

REPORT 2019



International League Against Epilepsy



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Share Your Picture!



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 tomaximise 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.

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	Costa Rica	Indonesia
Albania	Cote d'ivoire	Italy
Angola	Croatia	• Iran
Antigua and Barbuda	Cyprus	• Iraq
Aruba	Czech Republic	Ireland
Austria	Denmark	• Israel
Australia	Dominican Republic	• Jamaica
Argentina	• Dubai	• Japan
Azerbaijan	Ecuador	• Jersey
Bahamas	• Egypt	• Jordan
Bangladesh	El Salvador	Kazakhstan
Barbados	• Estonia	• Kenya
Belarus	Ethiopia	• Korea (Rep. of)
Belize	• Fiji	Kuwait
Belgium	Finland	• Lao
Bermuda	France	• Latvia
• Bhutan	• Gabon	Lebanon
Bosnia and Herzegovina	• Georgia	• Libya
Botswana	• Guam	• Lithuania
Bulgaria	Guatemala	 Malaysia
• Brazil	• Guyana	Maldives
Canada	• Ghana	• Malta
Cambodia	Greece	Martinique
Cameroon	Hungary	 Mauritius
Chile	Honduras	Mexico
China	 Hong Kong 	• Moldova (Rep. of)
Colombia	• Iceland	 Mongolia
Congo	• India	 Morocco



•	Mozambique
٠	Myanmar
•	Namibia
•	New Zealand
•	Nepal
•	Nicaragua
•	Niger
•	Nigeria
•	Norway
•	Pakistan
•	Panama
•	Puerto Rico
•	Peru
•	Poland
٠	Portugal
٠	Qatar
•	Romania
÷	Russia
•	Rwanda
•	Saint Lucia
•	Saudi Arabia
•	Scotland
٠	Serbia
•	Sierra Leone
٠	Singapore
٠	Slovakia
•	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:** 25.1K Profile visits: 2.848 Mentions: 309 New followers: +355 **Total followers:** 1,902



Top Tweet earned 4,476 impressions

Monday, February 11 is International Epilepsy Day 2019. Let's raise awareness of **#epilepsy** across the world! Find out how you can get involved and download resources at buff.ly/2FQc2Zj. #EpilepsyDay pic.twitter.com/Kiz14BsCxN



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Boost Post

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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





Monday, February 11 is International Epilepsy Day 2019. Let's get ready to raise awareness of #epilepsy across the world! This year your pictures will be shared on our interactive map - buff.ly/2MXcPJz #EpilepsyDay #epilepsy



INTERNATIONALEPILEPSYDAY.ORG

International Epilepsy Day Map | International Epilepsy Day

Share your picture with the hashtag #EpilepsyDay this Monday, February...

27,851 2,718 People reached Engagements 183 16 comments 429 shares

INSTAGRAM

@IntEpilepsyDay Account performance, February 2019:

Total followers: 1,003

New followers: +423



Top influencer...

THE WORLD HEALTH ORGANISATION

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/ 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'.





The InternationalEpilepsyDay.org website

Traffic to the InternationalEpilepsyDay.org website held steady this year, despit 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:

- Home 6,321 1.
- Resources 1,996 2.
- 3. Map - 1,724
- 4. Events - 757
- 5. Competition results - 586

Top countries visiting the website:

- USA 1.
- 2. UK
- France * 3.
- India 4.
- 5. The Philippines *

* New entrants to the top ten for 2019

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.



NEW! INTERACTIVE #EPILEPSYDAY MAP

This year we created added an interactive map to the website, displaying posts shared to socal media from around the world!



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RESOURCES



PERSONAL STORIES

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

This year we were again able to share a number of fantastic personal stories on the epilepsy.org

"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

10

2 It's been some months that she has seizures





10 INITEDNIATIONIAL EDILEDOV NIEW/C

8



PARKEVER

11



Personal Story

First Prize:

Linda Cambell (Scotland):
 Zoned Out (1)

Runners up:

12

- Farah (Fatemeh) Abbasi Siar (Iran):
 My Dream is a world without war (2)
- Ng, Wai Hung (Hong Kong):
 A Big Boy Story (3)
- Delyma Asnydar SS (Indonesia):
 A Sweet And Short Journey of An Epilepsy Warrior (4)
- Yvette Barrera-Molina (USA): Some Super Heros Fight Crime, Mine Fights Epilepsy (5)
- 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-7fb9nRxkdcsS9uRbg.

> You can view all **'Educational Video'** entries here: https://www.youtube.com/playlist?list=PLDtaVe7oIIXzgS_uzzsnN2xe-7Flp-4diq.



• • 0.15/200



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)



AWARENESS THROUGH THE MEDIA

A small sample of the media coverage received on International Epilepsy Day 2019:





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 <u>www.internationalepilepsyday.org/events</u>.



The **Epilepsy Foundation** (USA) staff celebrate #EpilepsyDay.



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 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".



International Epilepsy Day was celebrated at **Epilepsy Foundation India Mumbai** where around 150 patients and care-givers were present.



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.



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 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 Neuroscience at DG Research, the Head of the ERN program at DG Santé, 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.

"I wish my daughter simply to be happy"

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 Wierlinck (Belgium), Seán Kelly (Ireland), Alojz Peterle (Slovenia), Roberta Metsola (Malta), José Inácio 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 Destrebecg, 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, Kristl Vonck, Janet Mifsud, Caroline Morton and Francesca Sofia.

Two other significant events took place in



Delegation to the parliament, from left: Jakob Christensen representing ESBACE; Janet Mifsud, Member EAE; Ann Little, IBE Executive Director; Philippe Ryvlin, Co-chair EAE; Martin Brodie, IBE President and Co-chair EAE; Francesca So ia, Member EAE; Astrid Nehlig, Editor Epilepsia; Fred Destrebecq, EBC; Eugen Trinka, Chair ILAE-Europe and Member EAE; Michele Simonato, representing epiXchange.

2018. The first of these was the epiXchange workshop, with seven large EU-funded projects joining forces to organise the one-day event on 23 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 Hogan 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

Members of the **European Advocates** for Epilepsy Group

President: Brian Hayes (Ireland)

Vice President: Nathalie Griesbeck (France)

Members Heinz Becker (Austria), Bendt Bendtsen (Denmark), Franc Bogovič (Slovenia), Michal Boní (Poland), David Borelli (Italy), Paul Brannen (UK), Christian-Silviu Busoi (Romania), Matt Carthy (Ireland), David Casa (Malta), Nessa Childers (Ireland), Lefteris Christoforou (Cyprus), Kostas Chrysogonos (Greece), Deirdre Clune (Ireland), Miriam Dalli (Malta), Tanja Fajon (Slovenia), José Inácio Faria (Portugal), Eleonora Forenza (Italy), Lampros Fountoulis (Greece), Jens Gieseke (Germany), Theresa Griffin (UK), Jytte Guteland (Sweden), András Gyürk (Hungary), Marian Harkin (Ireland), Anna Hedh (Sweden), Liisa Jaakonsaari (Finland), Anneli Jäätteenmäki (Finland), Barbara Kappel (Austria), Karin Kadenbach (Austria), Seán Kelly (Ireland), Katerina Konečná, (Czech Republic) Miapetra Kumpula-Natri (Finland), Merja Kyllönen (Finland), Giovanni La Via (Italy), Jean Lambert (UK), Marian-Jean Marinescu (Romania), Costas Mavrides (Cyprus), Mairead McGuinness (Ireland), Roberta Metsola (Malta), Tilly Metz (Luxembourg), Ulrike Müller (Germany), James Nicholson (UK), Demetris Papadakis (Cyprus), Dimitrios Papadimoulis (Greece), Emilian Pavel (Romania), Alojz Peterle (Slovenia), Sirpa Pietikáinen (Finland), Pavel Poc (Czech Republic, Dominique Riquet (France), Paul Rübig (Austria), Sofia Sakorafa (Greece), Christel Schaldemose (Denmark), Annie Schreijer-Pierik (Netherlands), Olga Sehnalová (Czech Republic), Igor Šoltes (Slovenia), Maria Spyraki (Greece), Neoklis Sylikiotis (Cyprus), Eleftherios Synadinos (Greece), Claudiu-Ciprian Tânâsescu (Romania), Patrizia Toia (Itlay), Nils Torvalds (Finland), Ivo Vajgl (Slovenia), Julie Ward (UK), Theodoros Zagorakis (Greece), Tomáš Zdechovský, (Czech Republic), Jana Žitňanská (Slovakia).

global panel of speakers from Europe, Asia, Africa, and North and South America, at which it was reported that the upcoming EU Horizon Europe framework for research would be calling for bold inspirational approaches with wide societal relevance, including open science, global challenges and open innovation pillars. Also looking to develop a global perspective, a call under the H2020 project titled 'Coordinating European brain research and developing global initiatives' was underway with the European Brain Council's European Brain Research Area (EBRA) proposal being selected to coordinate the project.

So, it was with this, not-insignificant, background of activities, raising the call for the global perspectives that are now required in research, that a lunch meeting took place in the parliament in Strasbourg on Tuesday 12 February 2019, the day after International Epilepsy Day.

Invitations to the meeting were extended to the 67 MEPs who form the membership of the European Advocates for Epilepsy group and the event was hosted, once again, by Brian Hayes MEP. At the lunch, 12 MEPs, from Czech Republic, France, Germany, Ireland, Finland, Luxembourg, Romania and Slovenia, voiced their support for the 6 million people living with epilepsy in Europe. In turn, the MEPs heard from speakers about the continued unmet needs of people living with epilepsy and the need for improved services, novel new treatments and actions designed to educate the public about epilepsy and, thereby, reduce discrimination.

In welcoming all those present, Brian Hayes highlighted the success of the MEP group since its launch in 2011. He advised that he would be retiring from politics at the end of the current EU parliamentary term but would be happy to assist in identifying an MEP to assume the chair once the elections were completed in May. Of note, the average turnover of MEPs at the time of elections is 50%. This means that about half of the membership of the MEP group would be lost, requiring fresh efforts to rebuild it post-election.

Speaking in Strasbourg, Prof Philippe Ryvlin, co-chair of Epilepsy Alliance Europe, thanked Brian Hayes and the MEP group for the support they had provided over the previous seven years. Notable achievements included the Written Declaration on Epilepsy 22/2011, that had been signed by

459 MEPs and had resulted in major funding for epilepsy research in the Framework Programme 7 (FP7). Many of the projects funded by FP7 now formed the epiXchange network. Other epilepsy projects that had received EU funding since 2011 included E-PILEPSY, the pilot European Reference Network (ERN) project; EpiCARE, an ERN focussed on rare and complex epilepsies; and ESBACE, a project funded by DG Sante that surveyed epilepsy prevalence and cost burden in a number of countries. Prof Ryvlin highlighted the need for a global focus on epilepsy research if progress is to be made in identifying new and novel treatments for the 30 - 35% of people with epilepsy whose seizures currently are not controlled by existing treatments. There were new opportunities for such global research initiatives through the European Brain Research Area (EBRA).

An issue for concern was the lack of support in Europe for the WHA Resolution on Epilepsy, approved by the World Health Assembly in 2015, with report back in 2018. Few countries had addressed the recommendations of the resolution and efforts were now underway for a call to action. While support had been received from some countries including Russia, China and Brazil, there had been no support from EU Member States, despite their support for the EU Written Declaration in 2011. The argument was that epilepsy was too narrow a topic. However, the counter arguments were that epilepsy encompassed several hundred diseases; was sufficiently wide to have been selected for an EU-funded European Reference Network (ERN); 50 million people worldwide had been diagnosed with epilepsy; and it ranked second in the league of years of life lost.

In her presentation, Francesca Sofia, an Italian mother of a young child with epilepsy, said that her biggest wish was for her daughter simply to be happy, adding that this was a wish shared by all parents for their children. Francesca's daughter Bea has a complex form of epilepsy which is resistant to medication. She continues to have seizures and requires a lot of support.

Despite the hardships that life has thrown at her, Bea remains a happy loving 9-year old, who goes to school and who yearns to have friends. But the sad situation is that she has never had a friend and has never been invited to a play-date or party by classmates. Any invitation sent by Fran-

cesca to her daughters classmates for play dates or parties have always been declined by their parents. A strong indication that there is still huge misconception and stigma attached to a diagnosis of epilepsy. And if the parents are discriminatory towards Bea, this is likely to run off onto their young children.

Sofia's story of her daughter's struggles shows clearly the continued need for basic education about epilepsy in the community and undermines the reality that many people with epilepsy face - that epilepsy is more than seizures.

Fred Destrebecq, Executive Director of EBC outlined the purpose and expectations of EBRA, a consortium of the Network of European funding for Neuroscience research (NEURON), the Joint Programme Neurodegenerative Disease Research (JPND) and the Human Brain Project (HBP). The EU was seeking projects that would address the problems of duplication and fragmentation of research efforts and that would encourage more collaboration and better coordination of brain research at EU and global levels. This would lead to improved access to research systems and data sources by all stakeholders involved in the neuroscience research area, resulting in better use of the investments that are made in brain research. The critical mass and economies of scale thus achieved would facilitate the development of new global initiatives and quicker translation of successful outcomes to clinical applications.

Huge investment has been provided by the EU for brain research to a number of initiatives. Although the initiatives generated a considerable amount of knowledge and innovative approaches, more coordinated efforts are needed to avoid fragmentation, to identify gaps and highlight priorities, in order to support and foster translation into new health interventions.

The EBRA Consortium will foster alignment and co-ordination of research strategies across European and global brain initiatives; facilitate the emergence of research projects in specific areas in active clusters selected for involvement in EBRA, and provide them with support for effective collaboration, including enabling sharing of data and access to research infrastructures; and increase the visibility of the brain research portfolio as a whole and promote the uptake of EBRA results to key stake-میں م ا م م

THE SPEAKERS



Brian Hayes MEP Brian Hayes served as a member of Dail Eireann (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 drug response.



Francesca Sofia Dr Francesca Sofia is a molecular biologist with a PhD in neuroscience. She specialized 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 Science Compass, an enterprise that provides services and tools for effective investments in the biomedical sector to non-profit organizations.



Frederic Destrebecq

Frédéric 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 ongoing relationships with its member associations and other stakeholders, as well as representing the organisation in 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.



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 (IDEE) 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).



SAVE THE DATE! FEBRUARY 10TH 2020