



International Bureau for Epilepsy

ANNUAL REPORT 2017



OUR VISION

IBE has a vision of the world where everywhere fear and ignorance about epilepsy are replaced by understanding and care.

OUR MISSION

IBE exists to improve the social condition and quality of life of all people with epilepsy and those who care for them.

International Executive Committee 2017-2021

President: Martin Brodie (Scotland), **Secretary General:** Mary Secco (Canada), **Treasurer:** Anthony Zimba (Zambia)

Vice Presidents:

VP Africa: Jacob Mugumbate (Zimbabwe), *VP Eastern Mediterranean:* Hassan Hosny (Egypt),

VP Europe: Natela Okujava (Georgia), *VP Latin America:* Tomás Mesa (Chile), *VP North America:* Philip Gattone (USA),

VP South East Asia: Satish Jain (India), *VP Western Pacific:* Ding Ding (China)

Immediate Past President: Athanasios Covanis (Greece)

ILAE Ex Officio Members:

ILAE President: Sam Wiebe (Canada), *ILAE Secretary General:* Ed Bertram (USA), *ILAE Treasurer:* Helen Cross (UK)

Partners and Collaborators

- Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC)
- Official working relations with the World Health Organization (WHO)
- Member of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO)
- Board Member of the European Federation of Neurological Associations (EFNA)
- Associate Member of the European Patients' Forum (EPF)
- Close working partnership with the International League Against Epilepsy (ILAE)
- Observer status on the PCWP Committee of the European Medicines Agency (EMA)



Income sources

- IBE's activities are funded through membership subscriptions, congress income and grant funding from the pharmaceutical industry.
- Industry funding amounted 3.7% of total income. IBE received industry-related income from two companies in 2017 - Shire International GmbH and UCB Pharma. The higher contribution (82.2% of total) was received from Shire International GmbH.
- In 2017, non-industry income accounted for 96.3% of all income.



MARTIN BRODIE President's Report

Doesn't time fly! It's only just over a year since I took over the presidency of IBE. Although my official term of office began during the 32nd International Epilepsy Congress in Barcelona in September 2017, the previous President, Thanos Covanis, and his committee had kindly invited me to 'shadow' their work following my election in January and so I have taken part in many IBE activities during much of last year.

A very successful International Epilepsy Day was celebrated around the world on Monday 13th February, with IBE and ILAE chapters marking this awareness day with many local activities. In Europe, a significant global workshop took place in the parliament in Brussels, which was attended by representatives from Europe as well as from the US and Canada. This was the start of what has become an international effort towards a global alliance for epilepsy research. There was particular focus on including people with epilepsy and those who care for them as partners in the research agenda and not just as recipients of research activities, as was previously largely the case. A new animated video has been created, with Campi, the sea horse, and his parents visiting the doctor. As I write, we are preparing the fourth in this series in time for International Epilepsy Day 2019. These short videos have been translated and subtitled into a number of languages. The Creating Artistic Waves competition received 140 entries from 25 countries around the world.

February also saw the 4th East Mediterranean Epilepsy Congress take place in Luxor on the east bank of the Nile River in Egypt, an area steeped in ancient history. The congress attracted close to 400 delegates from 30 countries. Three months later, from 5th to 7th May, the 3rd African Epilepsy Congress took place in Dakar, Senegal with a similar number of delegates. These regional congresses, organised jointly by IBE and ILAE, play an important role in providing training opportunities and increasing knowledge about epilepsy for all those involved in the field in these regions.

Our Promising Strategies Programme continued apace with projects in Tibet, China and Colombia receiving funding in 2017. The Colombian project focussed on eliminating the worms affecting diseased pigs, which were responsible for

spreading neurocysticercosis in one region of the country. Its success has led the government to consider rolling it out throughout the entire Caribbean coastal region of Colombia!

The official start of the 4-year term of office for myself and my colleagues began at the time of the General Assembly on 5th September in Barcelona. The remaining three months of the year was the opportunity to begin putting in place some of the new activities that I believe will help move IBE forward, with a particular focus on youth. The EpilepsyNext programme, with five modules already identified, was fine-tuned prior to its launch. This is a major global programme, that will require a major level of funding to fully implement. I believe that it is imperative for us to support young people with epilepsy by making available the tools and training that will provide them with the best opportunity to excel in their chosen paths in life. By the year end, plans were already in place for the first Latin American Young Adult's Summit and the Golden Light Awards, to be held in Costa Rica in 2018.

I also set up three new Commissions and identified their global membership. The Education Commission is chaired by Margarete Pfäfflin (Germany), the Research Commission by Kheng-Seang Lim (Malaysia) and the eSolutions Commission by Najib Kissani (Morocco). In next year's report, I will have the opportunity to share their achievements with you. I warmly thank the new chairs and the commission members for giving their time and dedication to the global IBE agenda.

A new avenue to promote our work and that of its members came via the new monthly IBE platform in Epilepsy & Behavior. The journal provides IBE with access to a wider audience with which to share developments and initiatives as well as commentaries on personal issues. I hope that many individuals and chapters will take advantage of this opportunity!

As the year drew to a close, I believe that we had placed ourselves in an excellent position to introduce a range of initiatives, and to further develop those already in place, to ensure that we can support our chapters around the world in their vital work for people with epilepsy and those who care for them. Keep up the good work!

FINANCIAL REPORT

Income and Expenditure Account

Year ended 31st December 2017

With comparative totals for 2016

	2017 US\$	2016 US\$
INCOME	1,550,009	649,269
EXPENDITURE	(941,659)	(916,059)
OPERATING (DEFICIT)/SURPLUS FOR YEAR	<u>608,350</u>	<u>(266,790)</u>

Balance Sheet

Year ended 31st December 2017

With comparative totals for 2016

	2017 US\$	2016 US\$
CURRENT ASSETS		
Debtors	290,600	174,692
Cash in hand and at bank	2,720,460	2,288,511
Amount held on behalf of the IBE/ILAE Joint Task Force	66,618	69,893
	<u>3,083,678</u>	<u>2,533,096</u>
CREDITORS (Amounts falling due in one year)	(426,131)	(483,899)
NET CURRENT ASSETS	<u>2,315,988</u>	<u>2,315,988</u>
NET ASSETS	<u>2,657,547</u>	<u>2,049,197</u>
CAPITAL AND RESERVES		
General Reserve	2,601,894	1,993,544
Restricted and designated funds	55,653	55,653
	<u>2,657,547</u>	<u>2,049,197</u>

The financial statements were approved on 1 September 2018 and signed by:

Martin Brodie, President

Ann Little, Executive Director

Statement of Income and Expenditure

Year ended 31st December 2017

With comparative totals for 2016

	2017 US\$	2016 US\$
INCOME		
Congress income received	1,436,373	536,491
IBE/ILAE JTF management fee	16,173	16,450
IBE/ILAE JTF reimbursement of expenses (IBE 50%)	12,889	18,957
Membership dues and solidarity fund	13,129	14,323
Investment income	14,617	9,518
Restricted gifts and donations	56,828	53,530
TOTAL INCOME	1,550,009	649,269
EXPENDITURE		
Congress expenditure	810,258	543,720
Office expenses	16,364	21,367
Printing and postage	133	215
Travel	45,894	51,718
Global Campaign costs	6,992	16,433
Accountancy fees	6,753	5,791
Audit fees	8,870	5,186
Administrator costs	10,528	13,647
Staff costs	115,254	107,627
Employer's PRSI	11,845	11,606
Bank charges	959	1,342
Rent	3,053	14,725
Promising Strategies	7,737	-
Website costs	4,276	10,129
IBE JTF expenditure	11,090	25,728
International Epilepsy Day	12,669	8,318
Professional fees	8,616	340
Bad debts	-	35,880
	1,081,291	873,772
(Profit)/Loss on foreign exchange	(139,632)	44,287
TOTAL EXPENDITURE	941,659	916,059

FINANCIAL REPORT continued

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2017

IBE/ILAE Joint Task Force

The IBE/ILAE Joint Task Force programme is a joint 50:50 initiative of the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE). Its aim is to raise the profile of epilepsy across Europe by undertaking new research and educational activities. The initiative received corporate sponsorship and the fund is jointly owned by IBE and ILAE. IBE administer the programme and the fund, and received a management fee of US\$16,173 (2016: US\$16,450).

	2017 US\$	2016 US\$
Opening balance	69,893	104,060
Bank interest received	-	25
Expenditure incurred	(12,889)	(34,737)
	<hr/>	<hr/>
Closing balance	<u>66,619</u>	<u>69,893</u>

Congress Financial Information

The International Bureau for Epilepsy and the International League Against Epilepsy (ILAE) engages the services of a contracted International Director of Meetings (IDM) under the terms of an Agreement dated 2 February 2016. The IDM is charged with the organisation of various European and International Congresses.

The 2017 financial statements reflect the portion of assets, liabilities, net revenues and expenses held by the International Director of Meetings on behalf of the International Bureau for Epilepsy. An analysis of the proportion of congress assets, liabilities, income and expenses applicable to the Bureau is as follows:

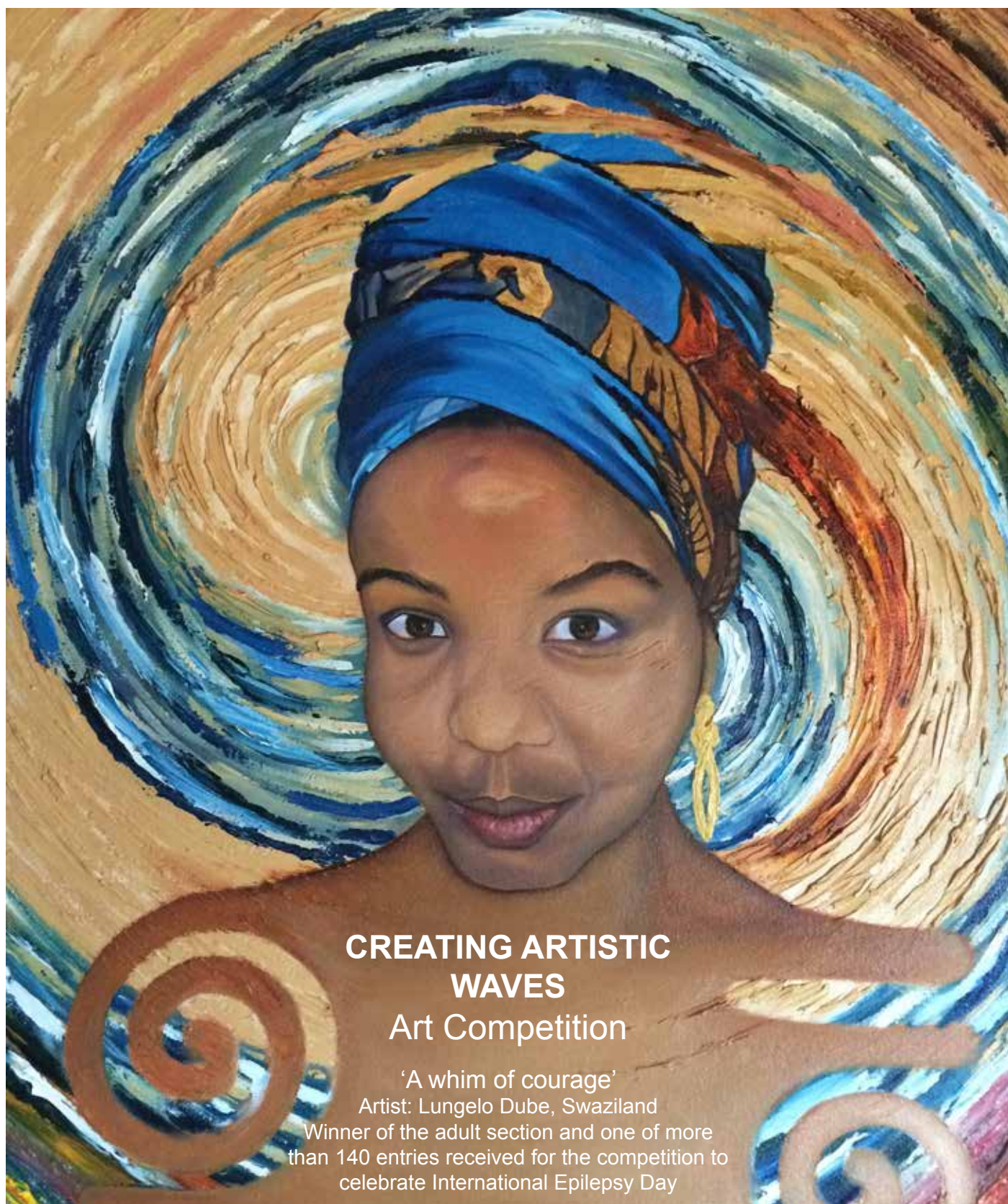
	2017 US\$	2016 US\$
Cash at bank	338,809	291,601
Debtors and prepayments	284,073	173,955
Creditors	(267,061)	(267,366)
Bank overdraft	(33,085)	(63,552)
Deferred income	-	(11,159)
IDM-Congress income received	1,436,373	536,491
IDM-Congress expenses	(810,258)	(543,720)
	<hr/>	<hr/>

Working for people with epilepsy and those who care for them across the globe

In 2017, IBE had 137 chapters in 103 countries
With the world population estimated at 7.6 billion,
6.8 billion people or 89% of the world's population
live in countries served by an IBE chapter



Albania	Ecuador	Israel	Netherlands	South Africa
Argentina	Egypt	Italy	New Zealand	Spain
Australia	Estonia	Jamaica	Niger	Sri Lanka
Austria	Ethiopia	Japan	Nigeria	Swaziland
Bangladesh	Fiji	Kazakhstan	Norway	Sweden
Belgium	Finland	Kenya	Pakistan	Switzerland
Brazil	France	Korea	Panama	Taiwan
Bulgaria	Gambia	Lebanon	Paraguay	Tanzania
Cameroon	Georgia	Lithuania	Peru	Thailand
Canada	Germany	Luxembourg	Philippines	Togo
Chile	Ghana	Macedonia FYR	Poland	Tunisia
China	Greece	Malawi	Portugal	Turkey
Colombia	Guatemala	Malaysia	Romania	Uganda
Congo, DR	Guyana	Malta	Russia	UK
Costa Rica	Honduras	Mauritius	Scotland	USA
Croatia	Hungary	Mexico	Senegal	Uruguay
Cuba	Iceland	Moldova	Serbia	Venezuela
Cyprus	India	Mongolia	Sierra Leone	Zambia
Czech Republic	Indonesia	Morocco	Singapore	Zimbabwe
Denmark	Iran	Namibia	Slovakia	
Dominican Rep	Ireland	Nepal	Slovenia	



CREATING ARTISTIC WAVES Art Competition

'A whim of courage'
Artist: Lungelo Dube, Swaziland
Winner of the adult section and one of more than 140 entries received for the competition to celebrate International Epilepsy Day



International Epilepsy Day

International Epilepsy Day

Organised jointly by the International Bureau for Epilepsy and the International League Against Epilepsy, International Epilepsy Day provides the platform for people with epilepsy to share their experiences and stories with a global audience and to build a stronger epilepsy community.

It has been developed to advocate for appropriate legislation to guarantee human rights of people with epilepsy and to empower people with epilepsy to maximise their quality of life.

Towards a Global Alliance on Epilepsy Research

Workshop in the European Parliament
hosted by Brian Hayes MEP

The workshop on 7th February, organised by the Epilepsy Alliance Europe task force, was attended by some of the most senior representatives of a number of agencies and associations from Europe and North America. The purpose of the meeting was to see how resources in the US, EU and possibly Asia, might be pooled so that each region was not working in a silo but as a joint collaborative unit.

The European Written Declaration on Epilepsy in 2011, supported with the signatures of 459 MEPs, and the more recent WHO Resolution on epilepsy, approved unanimously by the World Health Assembly in 2015, recognised the importance of the issue.

The workshop also demonstrated to the European Parliament “the quiet but deliberate work that has been going on since 2011”, Mr Hayes said in his opening address.



Campi visits the doctor

In the first episode of the Campi animated videos, introduced in 2016, we met Campi and his schoolfriends. In the second in the series of short animated films created especially for young children was launched to celebrate International Epilepsy Day 2017. In this episode, Campi visits Dr Christina Langoustina with his mother and father to find out what is causing Campi to have seizures.



International Epilepsy Day - Social Media

Surge in Social Media activity

Twitter <http://www.twitter.com/IntEpilepsyDay>

@IntEpilepsyDay account performance, February 2017

Tweet impressions: 59.6k (+585.6%)

Profile visits: 4,265 (+499.9%)

Mentions: 247 (+1,664.3%)

Top Tweet: 9,137 impressions

Top media Tweet: 5,888 impressions

Total Followers Sep 2016: 557

Total Followers Feb 2017: 926 (+66%)

Facebook <https://www.facebook.com/epilepsyday/>

International Epilepsy Day Page performance, February 2017:

Page Likes: +522 (+358%)

Page Views: 1899 (+562%)

Post Engagements: 10,152 (+1,029%)

Reach: 36,403 (+731%)

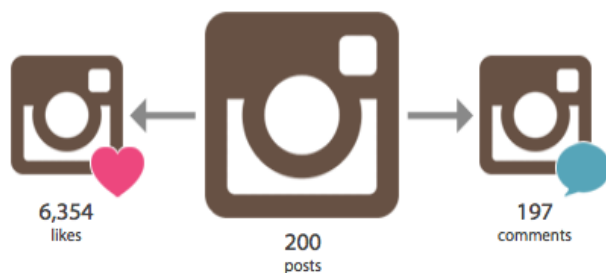
(100% organically generated activity)

Total Page Likes Sep 2016: 5,556

Total Page Likes Feb 2017: 6,221 (12% increase)

Instagram <https://www.instagram.com/IntEpilepsyDay/>

NEW FOR 2017! Follow @IntEpilepsyDay on Instagram



From February 11 to February 15, 2017 #EpilepsyDay was the most used hashtag on Twitter among the health community, being used 1,939 times*



World Health Organization

International Epilepsy Day is recognised annually by the World Health Organization (WHO)

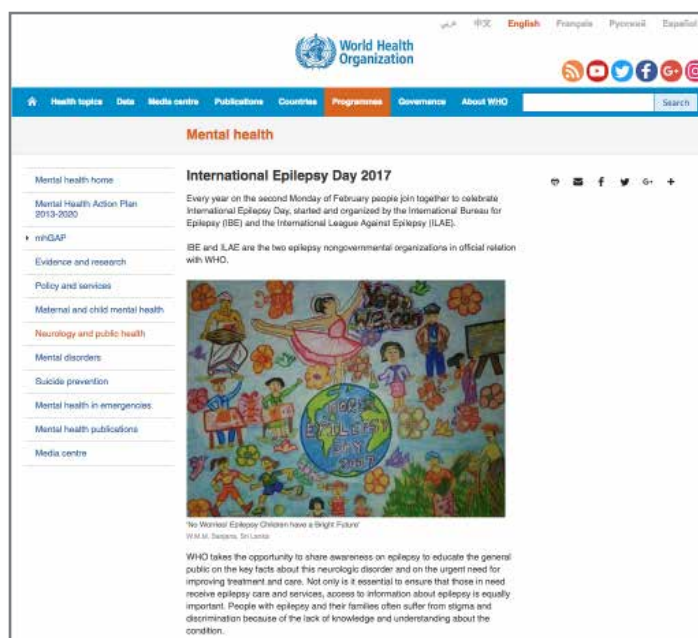
WHO was Twitter's top Health Influencer during the period, with 3.3 million followers of their account.

The most popular health-related URL in a tweet during the period was WHO's epilepsy factsheet:

<http://www.who.int/mediacentre/factsheets/fs999/en/>

WHO's factsheet Tweet was shared over 1,100 times and their Facebook post over 1,300 times.

They also shared a webpage dedicated to International Epilepsy Day featuring the artwork of W.M.M. Sanjana, a young person from Sri Lanka, who was one of the runners-up in the children's category of the Creating Artistic Waves competition for International Epilepsy Day.



Websites, e-Zines and Social Media



Communication is essential to our work. It provides the platform to promote what we do, to encourage discourse with our chapters, and to inform the wider world about epilepsy and about the efforts we undertake to improve life quality for all those affected by epilepsy around the world. Since IBE's first printed newsletter, a one page letter, typed on a manual typewriter, copied and mailed out to chapters and supporters in 1961, how IBE communicates its message has taken giant steps forward. First came the electric type-

writer, followed by the fax machine, the computer, email and the world wide web. IBE launched its first website in 2001 and now maintains 4 separate sites:

- ibe-epilepsy.org
- internationalepilepsyday.org
- epilepsyallianceurope.org
- globalcampaignagainstepilepsy.org

The benefit of new technology has facilitated the creation of new communication streams including eZines and social media. In recent years, social media channels, in particular Facebook and Twitter, have been adopted, recognising the need in the modern era, for instantaneous delivery of news as it happens.

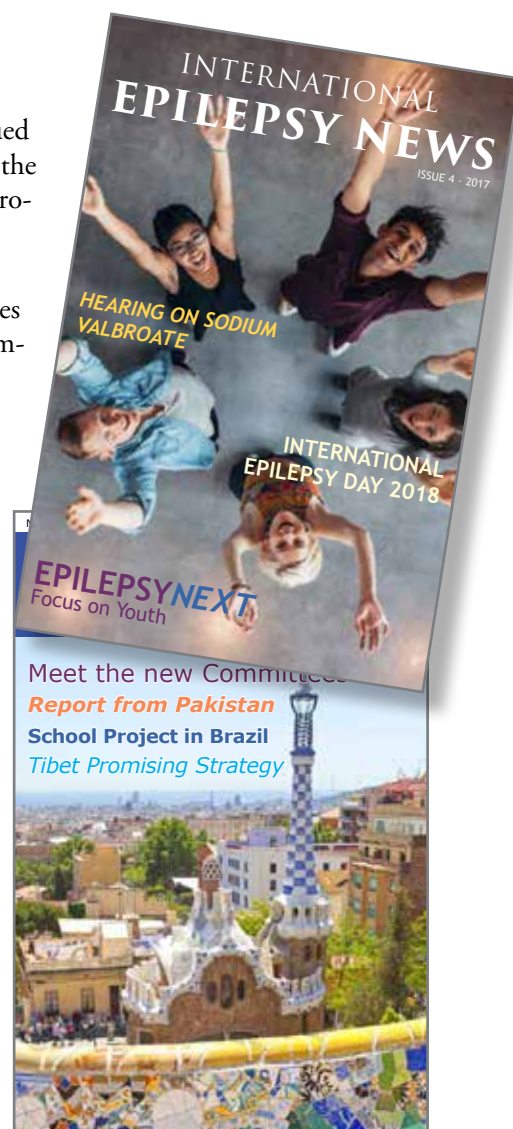
However, despite the marvels of modern technology, one-to-one communication - by email, phone and Skype - still remain important communication channels, used at chapter and committee levels. Improving how we communicate our message to our internal and external audiences, is an issue that is continually under review.

International Epilepsy News

Entering its 54th year of uninterrupted publication, the IBE news magazine continued to be published each quarter during the year. Following the start of the new term of the International Executive Committee in Barcelona, a redesign of the magazine was introduced, with Issue 4-2017 showing its new look.

Published online and distributed to a database of over 3,000, IE News provides the opportunity to report on IBE activities, on events and news from its chapters, updates on projects in which IBE is involved, as well as information on external issues that impact on people with epilepsy.

The newsletter is also available to download from the IBE website ibe-epilepsy.org, where an archive of previous issues is stored.



IBE at Congress



Charlotte Dravet, France, receives a well-deserved standing ovation on being presented with the Lifetime Achievement Award at the Opening Ceremony in Barcelona.



With our partner, the International League Against Epilepsy (ILAE), IBE organises biennial international epilepsy congresses as well as regional congresses in Africa, Asia Oceania, East Mediterranean and Latin America. In addition to the scientific sessions, epilepsy congresses now also include teaching sessions and leadership programmes, with dedicated Epilepsy & Society programmes created specifically for people with epilepsy, their families and those who care for them. In 2017, the Epilepsy & Society Programmes took place at the regional meetings in Luxor and Dakar, with the presentations focussed on issues particular to the region in which the congress was being held.



The 4th East Mediterranean Epilepsy Congress took place in Luxor, Egypt from 16th to 18th February. This was the second time this regional congress has been held in this city on the Nile, a place with a fascinating and ancient history with temples and tombs on either side of the river, and where every day more wonders are revealed by modern archeologists. Despite the fact that there had been a significant decline in tourist numbers to Luxor in recent years, the congress attracted close to 400 delegates from 30 countries.

Three months later, from 5th to 7th May, the 3rd African Epilepsy Congress took place in Dakar, Senegal with a similar number of delegates. The two previous congresses had been held in Nairobi and Cape Town.

These regional congresses, organised jointly by IBE and ILAE, play an important role in providing training opportu-



nities and increasing knowledge about epilepsy for all those involved in the field in these regions. They also serve to enforce IBE's mission to end stigma and discrimination through epilepsy education in every region of the world.

Barcelona proved to be a very popular venue for the 32nd International Epilepsy Congress in Barcelona, with one of the highest delegate numbers for an international meeting in recent years. Apart from the excellent congress scientific programme, the congress was also significant as it marked the end of the term of office for the 2013-2017 IBE board and the start of the term for the incoming International Executive Committee.

The General Assembly was the occasion to formally ratify new chapters approved by the International Executive Committee since the previous assembly, to hear on progress made in a number of IBE projects and initiatives, and for chapters and the committee to meet informally during the assembly reception.





IBE's focus on youth

Planning for an exciting new initiative to help young people to grow in independence and to develop the skills and qualities necessary for a happy and productive life began in the last quarter of 2017.

The EpilepsyNext initiative will also challenge young people to use these attributes for the betterment of themselves and the global epilepsy family.

In the future it is hoped to develop and expand the initiative to introduce new modules to the programme but, as always, this will be funding dependent. As a start, five modules have been identified:

The TEA Room:

A safe online environment for teenagers with epilepsy to meet and discuss issues of relevance to them. This initiative was first developed by the Scottish Epilepsy Initiative charity and is now being expanded.

Young Adult Summit:

A coming together of young adults to share their experiences, identify challenges that prevent them from participating fully in their community and develop projects to address these challenges. By the end of 2017, plans were underway for the first summit - to take place during the Latin American Epilepsy Congress in Costa Rica in October 2018.

Leadership Training Programme:

Offering tailored high-quality support to young adults (18-30 years), who have the motivation to learn about advocacy, and to maximise their leadership potential equip them with the skills to become future leaders of epilepsy associations.

Golden Light Awards:

Adapting an award program already in place for Asian & Oceanian Epilepsy Congresses to focus on young people and to award those personally affected by epilepsy whose efforts had made a significant impact on their own lives or on the lives of others.

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.

Promising Strategies Program



IBE is committed to finding new and innovative solutions to the problems impacting people with epilepsy and their families world-wide. As part of this commitment, under its Promising Strategies Program (PSP), IBE has been providing a limited amount of financial support to IBE chapters on a competitive basis for initiatives aimed at improving the quality of life for people with epilepsy in resource challenged countries or regions. In the 11 years since it was established, PSP has provided more than US\$300,000 in funding to 83 projects in 38 countries. Two new projects were funded in 2017 in Tibet, China and Colombia.

Neurocysticercosis is the first cause of epilepsy in the Caribbean region. The Colombian project focussed on eliminating the worms affecting diseased pigs, which were responsible for spreading neurocysticercosis in one region of the country. One year on and already the project of FIRE, IBE's chapter in Colombia, is making an impact in the eradication of neurocysticercosis in one rural town. Its success has led the government to consider expanding it across the entire Caribbean coastal region.

In Tibet, medical resources are highly 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. The epilepsy treatment gap has been shown to be as high as 97%. And 60% of people will choose traditional Tibetan medicine. In the program, GPs and patients are the targeted population. There is an urgent need to train the local doctors in proper epilepsy control; to educate people with epilepsy to adhere to appropriate treatment; and increase public awareness of epilepsy. This is done by doctors from Chengdu and Kangding who are supported by PSP and who travel to these remote regions.

International Executive Committee 2017-2021

Management Committee



Mary Secco
Secretary General



Martin Brodie
President



Anthony Zimba
Treasurer

Immediate Past President and Vice Presidents



Athanasios Covanis
Immediate Past President



Jacob Mugumbate
VP Africa



Hassan Hosny
VP Eastern Mediterranean



Natela Okujava
VP Europe



Tomás Mesa
VP Latin America



Phil Gattone
VP North America



Satish Jain
VP South East Asia



Ding Ding
VP Western Pacific

ILAE Representatives



Ed Bertram
ILAE Secretary General



Sam Wiebe
ILAE President



Helen Cross
ILAE Treasurer



CONTACT DIRECTORY

Offices, Committees and Commissions

IBE HEAD OFFICE

Mrs Ann Little,
IBE Executive Director,
ibeexecdir@eircom.net
7 Priory Office Park
Stillorgan Road, Blackrock
Co Dublin, A94 FN26, Ireland.
T: +353 1 210 8850
E: annlittle@ibe-epilepsy.org
www.ibe-epilepsy.org

CONGRESS OFFICE

IBE/ILAE Congress Secretariat
7 Priory Office Park
Stillorgan Road, Blackrock
Co Dublin, A94 FN26, Ireland.
T: +353 1 205 6720
E: info@epilepsycongress.org
www.epilepsycongress.org

INTERNATIONAL EXECUTIVE COMMITTEE

President

Prof Martin J Brodie (Scotland)
E: Martin.Brodie@glasgow.ac.uk

Secretary General

Mrs Mary Secco (Canada)
E: mary@epilepsysupport.ca

Treasurer

Mr Anthony M Zimba (Zambia)
E: anthonymzmb@gmail.com

Immediate Past President

Dr Athanasios Covanis (Greece)
E: dracovanis@gmail.com

Regional Vice Presidents:

Africa

Mr Jacob Mugumbate (Zimbabwe)
E: mugumbatej@gmail.com

Eastern Mediterranean

Dr Hassan Hosny (Egypt)
E: drhassanhosny@yahoo.com

Europe

Dr Natela Okujava (Georgia)
E: natelaokujava@yahoo.com

Latin America

Dr Tomás Mesa (Chile)
E: tomasmesalatorre@gmail.com

North America

Mr Philip Gattone (USA)
E: pgattone@efa.org

South East Asia

Dr Satish Jain (India)
E: satjain55@hotmail.com

Western Pacific

Dr Ding Ding (China)
E: dding99@yahoo.com

ILAE Representatives

Prof Sam Wiebe, President
Prof Ed Bertram, Secretary General
Prof Helen Cross, Treasurer

COMMISSIONS

Education

Chair: Dr Margarete Pfäfflin (Germany) E: mpfaefflin@gmx.de
Secretary: Dr Janet Mifsud (Malta)
Members: Mrs Marina Clarke (South Africa), Mrs Arlette Honein (Lebanon), Dr Patricia Braga (Uruguay), Dr Hidemoto Kubota (Japan), Mr Graeme Ambler (New Zealand), Dr Avirmed Tovudorj (Mongolia)

e-Solutions

Chair: Dr Najib Kissani (Morocco)
E: najibkiss@gmail.com
Secretary: Mr Graeme Shears (Australia)
Members: Dr Alicia Bogacz (Uruguay), Mrs Harmiena Riphagen (Namibia), Dr Yuan-fu Tseng (Taiwan), Dr Dawn Eliashiv (USA), Dr Cigdem Ozkara (Turkey), Dr Victor Patterson (UK), Dr Hasan Aziz (Pakistan)

Research

Chair: Dr Kheang-Seang Lim (Malaysia) E: kslimum@gmail.com
Secretary: Dr Manjari Tripathi (India)
Members: Mrs Farah Abassi (Iran), Mrs Anchor Hung (Hong Kong), Dr Khaled El Zamel (Qatar), Dr Jana Jones (USA), Dr Laura Guilhoto (Brazil), Dr Antonina Gavajuc (Moldova), Ms Rosemary Panelli (Australia)

IBE-ILAE INITIATIVES

Global Outreach Task Force

IBE co-chair: Mrs Mary Secco
E: mary@epilepsysupport.ca
ILAE co-chair: Dr Alla Guekht (Russia)

Epilepsy Alliance Europe Task Force

Administration: Mrs Ann Little
Co-chairs: Prof Martin J Brodie, Prof Philippe Ryvlin
Members: Dr Natela Okujava, Mrs Francesca Sofia, Dr Janet Mifsud, Prof Eugen Trinkla, Dr Liegen Lagae, Dr Kristl Vonck
E: annlittle@ibe-epilepsy.org
www.epilepsyallianceeurope.org

International Epilepsy Day

Celebrated annually on the 2nd Monday in February
www.internationalepilepsyday.org

Chapters - listed by region

AFRICA

CAMEROON

Association Camerounaise contre l'Epilepsie
s/c Coordination Diocésaine de la Santé, Bafia, Cameroon.
T: +237 7433 3375
santbafia@yahoo.fr
Contact: Sr Marie Christine Long
ASSOCIATE CHAPTER
Community Development and Epilepsy Foundation (CODEF)
c/o CODEF Board Chair, Mr David Ntuchu, PO Box 45 Bamenda, NWR, Cameroon.
T: +237 75 07 44 42
codefcameroon2002@gmail.com
Contact: Mr Nsom Kenneth Ninying

CONGO, DR

ASSOCIATE CHAPTER
MHCD Centre for Prevention and Treatment of Epilepsy
Luvungi Naturopathic Hospital, Luvungi/Uvira, DR Congo.
T: +243 994 931 840
moulymasu@gmail.com
www.mhcdafica.org
Contact: Dr Luc Mulimbalimba -Masururu

ETHIOPIA

Epilepsy Support Association of Ethiopia, PO Box 25516, Code 1000, Addis Ababa, Ethiopia.
T: +251 155 3617
dr.zenebe.gedlie@ethionet.et
Contact: Dr Zenebe Damtie

GAMBIA

Gambia Epilepsy Association
PO Box 2230, Serrekunda, Gambia.
T: +220 9955 414
gambiaepilepsy@yahoo.co.uk
Contact: Mr Paul Colley

GHANA

Ghana Epilepsy Association
c/o Box M230, Accra, Ghana.
T: +233 2166 5421 ext 4420
ayisu@hotmail.com
Contact: Mr Paul Ayisu

KENYA

Kenya Association for the Welfare of People with Epilepsy (KAWE)
60790-00200 Nairobi, Kenya.
T: +254 722 594 268
info@kawe-kenya.org
www.kawe-kenya.org
Contact: Dr Osman Miyanji

LESOTHO

PROVISIONAL CHAPTER
Epilepsy Lesotho
PO Box 13081, Maseru 100, Lesotho.
T: +266 58998542
nathabelentoli@yahoo.com
Contact: Ms Nthabeleng Hlalele

MALAWI

Malawi Epilepsy Association
PO Box E681, Postdotnet, Blantyre, Malawi.
T: +265 999 020 469
gondwefrancina@gmail.com
Contact: Mrs Francina Gondwe
MAURITIUS
Edyecs Epilepsy Group
442 Boulevard Rivalentz, Port Louis, Mauritius.
T: +230 2131733 +230 2081904
edyecs.org@intnet.mu
http://edycsepilepsy.intnet.mu
Contact: Mr Youssouf Noormamode

NAMIBIA

Epilepsy Namibia
PO Box, 11822 Klein Windhoek, Namibia.
T: +264 813 226 834
namep@epilepsynamibia.org
www.epilepsynamibia.org
Contact: Ms Harmiena Riphagen

NIGER

LNCEMNMC
Service de Psychiatrie, Hôpital National de Naimey, BP238 Niamey, Niger.
T: +227 72 24 42
djibo.doumamaiga@gmail.com
Contact: Dr Djibo Douma

NIGERIA

Epilepsy Association of Nigeria
No 2 Weeks Road by 84 Asa Road Aba, Abia State, Nigeria.
T: +234 708 1832837
drmoaniclinic@yahoo.com
Contact: Dr SE Nwkwue

RWANDA

Global Epileptic Connection (GECO)
25 Kibuye, Western Province, Rubavu District, Rwanda.
T: +250 787134589 / 788265713
globalepeleptic@gmail.com
www.gecorwanda.org
Contacts: Vedaste Rusagara and Philip Benimana

SENEGAL

Ligue Senegalaise contre l'Epilepsie
Clinique Neurologique Centre Hospital-Universitaire de Fann, BP 5035, Dakar-Fann, Senegal.
T: + 221 33 824 1800
agalodiop@gmail.com
lsce@orange.sn
Contact: Prof Amadou Gallo Diop/ Prof Moustapha Ndiaye

SIERRA LEONE

Epilepsy Association Sierra Leone
8 Mansaray Street, Rokupa, PO Box 38, Freetown, Sierra Leone.
T: +232 77215 519 +232 78535234
epilepsysl2014@gmail.com
www.epilepsyassocsl.org
Contact: Mr Max Bangura

SOUTH AFRICA

Epilepsy South Africa
Postnet Suite #131, Private Bag X3, Bloubaerg, 7443, Republic of South Africa.
T: +27 21 556 3753
nationaldirector.no@epilepsy.org.za
info@epilepsy.org.za
www.epilepsy.org.za
Contact: Ms Marina Clarke

SWAZILAND

Swaziland Epilepsy Organisation
PO Box 7220, Mbabane H100, Swaziland.
T: +268 4047028/ +268 76037032
admin@epilepsy.org.sz
www.epilepsy.org.sz
Contact: Mr Mbusomuni Mahlalela

TANZANIA, UNITED REPUBLIC OF

POCET, PO Box 65293, Dar Es Salaam, Tanzania.
T: +255 754 822 517
Contact: Mrs Aisia Matowo Mrema

TOGO

ASSOCIATE CHAPTER
Clinique de l'Epilepsie
155 Carrefour de Rio 11, B.P. 75 Lomé, Togo.
T: +228 22403018
kosodjehoun@yahoo.fr
Contact: Dr Kokou Sodjehoun

UGANDA

Epilepsy Support Association Uganda (ESAU)
Plot 695 Gombe B, Off Kayunga-Kinoni-Wakiso Rd, Wakiso Town Council, PO Box 16260, Wandegaya, Kampala, Uganda.
esauganda02@gmail.com
www.epilepsy.org.ug

ZAMBIA

Epilepsy Association of Zambia
Amanda Ethu Building, Kalundwe Road, PO Box 32443, Lusaka, Zambia.
T: +260 977 789042
E: eazepilepsy@hotmail.com
Contact: Ms Betty Nsachilwa

ZIMBABWE

Epilepsy Support Foundation
43 St. David Road, Hatfield, Harare, Zimbabwe.
T: +263 773 595 241
epilepsyzimbabwe@gmail.com
www.esf.org
Contact: Ms Rutendo Gwatinyanya

EASTERN MEDITERRANEAN

EGYPT

Egyptian Epilepsy Association
40 Safeya Zaghlol Street, Alexandria 21111, Egypt.
T: +203 303 3338
E: drhassanhosny@yahoo.com
Contact: Dr Hassan Hosny

IRAN

Iranian Epilepsy Association
No 1352, Resalat Exp, Tehran, Iran.
T: +982 188 463 271
E: iranepi@gmail.com
Contact: Dr Gharagzli

LEBANON

Association of Care of People with Epilepsy in Lebanon (ECAL)
Shams Building, Qayya'a al wosta, Saida, Lebanon.
T: +961 3 388 713
E: epilepsyl@hotmail.com
E: nahida.assi@gmail.com
Contact: Mrs Manar Sawwan or Mrs Nahida El Assi

ASSOCIATE CHAPTER

Avance School & Association for Epilepsy and Special Needs
Lebanon - Baabda, Street : Old road, Building : Le Serail.
T: +96 1 71022044
or +96 1 3772317
E: epilepsie.liban@hotmail.com
Contact: Mrs Arlette Honein

MOROCCO

Association Marocaine contre l'Epilepsie, BP 7010 Sidi Abbad, 40080 Marrakech, Morocco.
T: +212 663 081 035
E: najibkis@gmail.com
Contact: Prof Najib Kissani

TUNISIA

Tunisian Epilepsy Association
Child Neurology Dept., EPS Hedi Chaker 3029 Sfax, Tunisia
T: +21 674 242 564
E: chahnezct@gmail.com
Contact: Dr Chahnez Triki

EUROPE

ALBANIA

Shoqata "Epilepsia"

Sherbimi I Neurologjise,
QSUT "Nene Tereza",
Tirana,
Albania.
T: +355 69 20 59251
janazekja@gmail.com
E: epialbania@live.com
Contact: Prof Ilirjana Zekja

AUSTRIA

Epilepsie Dachverband Österreich (EDO)

Wichtelgasse 55/17-20,
1170 Wien,
Austria.
T: +431 489 5278
office@epilepsie.at
www.epilepsie.at
Contact: Mrs Liselotte Kastl-Soldan

BELGIUM

Belgian League Against Epilepsy (Flemish and French Division)

Epilepsie Liga,
Beleidsmedewerker Epilepsie Liga,
C. Heymanslaan
10 - 9000 Gent,
Belgium.
T: +32 9 332 57 95
info@epilepsieliga.be
www.epilepsieliga.be
Contact: Ms Emma Staut

BULGARIA

Association of Parents of Children with Epilepsy

Triadica district,
Strelbishte Bl 10,
entr. G floor 7 ap 67,
Sofia 1408,
Bulgaria.
T: +359 2 90 000 40
frde@abv.bg
www.frde.org
Contact: Mrs Veska Sabeva

CROATIA

Croatian Association for Epilepsy

General Hospital "Sveti Duh",
Sveti Duh 64,
10000 Zagreb,
Croatia.
T: +385 9137 12313
info@epilepsija.hr or
srkana@gmail.com
www.epilepsija.hr
Contact: Ana Srak or Latica Friedrich

CYPRUS

Cyprus Association of Support for People with Epilepsy

8 Epidavrou Str,
2114 Nicosia,
Cyprus.
T: +357 99412779
antigoni@cytanet.com.cy
Contact: Mrs A Kallimachou

CZECH REPUBLIC

Společnost "E"

Liskova 3 4200,
Prague 4,
Czech Republic.
T/F: +4202 4172 2136
info@spolecnost-e.cz
www.spolecnost-e.cz
Contact: Mrs Alena Červenková
ASSOCIATE CHAPTER

EpiStop

Videnska 800, Praha 4,
14059 Czech Republic.
T: +4202 6108827
info@epistop.cz
Contact: Ms Lucie Pomajskova

DENMARK

Dansk Epilepsiforeningen

Store Gråbrødrestræde 10, 1,
DK-5000 Odense C, Denmark.
T: +45 6611 9091
epilepsi@epilepsiforeningen.dk
Per@epilepsiforeningen.dk
Contact: Mr Per Olesen
www.epilepsiforeningen.dk

ASSOCIATE CHAPTER

Danish Epilepsy Centre

Børneambulatoriet,
1 Epilepsihospitalet,
Dr Sells vej 23,
4293 Dianalund, Denmark.
T/F: +45 582 64200
filadelfia@filadelfia.dk
vst@filadelfia.dk
www.filadelfia.dk
Contact: Mrs Vibeke Stubbings

ESTONIA

Estonian Epilepsy Association

Puusepp St 2, 51014 Tartu, Estonia.
T: +372 7318515
Inga.Talvik@kliinikum.ee
Contact: Ms Inga Talvik

FINLAND

Epilepsialiitto

Malmin kauppatie 26,
00700 Helsinki, Finland.
T: +358 50 400 9191
virpi.tarkiainen@epilepsia.fi
www.epilepsia.fi
Contact: Mrs Virpi Tarkiainen

FRANCE

Comité National pour l'Epilepsie

13 rue Fremicourt,
75015 Paris, France.
T: +33 153 806 664
SecretariatCNE@yahoo.com
www.cne.epilepsies.fr
Contact: Françoise Thomas-Vialettes

ASSOCIATE CHAPTERS

Epilepsie-France

133 rue Falguière, Bâtiment D,
75015 Paris, France.
T/F: +33 1 53 806 664
sophie.chouaki@epilepsie-france.com
www.epilepsie-france.fr
Contact: Ms Sophie Chouaki

GEORGIA

Epilepsy Environment Association of Georgia

Dept of Neurology,
Tbilisi State Medical University,
Jacob Nicoladze str. 6 apt 22,
380079 Tbilisi,
Georgia.
T: +99 599 253 551
natelaokujava@yahoo.com
Contact: Dr Natela Okujava

ASSOCIATE CHAPTER

Georgian Society of Young

Epileptologists

Institute of Neurology &
Neuropsychology,
83 Vaja Phavela Str,
Tbilisi, Georgia.
T: +99 532 291 29 47
irinatoidze@yahoo.com
Contact: Dr Irina Toidze

GERMANY

Deutsche Epilepsievereinigung eV

Zillestrasse 102, D-10585 Berlin,
Germany.
T: +49 30 342 4414
info@epilepsie-vereinigung.de
mlux@epilepsiezentrum.de
www.epilepsie-vereinigung.de
Contact: Ms Anne Söhnle and Ms
Michaela Pauline Lux

ASSOCIATE CHAPTER

Interessenvereinigung für

Anfallsckranke in Köln eV

Hoeningner Weg 361,
D-50969, Köln,
Germany.
T: +49 221 3605767
Einfo@epilepsie-online.de
Contact: Mr Tomas Porschen

PROVISIONAL CHAPTER

Landesverband für Epilepsie

Selbsthilfe Nordrhein-Westfalen eV
Hoeningner Weg 361, D-50969,
Köln, Germany.
T: +49 221 3605767
info@epilepsie-online.de
Contact: Mr Tomas Porschen

GREECE

Greek National Association

against Epilepsy

Mayromataion 2, 10682,
Mouseio, Athens, Greece.
T: +30 210 7705 785
graaepil@otenet.gr
www.epilepsy-greece.gr
Contact: Dr Athanasios Covanis or
Mrs Anastasia Vassou

ICELAND

LAUF - Icelandic Epilepsy Assoc

Hatun 10,
105 Reykjavik, Iceland.
T: +354 551 4570
E: lauf@vortex.is
www.lauf.is
Contact: Ms Frida Bragadottir

IRELAND

Epilepsy Ireland

249 Crumlin Road, Dublin 12,
Ireland.
T: +353 1455 7500
E: pmurphy@epilepsy.ie
www.epilepsy.ie
Contact: Mr Peter Murphy

ISRAEL

Israel Epilepsy Association

4 Avodat Yisrael, Box 1598,
Jerusalem 91014, Israel.
T: +97 2 5000283
gary@epilepsy.org.il
Contact: Mr Gary Jason

ITALY

Associazione Italiana contro l'Epilessia (AICE)

Via Burlamacchi 3, 20135, Milan,
Italy.
T: +393928492058
assaice@gmail.com
www.aice-epilessia.it
Contact: Dr Giovanni B Pesce

ASSOCIATE CHAPTER

Federazione Italiana Epilessie (FIE)

Via Fontana, 11, 20122 Milano,
Italy.
T: +39 339 85 81 510
T: +39 02 55 16 820
presidenza@fiepilessie.it
info@fiepilessie.it
www.fiepilessie.it
Contact: Mrs Simona Borroni

KAZAKHSTAN, REP OF SVS NEVRO

G. Almaty Street, Tulebayeva 38,
050004 Republic of Kazakhstan.
info@svsmedical.kz
www.ibe.kz
Contact: Dr Sergey Savinov

LUXEMBOURG

Association d'aide aux Personnes Epileptiques - AAPE

17 rue Charlemagne L-1328,
Luxembourg.
T: + 3525255291
aaape@pt.lu
Contact: Mrs Maryse Ardent

MALTA

Caritas Malta Epilepsy Association

5, Lion Street,
Floriana FRN 1514, Malta.
T: +356 99408781
maltaepilepsy@gmail.com
www.caritasmalta.org/epilepsy
Contacts: Mr Frank or Noel Portelli

MOLDOVA

Association Supporting Children with Special Needs

1-A, Constantin Stere str, Chisinau
MD-2009, Rep of Moldova.
T: +373 691 37 411
antoninagavajuc@yahoo.com
www.ascs.md/en
Contact: Dr Antonina Gavajuc

NETHERLANDS

Epilepsie Vereniging Nederland-EVN

Postbus 8105,
6710 AC Ede,
The Netherlands.
T: +31 318 672 772
info@epilepsievereniging.nl
www.epilepsievereniging.nl
Contact: Office

ASSOCIATE CHAPTERS

Epilepsiefonds

De Molen 35,
3994 Da Houten,
Netherlands.
T: +31 306 344 063
info@epilepsiefonds.nl
www.epilepsie.nl
Contact: Ms Marissa Piso

SEIN

Postbus 540,
2130 AM Hoofddorp,
Netherlands.
T: +31 23 558 8411
jwbarzilay@sein.nl
www.sein.nl/en
Contact: Mr Jean Willem Barzilay

Stichting Kempenhaeghe

Sterkselfeweg 65,
5591 VE Heeze,
Netherlands.
T: +31 40 227 9199
info@kempenhaeghe.nl
www.kempenhaeghe.nl
Contact: Office

NORWAY

Norwegian Epilepsy Association

Karl Johans Gate 7,
0154 Oslo,
Norway.
T: +47 2247 6600
nef@epilepsi.no
www.epilepsi.no
Contact: Mr Henrik Peersen

POLAND

Polish Association for People Suffering from Epilepsy

Ul Fabryczna 57,
15-482 Białystok,
Poland.
T/F: +48 8565 45751
zarebski@bialan.pl
www.padaczka.bialystok.pl
Contact: Mr Tadeusz Zarebski

PORTUGAL

EPI-APFAPE

EPI - Associação Portuguesa de Familiares, Amigos e Pessoas com Epilepsia

Av Bissaya Barreto,
n.º 268 R/c A,
3000-075 Coimbra,
Portugal.
T/F: +351 239 481 011
epicoimbra@epilepsia.pt
www.epilepsia.pt
Contact: Mrs Liliana Anastácio

ROMANIA

DELIA

Str. Motilor 64,
Cluj-Napoca,
Romania.
T: +40 757212745
asociatiadelia@gmail.com
www.epilepsie.ro
Contact: Mr Gelu Stanculescu

RUSSIAN FEDERATION

All Russian Charity Foundation

“Sodruzhestvo”,
Leningradskoye Shosse 114-57,
Moscow 125445
Russia Federation.
T/F: +79 161 421 898
mdorofeeva@inbox.ru;
www.epileptologhelp.ru
Contact: Dr Marina Dorofeeva

ASSOCIATE CHAPTER

Association of Doctors-Epileptologists and Patients

Ivana Babushkina st. 3-254,
Moscow 117292,
Russian Federation.
T: +7 916 616 09 58
doctorandpatient@yandex.ru
kiravoronkova@yandex.ru
www.epilepsy.medi.ru
http://www.epilepsia365.ru/
Contact: Prof Kira Voronkova

SCOTLAND

Epilepsy Scotland

48 Govan Road,
Glasgow G51 1JL,
Scotland.
T: +44 141427 4911
LYoung@epilepsyscotland.org.uk
www.epilepsyscotland.org.uk
Contact: Ms Lesslie Young

ASSOCIATE CHAPTERS

Epilepsy Connections

100 Wellington Street,
Glasgow G2 6DH,
Scotland.
T: +44 141 248 4125
smaxwell@epilepsyconnections.org.uk
www.epilepsyconnections.org.uk
Contact: Ms Shirley Maxwell

Scottish Epilepsy Centre Quarriers

Quarriers Village,
Bridge of Weir,
PA11 3SX,
Scotland.
T: +44 141 445 7750
gerard.gahagan@quarriers.org.uk
www.scottishepilepsycentre.org.uk
Contact: Mr Gerard Gahagan

SERBIA

Serbian Society For Epilepsy

Dunavski kej 7/11,
11000 Beograd,
Serbia.
T: +381 638 668 188
jmtmilov@gmail.com
Contact: Dr Doc Maja Milovanović

SLOVAKIA

Združenie občanov Slovenska postihnutých epilepsiou - AURA

Dúbravská.c. 1,
PO Box č. 70, Bratislava 45,
840 05, Slovakia.
T: +421 907531 908
zospe.aura@gmail.com
www.epilepsiask.sk
Contact: Dr Jozef Vrátil

SLOVENIA

Slovenian League against Epilepsy

Poljanska cesta 14,
SI-1000 Ljubljana,
Slovenija.
T: +386 1 432 93 93
epilepsija@epilepsija.org
www.epilepsija.org
Contact: Svetlana Simić Klobučarič

SPAIN

Federación Española de Epilepsia (FEDE)

Rambla Cataluña 52, Principal 2,
08007 Barcelona, Spain.
T: +34 655 918 445
presidente@fedeepilepsia.org
antoniorussi6764art@me.com
www.fedeepilepsia.org
Contact: Mr José Luis Domínguez
and Dr Antonio Russi

ASSOCIATE CHAPTERS

AME – Asociación Madrileña de Epilepsia

C/ Maria Teresa de Leon, 12,
Piso 4º B.,
28051 Madrid, Spain.
T: +34 618 354 707
info@epilepsiaespana.org
epilepsiaespana@gmail.com
www.epilepsiaespana.org
Contacts: Carment Barretón

Asociación Nacional de Personas con Epilepsia-ANPE

Calle Quince de Agosto,
19 Bjo. D,
Madrid 28026, Spain.
T: +34 660-22-05-81
info@anpepilepsia.org
www.anpepilepsia.org
Contact: Isabel Madrid Sánchez

SWEDEN

Swedish Epilepsy Association

PO Box 1386,
172 27 Sundbyberg,
Sweden.
T: +46 86694106
susanne.lund@epilepsi.se
www.epilepsi.se
Contact: Mrs Susanne Lund

SWITZERLAND

EPI-Suisse

Seefeldstrasse 84,
Postfach 313,
CH-8034 Zurich, Switzerland.
T: +41 4348 86880
dominique.meier@epi-suisse.ch
Contact: Ms Dominique Meier

ASSOCIATE CHAPTER

Swiss Epilepsy Foundation

Bleulerstrasse 60,
CH-8008 Zurich, Switzerland.
T: +41 44 387 6002
www.swissepipi.ch
martin.bieri@swissepipi.ch
Contact: Dr Martin Bieri

TURKEY

Association of People with Epilepsy and their Carers

Cerrahpasa Mah,
Etyemez Tekke Sok,
Merih Is Merkezi,
No 45 Buro,
52 Fatih, Istanbul, Turkey.
T: +90 212 529 77 80
Mob: +90 544 625 32 58
ebru_ozturk05@yahoo.com
Contact: Ms Ebru Öztürk

UK

Epilepsy Action

New Anstey House,
Gate Way Drive, Yeadon,
Leeds LS19 7XY, UK.
T: + 441 132 108 800
E: plee@epilepsy.org.uk
www.epilepsy.org.uk
Contact: Mr Philip Lee

ASSOCIATE CHAPTERS

SUDEP Action UK

12a Mill Street, Wantage,
Oxon , OX12 9AQ, UK.
T: +44 1235 772850
E: jane.hanna@sudep.org
https://www.sudep.org/
Contact: Ms Jane Hanna

Epilepsy Society

Chesham Lane,
Chalfont St Peter,
Buckinghamshire,
SL9 0RJ, UK.
T: +44 1494 601300
E: angela.geer@epilepsysociety.org.uk
www.epilepsysociety.org.uk
Contact: Ms Angela Geer

LATIN AMERICA

ARGENTINA

Asociación de Lucha Contra la Epilepsia - ALCE
Tucumán 3261 1189, Buenos Aires, Argentina. T: +54 114 8620 440
E: asoalce1961@gmail.com
www.alce.org.ar
Contacts: María Beatriz González Gartland and Claudia Mercedes Triguero

ASSOCIATE CHAPTERS

FUNDEPI

Medrano 1970 1° B (1425), Ciudad Autónoma de Buenos Aires, Argentina.
T: +54 114 127 0233
E: ramosmejia.epilepsia@gmail.com
http://www.cefundepi.org.ar/
Contact: Dr Silvia Kochen

Asociación Argentina de Lucha Contra la Epilepsia - ALAE

Medrano 1970 1° B (1425), Ciudad Autónoma de Buenos Aires, Argentina.
T: +54 114 127 0233
E: ramosmejia.epilepsia@gmail.com
http://alaeargentina.blogspot.com.ar/
Contact: Dr Jorge Loventio

BRAZIL

Associação Brasileira de Epilepsia
Rua Lourenço Marques 308, CEP 04547-100, São Paulo, SP Brazil.
T: +55 11 973019097
E: abe@epilepsiaibrasil.org.br
www.epilepsiaibrasil.org.br
Contact: Dr Maria Alice Albuquerque

CHILE

Asociación Nacional de Ligas Chilenas contra la Epilepsia - ANLICHE
Patriotas Uruguayos 2236, Código Postal: 8340594, Santiago de Chile, Chile.
T: +56 2 2699 2288, ext 300 or 301
E: daniela.poblete@liche.cl
www.ligaepilepsia.cl
Contact: Dr Jorge Förster

COLOMBIA

Fundación Instituto de Rehabilitación para Personas con Epilepsia - FIRE
Calle Primera El Edén, Barrio Ternera, Cartagena, Colombia.
T: +57 1 3013355 or 57 5 6810300
E: fandinojaime@gmail.com or direccionfire@gmail.com
www.firecolombia.co
Contact: Dr J Fandiño-Franky

COSTA RICA

IBE Chapter Costa Rica
San Jose, Costa Rica.
E: pris1980@icloud.com
Contact: Dr Priscilla Monterray Alvarez

CUBA

Capitulo Cubano de la IBE
66 Street, Number 2715 Entre 27 y 29, San Antonio de los Baños, Atemisa CP 32500, Cuba.
E: fabelo@infomed.sld.cu
Contact: Dr Justo Reinaldo Fabelo Roche PhD

DOMINICAN REPUBLIC

Sociedad Dominicana Unidos por la Epilepsia (SODOUE)
Calle Dr. Cesar Dargam, No. 10 Suite 504, 5to Piso, La Esperilla, Santo Domingo Distrito Nacional, Rep Dominicana.
T: +1 809 476 7206
E: frmontero@yahoo.com
Contact: Dr Franklin Montero

ECUADOR

Centro Nacional de Epilepsia - APNE
Berrutieta Oe9-180 y Pasaje Acevedo, Quito, Ecuador.
T: +59 3290 5405
E: cnepilepsia@gmail.com
www.centronacionaldeepilepsia.com
Contact: Dr Galo Pesantez Cuesta

GUATEMALA

IBE Guatemalan Chapter
6a Calle 2-48, Zona 1, Guatemala City, Guatemala.
T: +50 222 382 107
E: neurologo@doctorhenrystokes.com
Contact: Dr Henry Stokes

GUYANA

The Epilepsy Foundation of Guyana - EFG
78 Irving and Anira Streets, Queenstown, Guyana.
T: +592 655 9219
E: epilepsyfoundationgy@gmail.com
E: thomas.singh@uog.edu.gy
Contacts: Thomas B Singh and Mallika Mootoo

HONDURAS

Fundación Hondureña de Epilepsia
Colonia Universidad Norte 3a, Calle Casa 4917, Honduras.
T: +504 2205 9581
E: fundahp@yahoo.com
Contact: Eduardo Enrique Rodas Quito

MEXICO

Group "Acceptation" of Epilepsy (GADEP)
San Francisco 1384, 7° Piso B, Col. Del Valle, Mexico DF 03100, Mexico.
T: +525 5520 03474
E: lilianuor@yahoo.com
www.epilepsiahoy.com
Contact: Dr Lilia Nuñez Orozco

PANAMA

Bureau Panameño contra la Epilepsia - BUPACE
Policlinica San Fernando Sur, PO Box 363, 9A Panama 6 - 11202 Panama.
T: +507 229 0300
E: dtiana24@yahoo.com.mx
Contact: Ms Diana Triana

PARAGUAY

Asociación Paraguaya contra la Epilepsia
Tte Vera 1883, c/ Viena, Paraguay City, Paraguay.
T: +595 981 446941
e-mail: silvitaabente@hotmail.com/silvitaabente@gmail.com
E: mafreca@yahoo.com.ar or silvitaabente@gmail.com
Contact: Dr Marta Cabrera and Ms Silvia Abente

PERU

Peruvian Association of Epilepsy
Los Nandues 160-401, Surquillo, Lima, Peru.
T: +5 114 420 961
jjjperu@hotmail.com
Contact: Dr Julio Espinoza

URUGUAY

Asociación Uruguaya contra la Epilepsia
8 de Octubre 2610, Montevideo CP 11 600, Uruguay.
guareg52@hotmail.com
abogacz@hotmail.com
Contact: Dr Alicia Bogacz and Ms Isabel Rega

VENEZUELA

Venezuelan National Bureau
Quebrada Honda a Santa Rosa, Edif Tachira PB Local 3, Al lado de la Sinagoga Mariperez, Caracas 1050, Venezuela.
T: +582 125 782 737
rscull@yahoo.com
Contact: Mr René Scull

NORTH AMERICA

CANADA

Canadian Epilepsy Alliance/ Alliance Canadienne de l'Epilepsie
620 St Margaret's Bay Road Halifax Nova Scotia B3N 1K7 Canada
T: +1 902 477 6846 (work) or +1 902 430 3602 (cell)
dpfloyd62@gmail.com
www.canadianepilepsyalliance.org
Contact: Mrs Deirdre Floyd

JAMAICA

Jamaican Epilepsy Association
Andrews Memorial Hospital 27 Hope Road, Kingston 10, Jamaica WI.
T: +876 968-8274
jaepilepsy@gmail.com or jaepilepsy.director@gmail.com
Contact: Mrs. Joy McHugh or Mrs Jennifer McCallum

USA

Epilepsy Foundation
8301 Professional Place Landover, MD 20785-2238, USA
T: +1 301 918 3756
pgattone@efa.org
www.epilepsyfoundation.org
Contact: Mr Phil Gattone
ASSOCIATE CHAPTERS
Epilepsy Foundation of New Jersey
1 AAA Drive Suite 203 Trenton NJ 08691, USA
T: +1 6090 392 4900
ejoice@familyresourcenetwork.org
www.efnj.com
Contact: Mr Eric Joice

LGS Foundation

80 Orville Dr Suite, 100 Bohemia, NY 11716 USA
T: +17183743800
info@lgsfoundation.org
www.lgsfoundation.org
Contact: Mrs Christina SanInocencio

The Anita Kaufman Foundation

PO Box 11, New Milford, New Jersey 07646, USA
T: +1 201 655 0420,
debra@akfus.org
www.akfus.org
Contact: Mrs Debra Josephs

SOUTH EAST ASIA

BANGLADESH

Bangladesh Epilepsy Association
3/1 Lake Circus Kalabagan,
Dhaka 1205, Bangladesh.
T: +88 028 114 846
epilepsy_bd@yahoo.com
Contact: Dr MA Mannan

HONG KONG

The Hong Kong Epilepsy Assoc.
c/o G/F, Wang Lai House, Wang
Tau Hom Estate, Kowloon, Hong
Kong. T: +852 2794 7006
hkea.hkepilepsy@gmail.com
http://www.hkepilepsy.com/
Contact: Mr Ted Chiu

ASSOCIATE CHAPTER

Enlighten Hong Kong Ltd
C1, 7/F, Wui Hwa Industrial Bldg
No. 41 Wing Hong Street Cheung
Sha Wan, Kowloon, Hong Kong.
T: +852 2820 0111
baty.yuen@enlightenhk.org
www.enlightenhk.org
Contact: Batty YUEN

INDIA

Indian Epilepsy Association
"Swetambara",
16/217 A Kazhuthumuttu,
Behind KSEB sub Station,
Thoppumpady,
Kochi - 682005,
Kerala, India.
T: +91 988 627 423 or
+91 484 222 7292
sgiea2017@gmail.com
www.epilepsyindia.org
Contact: Dr Rajendran Balaraman

INDONESIA

PERPEI

Sanglah Hospital Neurology Dept,
Jl. Kesehatan No.1,
Denpasar 80224,
Bali, Indonesia.
T: +62 361 246 082
ansigeg@yahoo.com
perpeipusat@perpei.com
www.perpei.com
Contact: Dr Anna Sinardja

ASSOCIATE CHAPTER

Yayasan Epilepsi Indonesia
Tebet Mas Indah Kav. E-5,
Tebet Barat I,
Jakarta 12810,
Indonesia.
T: +62 218 4991458
aska.primardi@ina-epsy.org
www.ina-epsy.org
Contact: Mr Aska Primardi

NEPAL
Nepal Epilepsy Association
"Orange Home" 737/49,
Narayan Gopal Sadak,
Ward No 2,
Lazimpat,
Kathmandu Metropolitan City,
Nepal.
T/F: +977 1 4412945
nepeas@yahoo.com
shankar.malakar@gmail.com
www.nepilepsy.org.np
Contact: Mr Shankar Lal Malakar
and Mr Kabindra Man Pradhan

PAKISTAN

Epilepsy Support Pakistan
National Epilepsy Centre,
Rafiqi Shaheed Road,
Karachi 75510, Pakistan.
nec.jpmc@yahoo.com
Contact: Dr Zarine Mogal

SRI LANKA
Epilepsy Association of Sri Lanka
Tertiary Care Neurology,
Institute of Neurology,
National Hospital of Sri Lanka.
epilepsyl2016@gmail.com
jithangi@gmail.com
Contact: Dr Jithangi Wanigasinghe

THAILAND

Epilepsy Assoc of Thailand
Faculty of Medicine,
Chulalongkorn University,
Bangkok 10330, Thailand.
T: +66 81 6555358
s_phancharoen@hotmail.com
Contact: Dr Suwannee
Phancharoen

WESTERN PACIFIC

AUSTRALIA

Epilepsy Australia Ltd
587 Canterbury Road, Surrey Hills,
Victoria, 3127, Australia.
gshears@epilepsyfoundation.org.au
www.epilepsyaustralia.net
Contact: Mr Graeme Shears

ASSOCIATE CHAPTERS

**Epilepsy Association of South
Australia & the Northern
Territory Inc.** PO Box 12,
Woodville, South Australia 5011.
T: +61 8 84 485 600
rwakefield@epilepsycentre.org.au
www.epilepsycentre.org.au
Contact: Ms Robyn Wakefield

Epilepsy Action Australia
PO Box 879,
Epping NSW 1710, Australia.
T: +61 2 9856 7087
cireland@epilepsy.org.au
www.epilepsy.org.au
Contact: Mrs Carol Ireland

Epilepsy Queensland
PO Box 1457, Coorparoo BC 4151,
Queensland, Australia.
T: +617 3435 5000
epilepsy@epilepsyqueensland.
com.au
www.epilepsyqueensland.com.au
Contact: Ms Helen Whitehead

Epilepsy Association Act Inc.
27 Mulley Street, Holder ACT
2611, PO Box 3744,
Weston ACT 261, Australia.
T: +61 2 6287 4555
epilepsy@epilepsyact.org.au
www.epilepsyact.org.au
Contact: Ms Lisa Roulstone

PROVISIONAL CHAPTER

Epilepsy Foundation
587 Canterbury Road, Surrey Hills,
VIC 3127 Australia
T: +61 3 8809 0651
gshears@epilepsyfoundation.org.au
www.epilepsyfoundation.org.au
Contact: Mr Graeme Shears

CHINA

China Association Against Epilepsy
Rm. 5101 Bldg 2,
Beijing Exhibition Center Hotel,
135 Xi Zhi Men Wai Avenue,
Beijing 100044, PR China.
T: +861 065 250 423
caae2008@sina.com
Contact: Dr Shichuo Li

FIJI

Epilepsy Fiji
C/- Level 1, East Wing, PO Box
GC 36, Garden City Business
Park, Raiwai, Suva, Fiji Islands.
T: +679 327 5160
epilepsyfiji@gmail.com
Contact: Dr Zeizal Haniff

JAPAN

Japan Epilepsy Association Inc.
Fukushizaidan Building 7F,
Minamiotsuka 3-43-11,
Toshima-ku, Tokyo, 170-0005, Japan.
T: +81 3320 25661
jea@e-nami.or.jp
www.jea-net.jp
Contact: Dr Hidemoto Kubota

ASSOCIATE CHAPTER

Epilepsy Hospital Bethel
27-4 Hata-Mukaiyama-Minami
Kitahase, |
Iwanuma City 989-2455, Japan.

T: +81 2232 41211
bethelpj@topaz.ocn.ne.jp
Contact: Dr Takashi Soga

KOREA

Korea Bureau for Epilepsy (KBE)
#301, Buwon Bldg, Jahamun-ro 276,
Jongno-gu, Seoul, Korea
P.O Box 110-816
T: +82 2394 2320
E: epilepsy-kr@daum.net
E: danurif@gmail.com
www.epilepsy.re.kr
Contact: Dr Hee Joo Kim

MALAYSIA

Malaysia Society of Epilepsy
Jabatan Neurologi,
Kuala Lumpur Hospital,
505086 Jalan Pahang,
Kuala Lumpur, Malaysia.
T: +603 2615 5405
E: kslimum@gmail.com
Contact: Dr Lim Kheng Seang

MONGOLIA

Mongolian Epilepsy Association
Mongolian National University of
Medical Sciences, S Zorig Street,
Sukhbaatar District,
Ulaanbaatar 14210, Mongolia.
T: +976 9917 7153
E: tovuudorj@yahoo.com
Contact: Dr A Tovuudorj

NEW ZEALAND

Epilepsy New Zealand (ENZ)
6 Vialou St., PO Box 1074,
Hamilton 3240, New Zealand.
T: +61 7 834-3556
E: ceo@epilepsy.org.nz
www.epilepsy.org.nz
Contact: Mr Graeme Ambler

PHILIPPINES

**Epilepsy Awareness and
Advocacy Inc**
151-B Scout Rallos Extension,
Sacred Heart Kamuning,
Quezon City 1103, Philippines.
T: +632 414 4638
E: ph.eaai@yahoo.com
E: benglagman_calilung@yahoo.com
Contact: Dr Beng Calilung
psmxv@hotmail.com
Contact: Dr Victoria Abaez

SINGAPORE

Singapore Epilepsy Foundation
149 Rocher Road,
#04-06 Fu Lu Shou Complex,
188425 Singapore.
T: +65 3344 302
E: derrick.chan.ws@singhealth.
com.sg
Contact: Dr Derrick Chan Wei Shih

ASSOCIATE CHAPTER

Epilepsy Care Group
2 Kallang Avenue, #08-08 CT
Hub, Singapore 339407.
T: +65 6358 0566
E: ecgs93@singnet.com.sg
www.epilepsycare.org
Contact: Mr Sherman Goh

TAIWAN

Taiwan Epilepsy Association
B1F No 41, Alley 66 Lane 155,
Tun-Hwa N. Road,
Taipei 105, Taiwan.
T: +886 2 25149682
E: taiwan.epilepsy@gmail.com
E: didikun@gmail.com
www.epilepsy.org.tw
Contact: Dr Marshal Mo-Song Hsieh

INTERNATIONAL EPILEPSY DAY 2019

VIDEO COMPETITION



International
Epilepsy Day

AS PART OF OUR INTERNATIONAL EPILEPSY DAY CELEBRATIONS FOR 2019, WE INVITE YOU TO ENTER OUR VIDEO COMPETITION WITH CASH PRIZES FOR THE WINNING ENTRIES!

The winning videos will be selected based on their success in telling an inspiring personal story or in using a novel means of increasing knowledge and awareness of epilepsy. In each category, there will be one 1st Prize of US\$500 and five Runners' Up prizes of US\$100.

CATEGORY ONE:

My Personal Story

People with epilepsy, their families, friends and carers, can create non-professional individual short videos, using a smart phone or personal camera, to inspire others or to highlight problems faced.

CATEGORY TWO:

Educational Video

Open to organisations and support groups who have developed professionally produced videos to educate the public, policy-makers, and people with epilepsy themselves, about epilepsy during the past 3 years.

DEADLINE: 14TH DECEMBER 2018

VISIT WWW.INTERNATIONALEPILEPSYDAY.ORG FOR MORE



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— *Save the Date!* —

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Find out how you can take part at
www.internationalepilepsyday.org

INTERNATIONAL BUREAU FOR EPILEPSY

7 Priory Office Park
Stillorgan Road , Blackrock
Dublin A94 FN26
Ireland
T: +353 1 2108850
E: annlittle@ibe-epilepsy.org
www.ibe-epilepsy.org

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