple Day and International Women's Day (dedicating it to our Women with Epilepsy) augments awareness through media coverage about epilepsy.
9. In the last four years, the group decided to concentrate only on telecasts of the aforementioned epilepsy documentary, which is considered to be best value for money since the message reaches nearly every house in Pakistan as well as neighboring countries like Afghanistan, Iran, India and others where our television channels are widely watched. Moreover even at the global level, wherever Pakistanis are watching their home television networks, the awareness message is received. This documentary is produced in four provincial languages and is aired on commercial provincial television networks. Each telecast cycle has twice a day airing for three months, in a near-prime time viewing slot. Ten telecast cycles of this ongoing activity have been completed.

and to record detailed interviews of his life with epilepsy, to be used later in the awareness documentary. Mr. Edhi was a people's man and his message on various issues about epilepsy leaves a lasting effect on the masses. His opening up of the chapter on his life with epilepsy has pleasantly surprised all and has been a major motivation to people with epilepsy.

As we are finalizing this article a famous young classical-trained dancer, who has performed internationally and who is also a television actress, has spoken publicly about having epilepsy and the discriminations she has faced, not only in this country, but, across the border where she was refused admission to a dance school because of epilepsy.

Parallel to the awareness campaign, the volunteer group has succeeded in building a National Epilepsy Centre (NEC), located in a public sector hospital in Karachi. This tertiary-care facility for holistic management of epilepsy has completed 10 years of service, especially to underprivileged people with epilepsy. To date more than 8,500 people with epilepsy are registered. Here detailed medical notes and close monthly follow up records are maintained as hard copy and electronically. Video-monitored interictal EEGs are done at a token cost; with more than 14,300 EEGs archived to date. Neuroradiology services are provided by the radiology department of the public hospital at highly concessional rates. Every patient is provided with one month's total supply of all antiepileptic medicines at a token cost (around 8% of market cost) and compliance is ensured.

We summarize below the various public awareness activities conducted by the volunteer group under various projects of the NGO, Neurology Research and Patient



EPILEPSY (MIRGI) IS TREATABLE

It is NOT caused by evil spirits, djinns, witchcraft or any other such causes

• Epilepsy is a commonly occurring medical disorder
• It occurs due to repeated abnormal electrical discharges of cells in the brain. • Seizure can temporarily affect the person's consciousness and may cause the body to perform actions or speak at will.
• Accordingly, the person gets disoriented from the surroundings and appears to be 'lost' in his thinking.

• If you witness someone having an epileptic attack: Do not panic. • Make the person lie on the ground. • A safety matting around the neck. • Do not forcibly try to restrain their limbs. • Do not attempt to stop the person from eating or drinking.

• Like any other chronic illness, it is not curable at any age but is relatively controllable with modern anti-epileptic drugs, including oral and injectable ones.

• Religious texts (including the Holy Quran) were revealed after an ultimate control of proper control. • Muslims are free to practice their religion. • Muslims are free to practice their religion in the form of Hajj, Umrah, Zakat and other religious activities. • Muslims are free to practice their religion throughout Pakistan.

• Epilepsy is a treatable medical disorder, just like high blood pressure, diabetes, etc. • It is not a communicable disease. • It is not spread from person to person. • It is not related to any other such diseases, including oral and injectable ones.

• Children with epilepsy should study in normal schools. • They are not different from other children and can give their best in all fields of education and sports. • They are not different from other children and can give their best in all fields of education and sports. • They are not different from other children and can give their best in all fields of education and sports.

Take a video of the attack with your mobile camera. This will help in better diagnosis.

Do not discriminate a person with epilepsy. Give them equal opportunities so that they do not develop an inferiority complex.

For diagnosis and treatment contact your nearest district or contact us for following address:
 Comprehensive Primary Care Programme of Pakistan, Neurology Field (NCP) in Department of Neurology, Jinnah Postgraduate Medical Centre, Karachi, Pakistan.
 Tel: 35773934, 35773935 Email: jinnahpostgraduate@pcp.org
 Website: http://www.necp.org

SPECIAL EDITION

مرگی قابل علاج

ادویات کے استعمال سے اس مرض پر قابو پایا جا سکتا ہے

Epilepsy is a treatable disorder

Dr. ...

Dr. ...



International
Epilepsy Day

EPILEPSY IS MORE THAN SEIZURES

12th FEB 2018

SAVE THE DATE !

WE'RE GETTING READY FOR INTERNATIONAL EPILEPSY DAY 2018 - ARE YOU?

- We'll soon be sending you news on our fantastic photo competition - Life is Beautiful - with great prizes
- Watch out for information on our other plans for the day
- Help us to spread the word by identifying a chapter advocate to tell their story of living with epilepsy

#EPILEPSYDAY #EPILEPSYIS

epilepsy.org

