

Toolkit For Advocates

Step up against stigma this International Epilepsy Day

The World Health Organization estimates that approximately 50 million people worldwide live with epilepsy. When treated properly, epilepsy can often be managed effectively. Despite this, many people with epilepsy continue to face stigma and discrimination due to long-held misconceptions and myths. As a result, they may be excluded from certain activities, making it difficult for them to live a full and active life.

50% of people living with epilepsy report social stigma.¹

Discrimination and stigma take many forms. A child with epilepsy may be excluded from school activities or social events, and an adult with epilepsy may feel overlooked for a job they could easily handle.

*Epilepsia*² a leading epilepsy journal, published a special report in January 2022, on stigma and epilepsy. A task force of the International League Against Epilepsy conducted the study.

¹ Baker GA, Jacoby A, Buck D, Stalgis C, Monnet D. Quality of life of people with epilepsy: a European study. Epilepsia. 1997 Mar;38(3):353-62. doi: 10.1111/j.1528-1157.1997.tb01128.x. PMID: 9070599.

² Kwon, C-S, Jacoby, A, Ali, A, Austin, J, Birbeck, GL, Braga, P, et al. Systematic review of frequency of felt and enacted stigma in epilepsy and determining factors and attitudes toward persons living with epilepsy—Report from the International League Against Epilepsy Task Force on Stigma in Epilepsy. Epilepsia. 2022; 63: 573– 597. https://doi.org/10.1111/epi.17135

Key findings from the study include:

- For people living with epilepsy, negative attitudes toward epilepsy have significant social implications.
- Attitudes towards epilepsy can vary not only between countries but also between geographical regions within a country.
- Epilepsy terminology contributes to the stigma associated with the disorder.

Misconceptions and myths often contribute to the stigma surrounding epilepsy. For example, many people assume that epilepsy is a mental illness, that it limits activities, or even that epilepsy is contagious.

This year's International Epilepsy Day campaign seeks to dispel these myths.

By sharing facts about epilepsy, we will challenge public misconceptions and myths.

#50MillionSteps Campaign

Our annual #50MillionSteps event will take place in the lead-up to International Epilepsy Day in 2023.

In the three years since the campaign began, nearly 300,000,000 steps have been taken.

This year, we want to achieve even more!

More steps. More awareness. More lives improved.

And our goal can only be achieved with your help.

Help us to raise awareness of epilepsy stigma by walking 50,000,000 steps - one step for each person living with epilepsy - ahead of International Epilepsy Day, 13 February 2023.



How To Take Part

Taking part is very easy. In the period between January 9 through February 13, 2023, simply count your steps as you walk.

A Fitbit or a step counter can help you keep track of your steps. Smartphones can also be used to track steps. If you don't have either, you can estimate your steps. As a guide, there are roughly 1,350 steps in a kilometer. The average person will generate 5,000 steps after walking over 3.8 kilometers.

Steps can be logged at our Step Counter at <u>www.50millionsteps.org.</u>³ We will reveal our grand total of steps on February 13th, International Epilepsy Day.

#50MillionSteps Fundraiser

The campaign provides an opportunity for chapters to raise funds to support the work they do. Consider encouraging your network to make a one-time donation or to donate based on the number of steps taken.

Please Note: <u>Campaign donations should be made directly to individual chapters.</u> <u>IBE will not collect donations for individual chapters.</u>

³ Step Counter will be active on the website between January 9th -13th 2023.

Share Your Event With Us!

This event is a fantastic way to get involved with vital awareness-raising activities. We'd love to see how you're participating, so please share your stories and pictures on social media and tag us on our social media channels.

facebook.com/InternationalBureauForEpilepsy

instagram.com/international_epilepsy



Make sure you tag your posts with #50MillionSteps and #StampOutStigma.

To help you promote your involvement, we have provided sample social media posts, logos, and graphics in our Toolkit below.

The graphics can be downloaded directly from this document and from <u>Resources - 50 Million Steps for Epilepsy</u>.

Thank you for your support!

When we walk in step together, nothing is impossible.

Campaign Toolkit

Campaign resources are freely available for use by individual advocates or non-profit organizations.

Commercial companies who wish to use the campaign resources should contact us for approval.

If you have any questions about the campaign or issues with downloading the graphics, please contact Marie Ennis O'Connor, Head of Communications at <u>communications@ibe-epilepsy.org</u>

Poster

- Poster 1 (<u>download .pdf</u>) (<u>download .png</u>)
- Poster 2 (download .pdf) (download .png)
- Poster 3 (download .pdf) (download .png)
- Poster 4 (<u>download .pdf</u>) (<u>download .png</u>)

Logo (Transparent Background)

- Steps Against Stigma (Purple) download .png
- Steps Against Stigma (White) download .png
- Steps Against Stigma (Black) download .png

Social Media Graphics

Download Graphics Set 1: Twitter

Twitter Header Images



Download zip file of images

Twitter Post Graphics



Download zip file of images

Download Graphics Set 2: Facebook

Facebook Cover Images



Download zip file of images

Facebook Post Graphics

Facebook & Instagram Story



Download zip file of images



Download zip file of images

Download Graphics Set 3: Instagram

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Instagram Graphics (Square)

Download zip file of images

Instagram Graphics (Portrait)



Download zip file of images

Editable Image Cards

- Facebook Image Card
- Twitter Image Card
- Instagram Image Card (Square)
- Instagram Image Card (Portrait)
- Instagram Story
- Facebook Story

These blank templates can be customized with your own logo and images.

Note: These templates were designed using Canva. If you're unfamiliar with Canva you can <u>watch a tutorial here</u>

Sample Social Media Posts

Step up against #epilepsy #stigma this #InternationalEpilepsyDay! Visit 50MillionSteps.org to get involved in the campaign #StampOutStigma #50MillionSteps

@WHO estimates that approximately 50 million people worldwide live with #epilepsy. Join us and help walk #50MillionSteps - one for each person affected by epilepsy - ahead of International #EpilepsyDay 13 February. Visit 50MillionSteps.org for more information.

To raise awareness of #epilepsy #stigma we're asking you to help us walk #50MillionSteps Count your steps between 9 January and 13 February. Visit 50MillionSteps.org to take part.

In the three years since the #50MillionSteps campaign began, nearly 300,000,000 steps have been taken 1 This year, we want to achieve even more! More steps. More awareness. More lives improved. Take part at 50MillionSteps.org

Help us to raise awareness of *#epilepsy #stigma* by walking 50,000,000 steps - one step for each person living with epilepsy. Visit 50MillionSteps.org to take part. *#50MillionSteps #StampOutStigma*

I'm stepping up against #stigma i Join me in walking #50MillionSteps to raise awareness of the #stigma faced by many of the 50 million+ people who live with #epilepsy worldwide. Learn more at 50MillionSteps.org #StampOutStigma

Did you know? 50% of people living with #epilepsy report feeling stigmatized. Join me in walking #50MillionSteps to raise awareness of #epilepsy #stigma. Join our campaign at 50MillionSteps.org #StampOutStigma

Wondering how to take part in our #50MillionSteps campaign? In the period between January 9 through February 13, 2023, simply count your steps as you walk \uparrow and log them at 50millionsteps.org.