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ABOUT INTERNATIONAL EPILEPSY DAY
International Epilepsy Day, a joint initiative created by the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE), is a global event celebrated annually on the 2nd Monday of February, to promote awareness on epilepsy right around the world. With IBE and ILAE representation in more than 120 countries, this is a powerful opportunity to highlight the problems faced by people with epilepsy, their families and carers, in every region of the world.

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.

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PARTICIPATION AROUND THE WORLD
International Epilepsy Day events and participation were seen in 139 countries around the world on February 11th, making International Epilepsy Day 2019 the biggest yet!

Countries shown in pink are new countries seen to be involved this year:

- Aruba
- Albania
- Angola
- Antigua and Barbuda
- Aruba
- Austria
- Australia
- Argentina
- Azerbaijan
- Bahamas
- Bangladesh
- Barbados
- Belarus
- Belize
- Belgium
- Bermuda
- Bosnia and Herzegovina
- Botswana
- Bulgaria
- Brazil
- Canada
- Cambodia
- Cameroon
- Chile
- China
- Colombia
- Congo
- Costa Rica
- Cote d’Ivoire
- Croatia
- Cyprus
- Czech Republic
- Denmark
- Dominican Republic
- Dubai
- Ecuador
- Egypt
- El Salvador
- Estonia
- Ethiopia
- Fiji
- Finland
- France
- Gabon
- Georgia
- Guam
- Ghana
- Greece
- Guatemala
- Guyana
- Guinea
- Hungary
- Honduras
- Hong Kong
- Iceland
- India
- Indonesia
- Iran
- Iraq
- Ireland
- Israel
- Jamaica
- Japan
- Jersey
- Jordan
- Kuwait
- Kyrgyzstan
- Kenya
- Korea (Rep. of)
- Kuwait
- Laos
- Latvia
- Lebanon
- Libya
- Lithuania
- Luxembourg
- Madagascar
- Malawi
- Malaysia
- Maldives
- Malta
- Martinique
- Mauritius
- Mexico
- Moldova (Rep. of)
- Mongolia
- Morocco
- Mozambique
- Myanmar
- Namibia
- Nepal
- New Zealand
- Nigeria
- Norway
- Pakistan
- Panama
- Puerto Rico
- Peru
- Poland
- Portugal
- Qatar
- Romania
- Russian Federation
- Saint Lucia
- Saudi Arabia
- Scotland
- Senegal
- Singapore
- Slovenia
- Somalia
- South Africa
- Spain
- Sri Lanka
- Sudan
- Swaziland
- Switzerland
- Sweden
- Taiwan
- Tanzania
- Thailand
- The Philippines
- Togo
- Tunisia
- Turkey
- Trinidad & Tobago
- UAE
- Uganda
- UK
- Ukraine
- Uruguay
- USA
- Uzbekistan
- Venezuela
- Vietnam
- Wales
- Zambia
- Zimbabwe
Our Social Media activity:

**TWITTER**
@IntEpilepsyDay Account performance, February 2019:
Tweet impressions: 25,119
Profile visits: 2,848
Mentions: 309
New followers: +355
Total followers: 1,902

**FACEBOOK**
International Epilepsy Day Page performance, February 2019:
Page engagements: 6,587
Reach: 87,478
Top post reach: 27,851
New followers: +739
Total followers: 7,573

**INSTAGRAM**
@IntEpilepsyDay Account performance, February 2019:
Total followers: 1,003
New followers: +423

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The World Health Organisation (WHO) were Twitter’s top Health Influencer during the period, with 4.7 million followers. For the third consecutive year, 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/](http://www.who.int/mediacentre/factsheets/fs999/en/) shared over 1,000 times.

As well as featuring International Epilepsy Day on the WHO epilepsy page, the organisation shared three feature stories: ‘Pilot studies help close the epilepsy treatment gap’, ‘The Fight against epilepsy in Ghana’ and ‘Scaling up epilepsy care in Myanmar’.
Traffic to the InternationalEpilepsyDay.org website held steady this year, despite a change in the domain name. The graph below shows the peak of traffic that took place on February 11th, with over 2,700 individual visitors while the month as a whole saw over 7,500 visitors to the website. The average amount of time spent per visit was very high, at 3 minutes 58 seconds and the average number of user actions (e.g. click-throughs) was 2.3.

**The most visited sections of the website:**
1. Home – 6,321
2. Resources - 1,996
3. Map - 1,724
4. Events - 757
5. Competition results - 586

**Top countries visiting the website:**
1. USA
2. UK
3. France *
4. India
5. The Philippines *
* New entrants to the top ten for 2019

**NEW! INTERACTIVE #EPILEPSYDAY MAP**
This year we created added an interactive map to the website, displaying posts shared to social media from around the world!

**CAMPI RETURNS!**
Campi, the friendly International Epilepsy Day mascot that was introduced in 2016, returned this year in a fourth chapter of the animated series. The video features a new character - Stella Starfish. Stella loves to play football but is worried because she has epilepsy. Together, Stella, Campi and friends learn about epilepsy and sport.

**PERSONAL STORIES**
This year we were again able to share a number of fantastic personal stories on the epilepsy.org website. You can read them here.

“Another time, seizures came with such force that I fell and I broke my right arm. The doctors put a plate in my broken arm. That’s when I started a foundation to help others living with epilepsy. I go to churches and schools to create awareness about epilepsy.”
- Fred Kiserem

“I’ve watched the evolution of neurological testing from the beginnings of EEG’s, MRI’s and CT Scans. Medical Science has learned how to measure the brain and its activities with extraordinary detail and accuracy.”
- Susan Fulmer
And the Oscars go to....!

International Epilepsy Day Video Competition Results

Personal Story

First Prize:
- Linda Campbell (Scotland): Zoned Out (1)

Runners up:
- Farah (Fatemeh) Abbasi Siar (Iran): My Dream is a world without war (2)
- Ng, Wai Hung (Hong Kong): A Big Boy Story (3)
- Delmya Asnydar SS (Indonesia): A Sweet And Short Journey of An Epilepsy Warrior (4)
- Jess McCallum (Australia): Jess McCallum She Beast (6)

Runners up:

Personal Story
- Farah (Fatemeh) Abbasi Siar (Iran): My Dream is a world without war (2)
- Ng, Wai Hung (Hong Kong): A Big Boy Story (3)
- Delmya Asnydar SS (Indonesia): A Sweet And Short Journey of An Epilepsy Warrior (4)
- Jess McCallum (Australia): Jess McCallum She Beast (6)

Thank you to all those who submitted short videos to our competition for International Epilepsy Day. There were two categories, Personal Story and Educational. First place in each category receives a prize of US$500, with five runners up in each category receiving US$100.

You can watch all the videos on these links:
- You can view all ‘Personal Story’ entries here: https://www.youtube.com/playlist?list=PLDtaVe7olIXygWvY-7fbj9vlkVxdS5yuRog.
- You can view all ‘Educational Video’ entries here: https://www.youtube.com/playlist?list=PLDtaVe7olIXzgS_uzzsnN2xe-7Flp-4diq.

Educational Video

1st Prize:
- Epilepsy Foundation (USA): Taking Charge of the Storm Jr. (7)

Runners up:
- Cairo University Epilepsy Unit (Egypt): Pregnancy Awareness (8)
- Norsk Epilepsiforbund (Norway): How to handle an epileptic seizure (9)
- Epilepsy Action (UK): Ali’s story: taking my medicine (10)
- Youth on the Move (Kenya): Njambi’s Tonic Seizure (11)
- China Bureau of Epilepsy (China): 2018 Street Interview About Epilepsy in Shanghai (12)

You can view all ‘Educational Video’ entries here: https://www.youtube.com/playlist?list=PLDtaVe7olIXzgS_uzzsnN2xe-7Flp-4diq.
AWARENESS THROUGH THE MEDIA
A small sample of the media coverage received on International Epilepsy Day 2019:

Above: An article on epilepsy and stigma in iAfrica

Right: Torie Robinson, epilepsy advocate (Scotland), speaks to Sky News UK on International Epilepsy Day

INTERNATIONAL EPILEPSY DAY EVENTS

Once again, events were held around the world this year to mark International Epilepsy Day 2019, 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.internationalepilepsyday.org/events.

Above: An article in Total Croatia News

Above: The Epilepsy Foundation (USA) staff celebrate #EpilepsyDay.

International Epilepsy Day was celebrated at Epilepsy Foundation India Mumbai where around 150 patients and carers were present.

Epilepsy Ireland, in association with FutureNeuro, held a free evening seminar for people with epilepsy, their families & carers, at the Royal College of Surgeons in Dublin.

Epilepsy Liga (Belgium), held an event at Thagaste in Ghent, entitled “Epilepsy, what does it do to your work, life and well-being”.

Asociación Nacional de Personas con Epilepsia (ANPE) held a talk at the School of Nursing in Las Palmas de Gran Canaria.

Epilepsy SA Free State and North West Branch held an Epilepsy Candle Lighting Ceremony on International Epilepsy Day!

Epilepsy Foundation (USA) staff celebrate #EpilepsyDay.
Two years ago, in February 2017, Epilepsy Alliance Europe organised a very significant meeting in the European Parliament in Brussels to highlight the need for a global effort if appropriate advances were to be made in addressing the unmet needs of epilepsy, both in Europe and around the world.

The event was organised by Epilepsy Alliance Europe joint task force of IBE and ILAE in Europe and hosted by the European Advocates for Epilepsy MEP group in the parliament. The meeting heard that, although very little progress had been made in improving medical outcomes of people with epilepsy during the last decades, a large amount of data derived from extensive pre-clinical research has become available which provided a strong rationale for the conduction of potentially ground-breaking academically-driven clinical studies tackling several priority issues that were acknowledged by the epilepsy community:

- prevention of epilepsy;
- prevention of sudden unexpected death in epilepsy (SUDEP);
- optimization of epilepsy surgery;
- worldwide development of mobile health programs to disseminate essential knowledge about epilepsy;
- assembling of a very large well-characterized cohort of persons with epilepsy that could be participate in all the above projects and in the development of personalized therapies for seizures, syndromes and related comorbidities.

All of these objectives would require recruitment and financial capacities that could only be achieved at the global level, and justify the building of a global alliance program for epilepsy research.

The closed invitation-only event was hosted by Brian Hayes, President of the 67-member-strong group of Members of the European Parliament (MEPs) who form the European Advocates for Epilepsy group in the parliament, a number of whom attended the event. Also present were some of the most senior representatives of a number of agencies and associations from Europe and North America. These included the Head of Sector for Neurosciences at DG Research, the Head of the ERN program at DG Sané, the NIH Program Director of Epilepsy, the Scientific Director of the Institute of Neurosciences of the Canadian Institute for Health Research, the Presidents of IBE and ILAE, the President of the American Epilepsy Society, the President and CEO of Epilepsy Foundation of America, the Chair of the Epilepsy Panel of the European Academy of Neurology, the President of the European Federation of Neurological Associations, and a number of other stakeholders, including the pharma industry.

This very successful meeting led to a follow-up event in January 2018, when a Breakfast Briefing was organised and, again, hosted by Brian Hayes MEP. The 2018 event was attended by several MEPs, including Mrs Lieve Wierinck (Belgium), Seán Kelly (Ireland), Aloj Peterle (Slovenia), Roberta Metsola (Malta), José Indúcia Faria (Portugal), and Franc Bogovič (Slovenia). Also present were Stéphane Hogan, Head of Sector for Neurosciences, DG Research & Innovation, European Commission; Anna Graca, DG Research & Innovation with responsibility for epilepsy; and Fredrick Destrebecq, Executive Director, European Brain Council. There to tell the epilepsy story on behalf of Epilepsy Alliance Europe were Helen Cross, Martin Brodie, Lieven Lagae, Philippe Ryvlin, Eugen Trinka, Kristi Vonck, Janet Mifsud, Caroline Morton and Francesca Sofia.

Two other significant events took place in 2018. The first of these was the epiXchange workshop, with seven large EU-funded projects joining forces to organise the one-day event on 31 May, in Brussels. The event was designed to gather a critical mass of epilepsy researchers in order to showcase the latest progress in research aimed to improve the way epilepsy is diagnosed and treated. The projects had been funded mainly through the 7th Framework Programme (FP7). Participants heard how, despite intensive and ongoing research, epilepsy research still faces several unmet needs, with major gaps in understanding the disease with large economic and societal costs. The event provided the opportunity to synergise the results of the seven diverse projects and to identify the several bottle necks which still remain.

Delegates included basic and clinical epilepsy researchers, big and small pharma, and patient organisations. Other participants included Dr Karim Berkouk, Dr Stefan Ho- gan and Ms Anna Graca from the European Commission’s Directorate-General Research & Innovation and representatives of the European Brain Council.

The meeting showed how a bottom-up approach is needed to coordinate research and policies with more collaborative research, including public partnerships, public private partnerships, and global co-operation.

On the following day, the EU Research Commission held a workshop titled ‘Shaping the Future of Epilepsy Research’ with a TOWARDS A GLOBAL ALLIANCE ON EPILEPSY RESEARCH

International Epilepsy Day event in the European Parliament reports on the unmet needs in the field of epilepsy and the status of epilepsy research priorities at a global level.

The event was organised by Epilepsy Alliance Europe joint task force of IBE and ILAE in Europe and hosted by the European Advocates for Epilepsy MEP group in the parliament.
Members of the European Advocates for Epilepsy Group

President: Brian Hayes (Ireland)

Vice President: Nathalie Grinbeck (France)

Members: Heinz Becker (Austria), Bendt Bendsten (Denmark), Franc Bogovic (Slovenia), Michal Boni (Poland), David Borelli (Italy), Paul Brannen (UK), Christian-Silviu Buoi (Romania), Mart Carthy (Ireland), David Casa (Malta), Nessa Childrey (Ireland), Lefteris Christoforou (Cyprus), Kostas Chrysoygos (Greece), Deirdre Chune (Ireland), Miriam Dalti (Malta), Tanja Fajon (Slovenia), José Inácio Faria (Portugal), Eleonora Forezzi (Italy), Lampsos Fouretoulis (Greece), Jens Gieseke (Germany), Theresa Griffin (UK), Jytte Guteland (Sweden), André Grycky (Hungary), Marian Harkis (Ireland), Anna Heil (Sweden), Liisa Jakonsaari (Finland), Anu Juliusenmäki (Finland), Barbara Kappel (Austria), Karin Kadenbach (Austria), Seán Kelly (Ireland), Katerina Konečná (Czech Republic), Mapierta Kumpula-Natri (Finland), Merja Kytöläinen (Finland), Giovanni La Via (Italy), Jean Lambert (UK), Marian-Jean Marinescu (Romania), Costas Mascrides (Cyprus), Maeired McGuinness (Ireland), Roberta Mesola (Malta), Tilly Metz (Luxembourg), Ulrike Müller (Germany), James Nicholson (UK), Demetris Papadakis (Cyprus), Dimitrios Papadopoulos (Greece), Emilien Pavel (Romania), Aloja Petere (Slovenia), Simona Perikkáinen (Finland), Pavel Péč (Czech Republic), Dominique Riquet (France), Paul Rübig (Austria), Sofia Sakorafa (Greece), Christel Schaldemose (France), Annie Schreiber-Perik (Netherlands), Olga Schmalzl (Austria), Igor Soltes (Slovenia), Maria Spyra (Greece), Neoklis Sylikiotis (Cyprus), Elefterios Synadinos (Greece), Claudia-Ciprian Tănase (Romania), Patrizia Toia (Italy), Nils Tortvold (Finland), Ivo Vajgl (Slovenia), Ivo Vajgl (Slovenia), Ivo Vajgl (Slovenia), Ivo Vajgl (Slovenia).

Brian Hayes MEP

Brian Hayes served as a member of Dáil Éireann (Irish Parliament) from 1997-2002 and 2007-2014, until his election to the European Parliament in May 2014. He was appointed to three European Parliament Committees - Economic & Monetary Affairs, Development, and Budgetary Control. He is a member of the Delegations to Iraq and South Africa.

Martin Brodie

Prof Martin Brodie is President of the International Bureau for Epilepsy (IBE) and Co-chair Epilepsy Alliance Europe. His involvement with IBE goes back more than 30 years, having served as a member of its board from 2005 to 2009. His research interests include antiepileptic drug neuropharmacology, randomised clinical trials, prognostic outcome studies, management of epilepsy and factors affecting antiepileptic response drug
to rare genetic diseases. Her career path changed when her youngest daughter was diagnosed with a rare form of epilepsy in 2011. In July 2014, she joined the Italian Epilep- sy Federation with the aim of fostering epilepsy research. Recently, she founded Scienze e Tolleranza, a non-profit initiative that provides services and tools for effective investments in the biomedical sector to non-profit organizations.

Fredéric Destrebecq

Fredéric Destrebecq is Executive Director of the European Brain Council. In this capacity, he is responsible for providing strategic direction and leadership while managing the day-to-day operations of EBC and its on-going relationships with its member associations and other stakeholders, as well as representing the organisation at various European and national forums.

Prior to this position, Fred served the European Union of Medical Specialists (UEMS) as Chief Executive Officer, and previously as Director for European Affairs.

Brian Hayes MEP

Brian Hayes MEP

Philippe Ryvlin

Dr Ryvlin is Professor of Neurology and Chair of the Department of Clinical Neurosciences at University Hospital of Lausanne (CHUV), Switzerland, and Director of the Epilepsy Institute (IDE) in Lyon, France.

He is President of the European Epilepsy Monitoring Association (EEMA), co-Chair of the Epilepsy Alliance Europe Task Force, founder of the European Network for Epilepsy Research (ENER), and coordinator of the EU funded pilot ERN - (E-PILEPSY).

Francesca Sofia

Dr Francesca Sofia is a molecular biologist with a PhD in neuroscience. She special-ised in healthcare economics and policy as a research program manager for a major Italian health foundation, dedicated to rare genetic diseases. Her career path changed when her youngest daughter was diagnosed with a rare form of epilepsy in 2011. In July 2014, she joined the Italian Epilepsy Federation with the aim of fostering epilepsy research. Recently, she founded Scienze e Tolleranza, a non-profit initiative that provides services and tools for effective investments in the biomedical sector to non-profit organizations.
International Epilepsy Day

SAVE THE DATE!

FEBRUARY 10TH 2020