



























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 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

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 in **120 countries** around the world on February 12th:

Iraq

•	Aruba	•	Czech Republic
•	Albania	•	Denmark
•	Aruba		Dominican Republic
•	Austria		Dubai
•	Australia		Ecuador
•	Argentina	•	Egypt
•	Bahamas	•	El Salvador
	Bangladesh	•	Estonia
	Belarus	٠	Fiji
•	Belgium	•	Finland
•	Bhutan		France
•	Bosnia and Herzegovina		Gabon
•	Bulgaria		Georgia
•	Brazil		Guam
•	Canada		Guyana
•	Cambodia		Ghana
•	Cameroon	•	Greece
			A No. of the Control

Hungary Honduras

Iceland

Indonesia Italy

India

Iran

Hong Kong

•	Ireland	•	Nicaragua
•	Israel	•	Niger
•	Jamaica		Nigeria
•	Japan	•	Norway
•	Jersey		Pakistan
•	Jordan		Puerto Ric
	Kenya	•	Peru
•	Korea (Rep. of)		Poland
٠,	Lao	•	Portugal
•	Latvia		Qatar
	Lebanon		Romania
•	Libya		Russia
٠,	Lithuania		Rwanda
•	Malaysia		Saudi Ara
•	Maldives		Scotland
•	Malta	•	Serbia
	Mauritius	•	Sierra Leo
•	Mexico	•	Singapore
•	Mongolia	:	Slovakia
•	Morocco	•	Slovenia
•	Mozambique	•	South Afri
•	Myanmar	•	Spain
•	Namibia	•	Sri Lanka

New Zealand

Sudan

•	Nepal	•	Swaziland
•	Nicaragua	•	Switzerland
•	Niger	•	Sweden
•	Nigeria	•	Taiwan
•	Norway	•	Tanzania
	Pakistan	•	Thailand
	Puerto Rico	•	The Philippines
	Peru	•	Tunisia
•	Poland		Turkey
•	Portugal	•	Trinidad & Tobag
•	Qatar		UAE
	Romania		Uganda
	Russia		UK
	Rwanda		Ukraine
	Saudi Arabia		Uruguay
•	Scotland		USA
•	Serbia		Uzbekistan
	Sierra Leone		Venezuela
•	Singapore	•	Vietnam
•	Slovakia	5.	Wales
•	Slovenia		Zambia
•	South Africa	1	Zimbabwe
•	Spain		

Chile

China

Congo

Croatia

Cyprus

Colombia

Costa Rica Cote d'ivoire













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A look at some of the awareness-raising media coverage and events from around the world on International Epilepsy Day 2018.

International Epilepsy Day leads to a surge in Social Media activity!



Posts shared on Twitter with the #EpilepsyDay hashtag were: 87.6% Retweets, 11.4% Original Posts and the rest replies. The demographic of users was 51.3% female and 48.7% male.

The 'heatmap' below shows the prevalence of the hashtag use across the world:



The World Health Organisation

The World Health Organisation (WHO) were Twitter's top Health Influencer during the period, with 4.32 million followers. For the second 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/

WHO's factsheet Tweet was shared over 1,000 times and their Facebook post over 1,300 times. They also <u>shared a webpage</u> dedicated to International Epilepsy Day focusing on their commitment to reducing the epilepsy treatment gap.

Top #EpilepsyDay Influencers

Top 10 by Mentions



@who 1,523



@intepilepsyday 1,264



@epilepsyireland 782



@invisibleman_17 483



@epilepsyfdn 360



@rickoshea 273



@alceepilepsia 118



:cm @irelandamtv3 105

@thejournal_ie 102



@tomasmarcos 101

Top 10 by Tweets



@intepilepsyday 489



@conefreypharmac 96



@epilepsyireland 70



@epstrong 50



@ibesocialmedia 48



@alceepilepsia 43





@rebelspeducator 36



@ffrepilepsie 32



@robcullen79 32

Top 10 by Impressions



@who 29.9M



@rickoshea 1.4M



@conefreypharmac 1.1M



@turkkizilayi 934.7K



@intepilepsyday 637.2K



@scienceirel 537.1K



@tedx 474.0K



@euscienceinnov 406.4K



@epilepsyfdn 363.7K



@yourhumorous 327.5K



A tweet from The World Health Organisation (WHO), shared over 1000 times

Our Social Media activity:

Twitter @IntEpilepsyDay Account performance, February 2018:

Tweet impressions: 59.4K

Profile visits: 4,833

Mentions: 288

New followers: +355

1,476 Followers

(59% increase on 2017)

Top media Tweet earned 4,365 impressions

International Epilepsy Day happens on Monday, February 12!

Share your photo with the **#EpilepsyDay** hashtag to raise **#epilepsyawareness** around the world!

@EpilepsyConnexn @EPICLongIsland @EpilepsieligaBE @EpilepsyFdn @epilepsiabrasil @EpilepsySWO pic.twitter.com/Agz9ExyzZu



Check out the latest on our @IntEpilepsyDay Instagram Selfie Wall! Tag your pictures with #EpilepsyDay epilepsy.org/international-... @epilepsyIreland @EpilepsyConnexn @EpilepsyFdn @Epilepsialiitto #Epilepsy pic.twitter.com/W0ATJ4m0kr

Facebook International Epilepsy Day Page performance, February 2018:

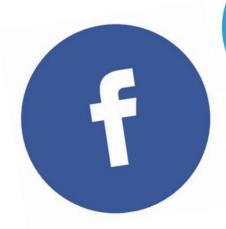
Page views: 2,982

Post Engagements: 6,320

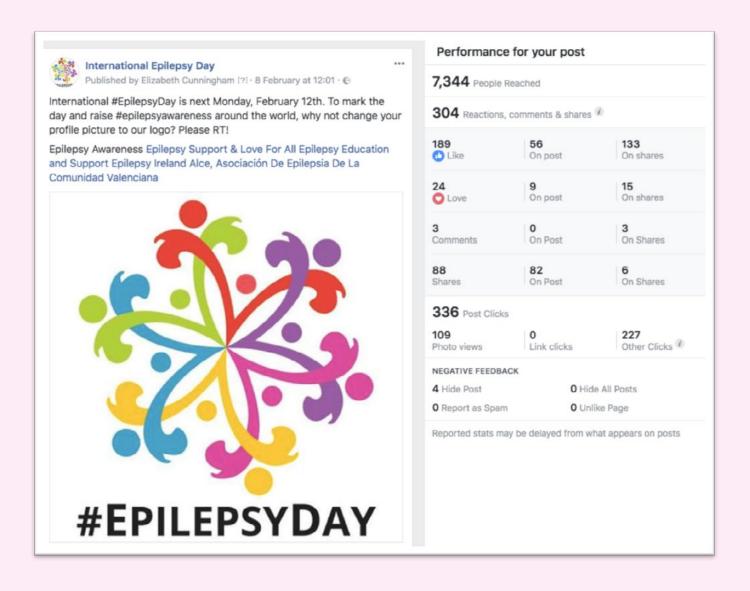
Reach: 22,316

New followers: +436

Total followers: 6,834







Instagram @IntEpilepsyDay Account performance, February 2018:

Total followers: 580

New followers: 462

3,938 **#EpilepsyDay posts**





































































The EpilepsyDay.org Website

A successful Epilepsy Day has meant a dramatic increase in the numbers of visitors to the Epilepsy. org website.

The graph below shows the peak of traffic that took place on February 12th, with over 2,700 individual visitors while the month as a whole saw over 8,600 visitors to the website.

The average amount of time spent per visit was very high, at 3 minutes 46 seconds and the average number of user actions (e.g. click-throughs) was 2.4.

The most visited sections of the website were:

- 1. Home 7,645
- 2. Competition results- 1,621
- 3. Resources 1,424
- 4. Events 752
- 5. Photography competition 695
- 6. Epilepsy Stories 617
- 7. Online Awareness 577
- 8. About 528
- 9. Morris Roos story 510
- 10. Selfie Wall 339

TOP TRAFFIC SOURCES:

Search: 3,134

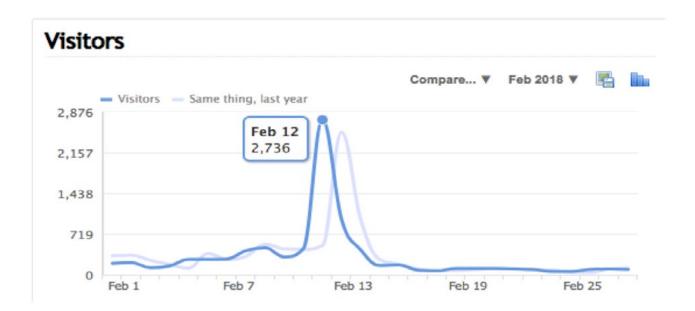
Direct: 2,463

Social media: 1,720

The International Epilepsy
Day social media profile
logo was downloaded
485 times in February

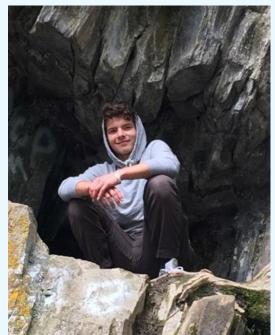
Top countries visiting the website were:

- 1. USA
- 2. UK
- 3. India
- 4. The Netherlands
- 5. Ireland
- 6. Italy
- 7. Canada
- 8. Germany
- 9. South Africa
- 10. Belgium



Personal Stories

This year we were again able to share a number of fantastic personal stories on the epilepsy.org website. You can <u>read them here</u>.



"Despite a lifetime of severe epilepsy – the many times I almost died; the illnesses that come with it in older age- I am so thankful to see the bright side of life everyday. To have my intellect, my colourful and bright life; to have humour and be a happy person, who always sees the sun coming up."

- 'Julie'

"A gentle heart, a gentle eye and a resilient nature next to none. That is Ryan. We all know that despite the impact that epilepsy brings, life is beautiful."

- Ryan's Mom



Campi Returns!

Campi, the friendly International Epilepsy Day mascot that was introduced in 2016, has been further developed with a third animated video. In the new video Suzie Squid shows Campi and friends what and what not to do if someone experiences a seizure. Watch it here.



The 'Life is Beautiful' Photo Competition

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

To celebrate International Epilepsy Day 2018, we ran an international photography competition for all ages with the theme 'Life is Beautiful'. The competition was a huge success, with over 2,500 photographs entered by over 600 individuals. This meant a mammoth task for our judging panel!

The IBE and ILAE wish to extend our gratitude to the judges: Mrs Carol d'Souza (India), Mrs Heather Davies (Scotland), Mrs Carina Jonkers (Netherlands), Dr Jorge Förster (Chile) and Mr Baiqiu Zhang



Over 12 Years Category

FIRST PRIZE (LEFT)

Leyla Emektar, Turkey Title: 'Oyuncu'

RUNNERS UP (OVER 12)

A. Sandipani Chattopadhyay, India

Title: 'Beautiful Mind'

B: Niraj Gera, India

Title: 'Bond of Memories'

C: Mithail Afrige Chowdhury,

Bangladesh

Title: 'U Will Like It'

D: Peng Yuan, China

Title: 'Harvest'

E: Ata Adnan, Bangladesh Title: 'Monsoon Splash'









Under 12 Years Category

FIRST PRIZE (BELOW)

Morris van der Smaal, 3 years, Netherlands

Title: 'Love makes life beautiful'





"Morris took the photo while playing with my phone. For me the picture represents the theme 'Life is beautiful' because there's so much love in it.

My daughter Roos (Rose in Dutch) was diagnosed with LGS one month before she turned 2. At that time I was 3 months pregnant with Morris.

Roos now is 6 years old and we all have found our way in a life with epilepsy. Roos is, despite of all her seizures, a very happy girl and her own small world is beautiful. She doesn't judge people, isn't hateful or intolerant; she's pure and enjoys her own beautiful world. We have the equipment to make life easier for her (and us); we have a good team of doctors and caregivers and we try to make the best of life, despite of all the unpredictable and stupid seizures. Roos's little brother, Morris, caught up on her (mentally) when he became one. So, though he is 2 years younger, he is her bigger little brother (or older younger brother).

Roos has lots of seizures every day and she often gets in a non-convulsive status epilepticus. In the picture she's in it.

For Morris it does not matter who or what Roos is and what she can or cannot do... Roos is just Roos... She is his big sister, he loves her and life is beautiful with her. And he is so right. Life is beautiful with her!"

- Iris van der Meer, mother of Morris van de Smaal

RUNNERS UP (UNDER 12)

A: Fatima Yusuf, 10 years, India

B: Abril Culebras Canas, 12 years, Spain

C: Tiago Terre Neves, 10 years, Portugal

D: Cate Gusentine, 12 years, USA

E: Amir Mohammad Dehghan, 10 years, Iran

Title: 'Little Miracle'

Title: 'Live the Moment'

Title: 'Beautiful day'

Title: 'Sunset Cows'

Title: 'Life is beautiful'











Awareness

A small sample of the media coverage received on International Epilepsy Day 2018:



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



Right: 'Ireland AM' discuss epilepsy with advocate Rob Cullen and neurologist Dr. Colin Doherty

International Epilepsy Day Events

Once again, events were held around the world this year to mark International Epilepsy Day 2018, 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.



The lovely epilepsy team in the **Swedish EpiCARE hospital** in Sahlgrenska University Hospital, Gothenburg, Sweden organised a epilepsy information day.



On International Epilepsy Day, **Epsilon Lebanon** launched a schools awareness campaign in collaboration with the Lebanese Ministry of Education



The staff and students at **Epilepsy Southwestern Ontario** supporting International Epilepsy Day!



Epilepsy South Africa Eastern Cape Branch kicked off International Epilepsy Day early by handing out information to train commuters. This was followed by an awareness talk at Notyatyambo CHC with some 60 people.



The Hong Kong Epilepsy Association, The Hong Kong Society for Rehabilitation, The Hong Kong Epilepsy Society, The Hong Kong Brain Foundation and The Hong Kong Neurological Society collaborated to launch the 1st International Epilepsy Day Hong Kong event.



At their headquarters in Curicó, **Liga Chilena contra la Epilepsia Oficial**, celebrated International Epilepsy Day with a relaxation workshop for their patients.

International Epilepsy Day in the European Parliament

A global alliance for epilepsy



The European Advocates for Epilepsy MEP group in the European Parliament, organised a Breakfast Briefing in the

Left to right: Dr. Janet Mifsud, Marian Harkin MEP and Prof. Martin Brodie, President IBE.

parliament in Brussels on 31st January to mark International Epilepsy Day. Hosted by its President, Brian Hayes MEP (Ireland), the 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 Destrebecq, Executive Director, European Brain Council.

There to tell the epilepsy story on behalf of Epilepsy Alliance Europe were Profs Helen Cross, Martin Brodie, Lieven Lagae, Philippe Ryvlin, Eugen Trinka and Kristl Vonck; Dr Janet Mifsud, Mrs Caroline Morton, and Mrs Francesca Sofia.

In opening the briefing, Brian Hayes MEP explained that the workshop focused on the need for a global alliance for epilepsy research and was a follow up to an important workshop held in 2017 and which involved representatives from the national health agencies in the US and Canada.

Epilepsy Advocates Group welcomes new members

As a result of International Epilepsy Day events, membership of the European Advocates for Epilepsy group grew from 55 MEPs to 63. IBE and ILAE is most grateful to the MEPs who have agreed to join the group and to be a watchful eye in the parliament for people with epilepsy and those who care for them across Europe.



Tanja Fajon Member, Slovenia



Eleonora Forenza Member, Italy



Karin Kadenbach Member, Austria



Ulrike Mueller Member, UK



James Nicholson Member, UK



Annie Schreijer-Pierik Member, Netherlands



Igor Šoltes Member, Slovenia



Nils Torvalds Member, Finland



lvo Vajgl Member, Slovenia

Save the date!



FEBRUARY 11th 2019