



International
Epilepsy Day

REPORT 2017

INTERNATIONAL
LEAGUE
AGAINST
EPILEPSY **ILAE**
Established 1909



About the day

- A joint initiative of the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE);
- Launched in 2015 and celebrated annually on second Monday of February;
- With IBE and ILAE national chapters in more than 120 countries worldwide, it's a powerful opportunity to highlight the problems faced by people with epilepsy, their families and carers.

Objectives

Developed in line with a strategy 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, International Epilepsy Day aims to highlight that:

- epilepsy still remains a hidden disease due to the stigma attached;
- it is treatable, yet 40% of people living with epilepsy in wealthier countries do not receive appropriate treatment. Over 70% of those living in low income countries cannot even access epilepsy medication regularly;
- lack of treatment imposes a huge financial burden on national health systems;
- research and legislation remain key issues in improving the quality of life of persons with epilepsy.

About IBE (ibe-epilepsy.org)

- IBE is an international umbrella organisation of national epilepsy associations, and was founded in Rome in 1961.
- IBE exists to improve the social condition and quality of life of people with epilepsy and those who care for them by increasing awareness, understanding and knowledge of epilepsy.
- IBE currently has a membership of 137 chapters, based in 102 countries worldwide.
- IBE is in official working relations with the WHO/OMS; has Special Consultative Status on the Economic and Social Council of the UN; is a member of the European Federation of Neurological Associations, the European Patient's Forum and is an observer on the European Medicines Agency.

About ILAE (ilae.org)

- ILAE was founded in 1909 and is the world's preeminent association of Epileptologists, neurologists and other healthcare professionals working in the field of epilepsy.
- ILAE is working towards a world where no persons' life is limited by epilepsy by ensuring that health professionals; people with epilepsy and their care givers; governments and the public, have the educational and research resources essential to understanding, diagnosing and treating persons with epilepsy.
- ILAE, with a membership policy of one member association (chapter) per country, has 121 chapters.

Acknowledgement: IBE would like to acknowledge the support provided by Secretary General, Sari Tervonen, in creating the programme of activities for International Epilepsy Day 2017.



**International
Epilepsy Day**

Putting Epilepsy in the Picture!



For **International Epilepsy Day 2017** we built on the tremendous success of the first two International Epilepsy Days, now celebrated in more than 40 countries, to make the activities already in place even bigger and better.

We further developed many of the initiatives that proved popular and provided our members with an even wider range of materials for adoption and adaptation to suit local situations.

#EpilepsyDay was again used on Social Media. This year we also asked people to share photographs- 'putting themselves in the picture' for the day. Our theme for 2017 - Putting Epilepsy in the Picture - highlights how important it is for people to talk openly about epilepsy.

A number of personal videos made by young adults, in a project part-funded by IBE under the Promising Strategies Program were made available on epilepsy.org.

Campi, the friendly International Epilepsy Day mascot that was introduced in 2016, has been further developed with a second animated video.

The Creating Artistic Waves art competition, which echoed the theme of Putting Epilepsy in the Picture, proved hugely successful. Read more and see the winning entries on pages 10 - 11.

As in previous years, we organised events in the European Parliament. This year's events took place in Brussels, and focused on the establishment of a taskforce that will look at the possibility of establishing a global alliance on epilepsy research. Read more on page 12.

And, of course, we assisted chapters and supporters around the world to celebrate the day!



International Epilepsy Day leads to a 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%)

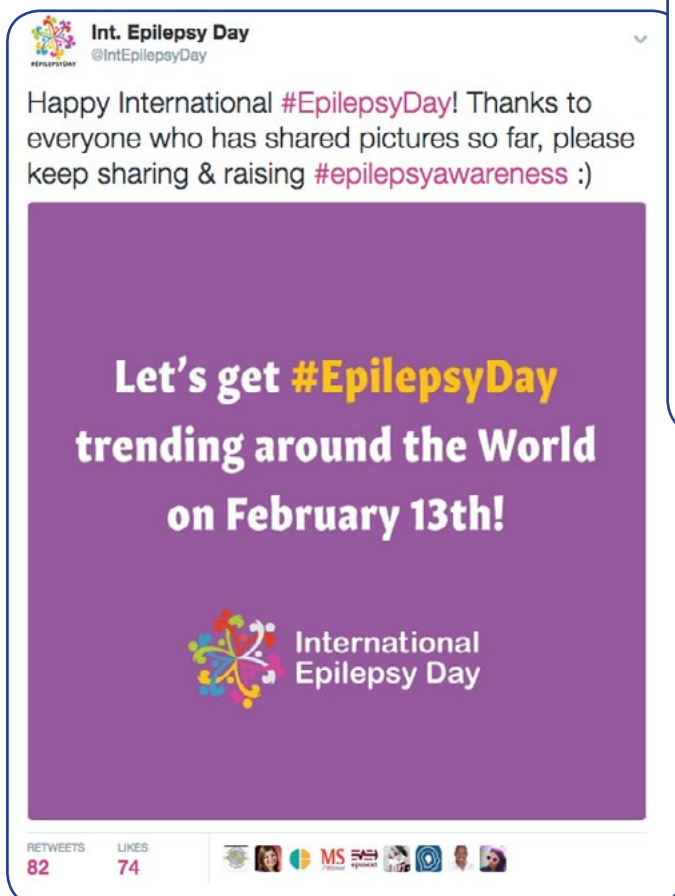
Followers: +263

Top Tweet: 9,137 impressions

Top media Tweet: 5,888 impressions

Total Followers Sep 2016: 557

Total Followers Feb 2017: 926 (+369 or 66%)



The total reach (number of people who have seen any tweet/post) of the hashtag #EpilepsyDay is over 147,000*

**figure taken from Hashtagify.com*



Top Media Tweet

Top Tweet

There has been a 66% increase in the number of @IntEpilepsyDay Followers on Twitter in the last 5 months!

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

**further details can be found here: <http://nodexlgraphgallery.org/Pages/Graph.aspx?graphID=95107>*

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)

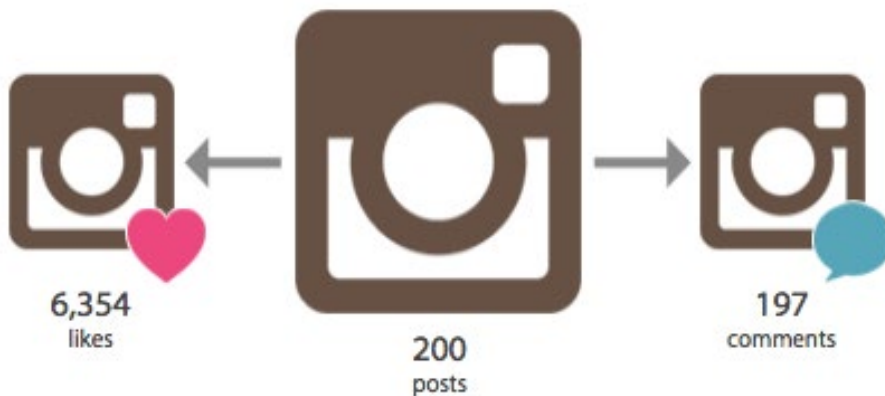
Our top Facebook post reached over 19,000 people, thanks to 594 reactions, comments & shares!

I am willing to help in any possible way for raising awareness about epilepsy in the educational field.

Total Page Likes Sep 2016: 5,556

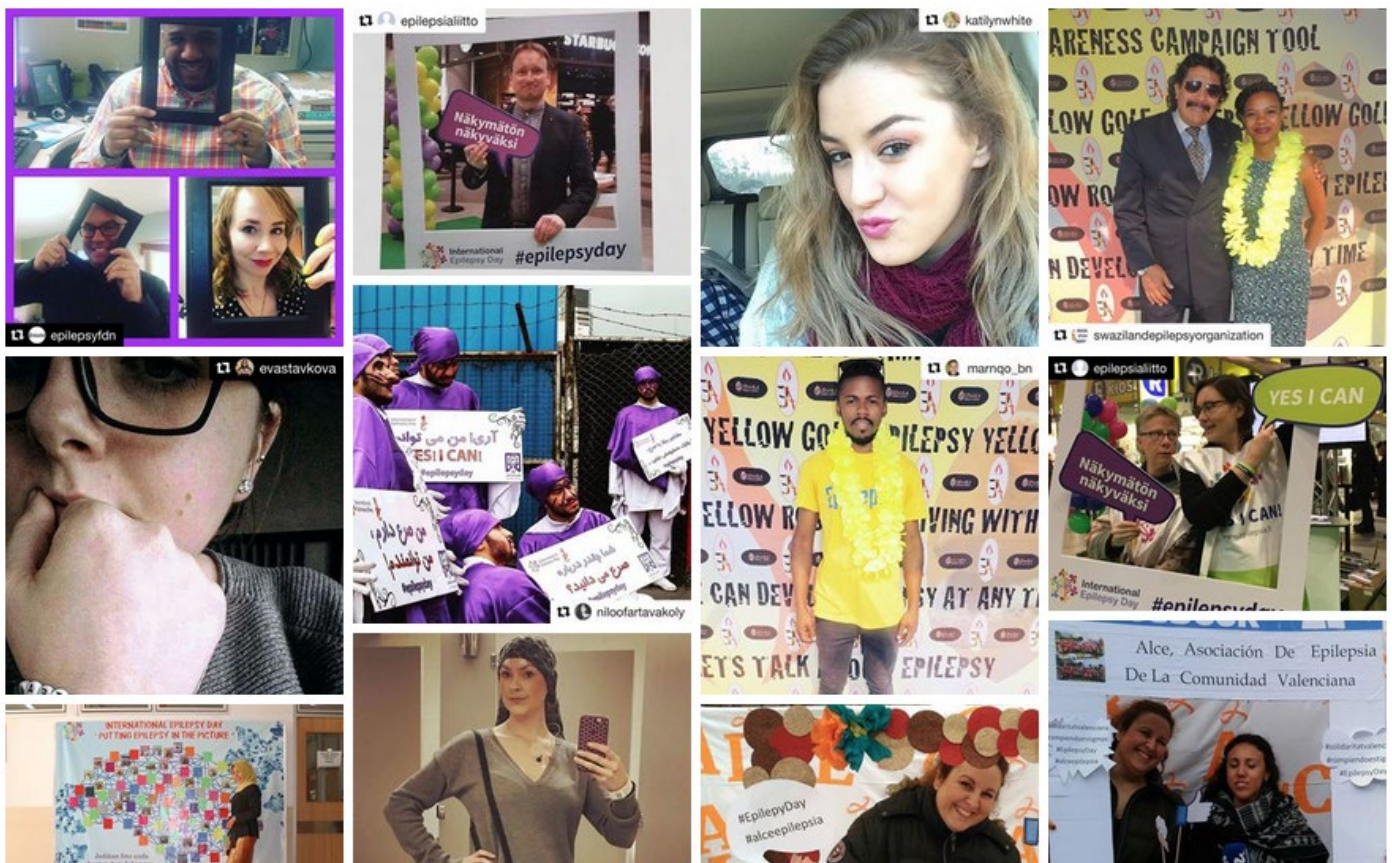
Total Page Likes Feb 2017: 6,221 (+665 or 12% increase)

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



New for 2017!

Follow **@IntEpilepsyDay** on Instagram



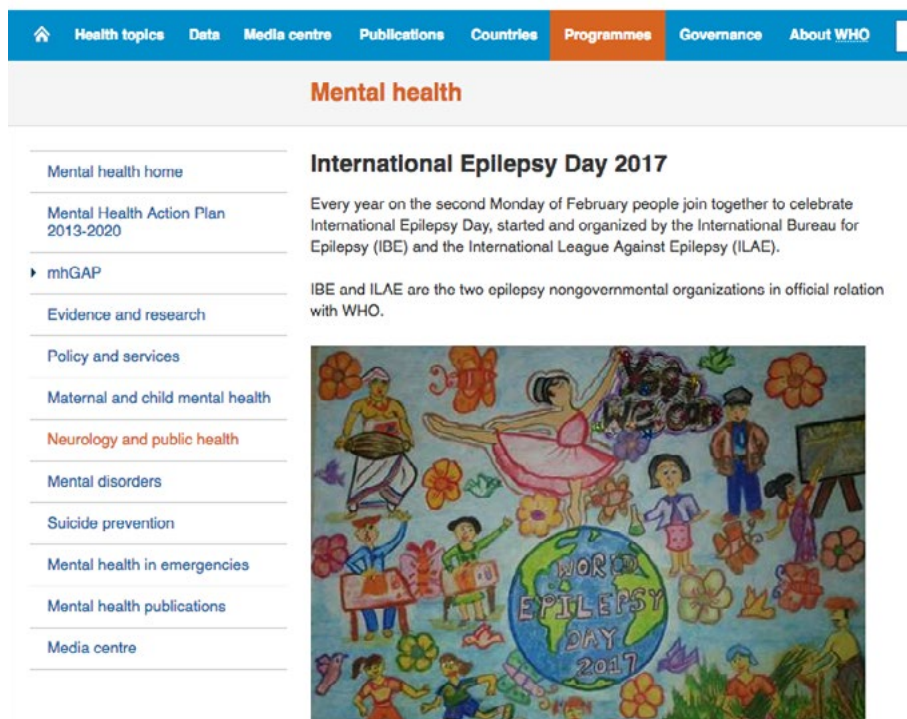
#EpilepsyDay Advocates

Thousands of people and countless organisations supported International Epilepsy Day in 2017, by sharing photos, messages of support or telling their stories. Here are a couple (of very different!) supporting groups that caught our attention.

The World Health Organisation

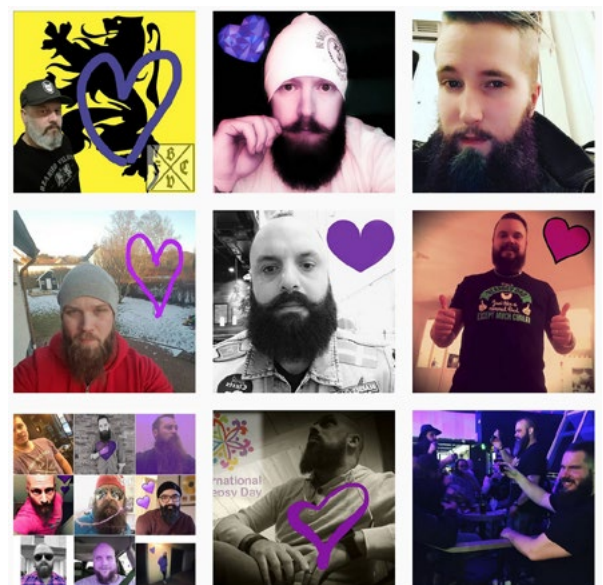
The World Health Organisation (WHO) were Twitter's top Health Influencer during the period, with 3.3million followers of their account. The most popular health-related URL in a tweet during the period was WHO's epilepsy factsheet: <http://www.who.int/mediacentre/factsheets/fs999/en/>

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 artwork by W.M.M. Sanjana of Sri Lanka, 'Artistic Waves' competition runner-up.



#BeardsAgainstEpilepsy: An Instagram Community

International Epilepsy day drew a huge amount of support from an unexpected place- the bearded community of Instagram users! ΒΕΑΡΔΕΔ VILLAINS are a brotherhood of beardies, so when one member asked the group to support #EpilepsyDay by sharing a picture and adding a purple heart, the response was overwhelming, with 114 pictures shared.



The EpilepsyDay.org Website

A successful Epilepsy Day has meant a dramatic increase in the numbers of visitors to the Epilepsy.org website. Hosting has had to be upgraded to cater for the influx!

The graph below shows the peak of traffic that took place on February 13th, with over 2,500 individual visitors but in the month to date there have been over 9,000 visitors to the website.

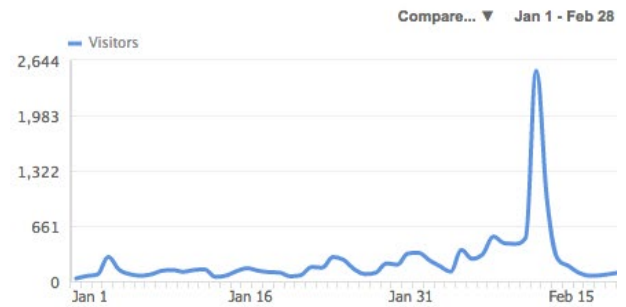
The vast majority of visitors are coming to the website via Facebook, highlighting its importance as a communication channel.

The Basics

Summary [Visitors](#) [Actions](#) [Uniques](#) [Time](#)

Visitors Expand	12,998	+134%
Actions Expand	30,926	+182%
Average actions	2.4	+20%
Total time	33d 4h	+124%
Average time per visit	3m 51s	-1%
Bounce rate	30%	+11%
Goals	38	0%

Visitors



A screengrab from epilepsy.org analytics

The most visited sections of the website are:

1. [Home Page](#) (12,964 +163%)
2. [‘Artistic Waves’ Competition results](#) (1,443 views *new*)
3. [Resources](#) (1,255 views +208%)
4. [Events](#) (1,166 views +295%)
5. [Epilepsy Stories](#) (949 views +223%)
6. [Online Awareness](#) (891 views +999%)

**Estamos conscientes
de la importancia del
liderazgo del IBE!**

Participation Around the World

Due to its great scale, it is very difficult to track all the activity relating to International Epilepsy Day but events and participation were seen around the world on February 13th. Countries involved include:

- Aruba
- Australia
- Belgium
- Canada
- China
- Dubai
- Egypt
- Estonia
- Fiji
- Finland
- France
- Guyana
- Ghana
- Greece
- Honduras
- Italy
- India
- Iran
- Ireland
- Jamaica
- Japan
- Kenya
- Lebanon
- Malaysia
- Malta
- Mauritius
- Mexico
- Nigeria
- Norway
- Portugal
- Qatar
- Scotland
- South Africa
- Spain
- Sri Lanka
- Swaziland
- Sweden
- Turkey
- UK
- USA
- Wales

Media Coverage

A small sample of the media coverage received on International Epilepsy Day 2017:



Above: A full-page article in The Times of Malta



Above: An article in Irish newspaper 'The Independent'



Right: A section on News channel 'Joy News' in Ghana

International Epilepsy Day Events

Once again, events were held around the world this year to mark International Epilepsy Day 2017, raising awareness of and educating the public about epilepsy as well as providing support to members of the epilepsy community. Below are a selection of images to illustrate the variety of events that took place. You can find out more by visiting www.epilepsy.org/events.



*Schools in Mpumalanga, South Africa
"Putting Epilepsy in the Picture"*

Courtesy of Marina Clarke at Epilepsy South Africa



The launch of Epilepsy Fiji

Courtesy of Dr. Shrish Acharya, Epilepsy Fiji



*The Epilepsy Association of Sri Lanka
held celebrations in Columbo*

*Courtesy of Jithangi Wanigasinghe,
Epilepsy Association of Sri Lanka*



Colourful celebrations held by Bethel Japan.

Courtesy of Bethel Epilepsy Clinic, Japan

The Swaziland Epilepsy Organization will always strive to make sure that people with epilepsy in Swaziland receive all the help they need.



*Epilepsia Liitto held a public photoshoot-
complete with frames and props!*

Courtesy of Epilepsia Liitto, Finland.

The 'Artistic Waves' Art Competition

The art competition to celebrate International Epilepsy Day 2017 was a fantastic success, attracting 140 entries from 25 countries around the world. We received entries from Aruba to Australia, from Malta to Malaysia and from Sweden to Sri Lanka.

Of the entries, 23 were submitted by children under 12 years of age and the remaining 117 entries came from adults. Among the artistic pieces submitted were paintings, photos and photo montages, sculptures, beadwork and embroidery as well as videos and music.

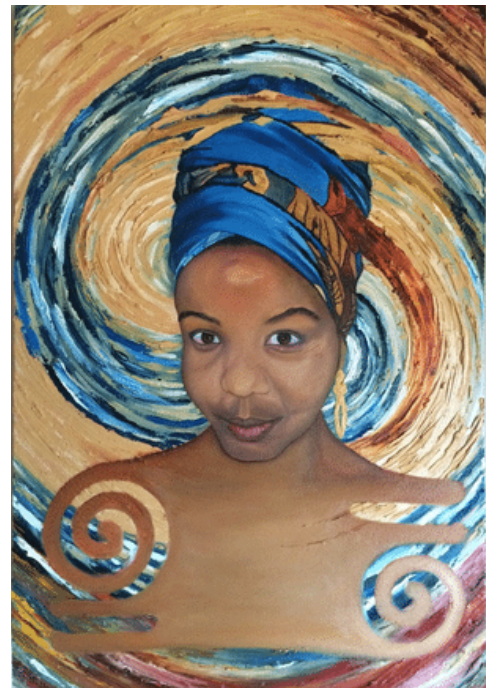
There were two categories - one for those aged under 12 years and the other for those over 12 years of age. In each category there was a first prize of US\$500 and two runners up prizes of US\$250.

Over 12 Years Category

FIRST PRIZE (RIGHT)

Artist: Lungelo Dube, Swaziland **Title:** A whim of courage

Lungelo said: The painting tells a profound story of beauty, courage and the constant battle of epilepsy. On the surface, beauty is not only an aesthetic to be relished by the beholder and third parties, but also skin deep. Epilepsy is a disease anyone can have; it shouldn't be seen as something bad but, rather, as a trait of the individual that's a part of their beauty



RUNNER UP (BELOW-LEFT)

Artist: Jinkun Liu, China **Title:** Window

Jinkun said: I see myself on a window after a seizure.

RUNNER UP (BELOW-RIGHT)

Artist: Vahid Darvish Zadeh, Iran

Title: Hope in darkness

Vahid said: The dark effects in around picture are negative attitudes toward epilepsy. Electricity is shown as a seizure mechanism. The hands tied with a purple bracelet shows the colour of epilepsy and its involvement. The two fish swimming in circles and also the beautiful butterflies show life flow, hope and happiness.



The judges were delighted with the quality of the artwork submitted to the competition and, while they found it very difficult to make final decisions on the prize-winners, working independently their final choices in both categories were strikingly similar. The members of the judging panel were Susanne Lund (Sweden), former IBE President; Harmiena Riphagen (Namibia), Secretary of the IBE African Regional Executive Committee, Ding Ding (China), IBE Vice President South East Asia, and Galo Pesantez Cuesta (Ecuador), Vice Chair of the IBE Latin American Regional Committee.

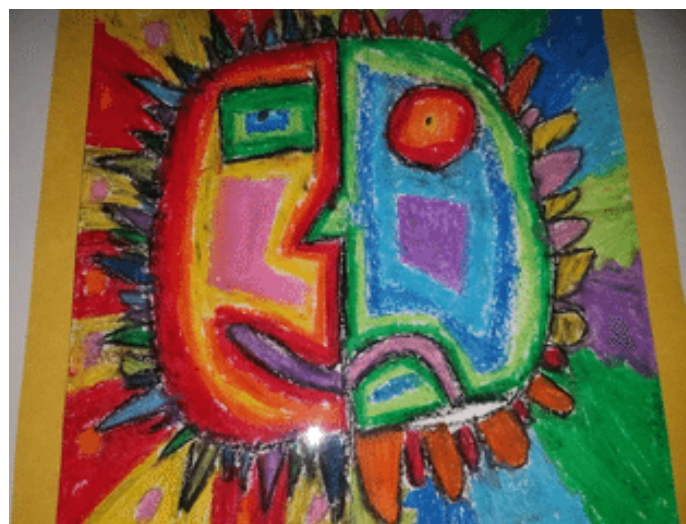
A gallery featuring all the entries is now available to view on epilepsy.org.

Under 12 Years Category

FIRST PRIZE (RIGHT)

Artist: Molly Foote, USA Age: 11 years
Title: Epilepsy: a self portrait

Molly said: I have epilepsy. I have learned that I am hardly any different to anyone else. But, I have a different perspective because of epilepsy. People with epilepsy are just as beautiful.



RUNNER UP (BELOW-RIGHT)

Artist: Lai Yihao, China Age: 7 years
Title: Simple and Happy

Yihao said: Although I have epilepsy I still feel happy.

RUNNER UP (BELOW-LEFT)

Artist: Malki Sanjana Warnakulasooriya, Sri Lanka Title: No worries!

Malki said: Children with epilepsy have a bright future.



Towards a Global Alliance on Epilepsy Research – Workshop in the European Parliament

Hosted by Brian Hayes MEP, President of the European Advocates for Epilepsy MEP group in the parliament

The purpose of this 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.



Brian Hayes MEP

The European Written Declaration on Epilepsy in 2011, which was 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.

A specific task force was set-up by ILAE/IBE to define potential research topics that would deserve or require a global approach. This work was built on previous efforts from the epilepsy community to delineate priorities in epilepsy research in the US, Europe and the Asia-Oceania region.

In parallel, the global epilepsy scientific community was contacted soliciting further proposals. Suggested priorities and proposals were consolidated and ranked through a web-based survey that was again disseminated to the community.

The workshop in the European Parliament on 7 February was attended by some of the most senior representatives of a number of agencies and associations from Europe and North America. These included Stéphane Hogan, Head of Sector for Neuroscience at DG Research; Enrique Terol, Head of the ERN program at DG Santé; Vicky Whittemore, NIH Program Director of Epilepsy; Anthony Phillips, Scientific Director of the Institute of Neurosciences of the Canadian Institute for Health Research; Emilio Perucca, ILAE President; Sam Wiebe, ILAE President-elect; Athanasios Covanis, IBE President, Eli Mizrahi, President of the American Epilepsy Society; Phil Gattone, President and CEO of Epilepsy Foundation of America; Paul Boon, Chair of the Epilepsy Panel of the European Academy of Neurology; Ann Little, President of the European Federation of Neurological Associations, and a number of MEPs and other stakeholders.



Left to right: Phil Gattone, President and CEO of Epilepsy Foundation of America, Emilio Perucca, ILAE President, Stéphane Hogan, Head of Sector for Neuroscience at DG Research; Athanasios Covanis, IBE President, Vicky Whittemore, NIH Program Director of Epilepsy.

Save the date!



International
Epilepsy Day

FEBRUARY 12TH 2018