

Toolkit For Advocates

Take A Step Against Stigma, Towards International Epilepsy Day 2024

Introduction

The World Health Organisation [WHO] estimates that approximately 50 million people worldwide live with epilepsy (although recent studies suggest this figure may be higher) and around 50 percent¹ will experience some form of stigma.

That is why, in 2022, WHO Member States unanimously adopted the 10-year Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders.²

The goal of this plan is to reduce the stigma, impact and burden of neurological disorders and to improve the quality of life of people with neurological disorders, their carers, and their families.

Epilepsy is given specific attention in this Plan, with global targets aimed at improving access to care and addressing the discrimination and human rights challenges impacting our community worldwide.

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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 IBE Guide To IGAP

However, low levels of health literacy, and high levels of misunderstanding and misconceptions about epilepsy, drive social stigma and exclusion, which can lead to the discrimination of people with epilepsy across all levels of society. For example, at work, at school or in the community.

Such lack of knowledge can also contribute to challenges in access to treatment due to misdiagnosis, inappropriate treatment decisions, inadequate provision of care, and insufficient support for people with epilepsy and those who care for them. In fact, due to the stigma surrounding epilepsy, in many parts of the world, those affected will not come forward to seek care.

Empowering and amplifying the voice and visibility of people with epilepsy, and those who care for them is a necessary step in the awareness-raising and advocacy that will be required to ensure we can meet this ambitious global target set out by IGAP.

Therefore, this <u>International Epilepsy Day</u>, we want to improve knowledge levels about epilepsy amongst all sectors of society by asking people with epilepsy and those who care for them to share their *Epilepsy Journey*.

In the weeks leading up to International Epilepsy Day, we are calling on everyone to join us on our epilepsy journey, and take a step against stigma!

#50MillionSteps Campaign

The #50MillionSteps campaign serves as the starting point for International Epilepsy Day (#EpilepsyDay) which takes place on February 12, 2024.

Aligned with the overarching goal of #EpilepsyDay, the campaign seeks to raise awareness, dispel myths, and improve knowledge levels about epilepsy. Both campaigns aim to build a more informed and supportive global community.

In the four years since the campaign began, nearly 500,000,000 steps have been taken.

The number of steps we achieved in 2023 exceeded our goal and expectations!

In the coming year, we want to achieve even more!

More steps. More awareness. More lives improved.

But we can only reach this goal with your support.

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, 12 February 2024.



How To Take Part

Joining the campaign is easy! From January 8 through February 12, 2024, all you need to do is count your steps as you walk. Then record your steps on our Step Counter at www.50millionsteps.org.³

We recommend logging your steps either at the end of each day or cumulatively at the close of the week so we can track the overall progress together and mark key milestones on our journey.

We will reveal our grand step total on February 12th, International Epilepsy Day.

³ Step Counter will be active from January 8th, 2024.

Additional Suggested Activities

Share Your Daily/Weekly Step Count on Social Media: Engage with the '50 Million Steps' community by sharing your daily step count on social media.

Sample post: "Stepping into Day 12 of the '50 Million Steps' campaign. Today's count: XXX steps. Every step is a step against #epilepsy stigma. Let's keep walking together! #StepsAgainstStigma #50MillionSteps"

Share a Selfie from Your Walk: Capture and share moments from your walks. Share your selfies on social media using the campaign hashtags #50MillionSteps #StepAgainstStigma.

Sample post: "Today, I'm taking a #StepAgainstStigma! Join me in the #50MillionSteps campaign as we walk together to dispel myths and raise awareness about epilepsy."

Or if you prefer you can create a short video to share on social media.

Post Facts About Epilepsy on Social Media: Our Toolkit includes samples of social media posts, logos, and graphics you can use to dispel common myths and misconceptions about epilepsy.

Walk and Talk: Organise a "Walk and Talk" event in your school, workplace, or local neighbourhood. This is a great opportunity to provide a space for open discussions about epilepsy, promoting understanding, and connecting communities.

Sponsored Walk: Encourage friends, family, and colleagues to sponsor each participant based on the number of steps they take.

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

Step Challenges: Create weekly step challenges with different themes or goals, for example, "High Energy Steps."

Fitness Classes: Partner with fitness studios or trainers to organize special fitness classes or workouts focused on step counts.

Get Creative With Your Steps!

In the '50 Million Steps' campaign, there's no one-size-fits-all approach to take part. So let your imagination run free and get creative with your steps!

&Biking: Pedal your way to our goal! Whether it's a leisurely ride or an exhilarating cycling session, log those cycling miles!

⚠ Step and Stretch: Combine your regular yoga, pilates, or Tai Chi routine with your daily steps. Perhaps a mindful walk to a serene outdoor spot for your yoga practice or integrating steps into your warm-up and cool-down.

Swim the Distance If you love the water, each lap in the pool adds to our final step count.

Skiing or Snowboarding: Embrace the winter wonderland and turn your snowy adventures into steps.

How To Convert Your Activities To Steps

You can use a Fitbit or a step counter to keep track of your steps. Or you can estimate your steps. As a reference, there are approximately 1,350 steps in a kilometer. The average person covers around 3.8 kilometers after taking 5,000 steps.

Converting steps to other forms of physical activity like running, yoga, or dancing involves estimating the equivalent energy expenditure or time spent based on typical associations.

- On average, running covers a certain distance per step. For simplicity, you can
 use a rule of thumb that approximately 2,000 steps are equivalent to running a
 mile.
- On average, a moderate-intensity yoga session might burn around 150-200 calories in 30 minutes. You could estimate that completing 5,000 to 7,000 steps might be equivalent to a 30-minute yoga session.
- For a moderate-intensity dance workout, you might estimate that 5,000 to 7,000 steps are equivalent to around 30 minutes of dancing.

 Approximately 1 minute of cycling can be equivalent to 1000-1500 steps. Using a fitness tracker with cycling metrics or heart rate monitoring can provide more detailed insights into energy expenditure during cycling sessions.

Download Our Step Conversion Chart Here

Whatever activity you choose, we want to see and hear about it! Be sure to tag us on your social media and share your pictures with us.



facebook.com/InternationalBureauForEpilepsy



instagram.com/international epilepsy



As we unite as a global community to achieve our target of 50 million steps, each step taken is a step on the path to increase awareness and dismantle the stigma surrounding epilepsy. Taken together, our steps become a journey of solidarity and the determination to forge a more inclusive and understanding society for the 50 million people living with epilepsy across the world.

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 communications@ibe-epilepsy.org

Poster

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

X (formerly Twitter) Header Images



Download zip file of images

X (formerly Twitter) Post Graphics



Download zip file of images

Download Graphics Set 2: Facebook

Facebook Cover Images



Download zip file of images

Facebook Graphics Square



Download zip file of images

Download Graphics Set 3: Instagram

Instagram Graphics (Square)



Download zip file of images

Facts About Epilepsy

To help you share relevant facts and figures across social networks, we've developed a document which you can download below:

Facts and Figures

IGAP

• IGAP Unpacked: A practical guide to WHO's 10-year Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (2022-2031)

Editable Selfie Card

This blank template can be customized with your own logo and images.

Why not use it to share a selfie from your walk and share it on social media?

Note: This template was designed using Canva. If you're unfamiliar with Canva you can follow a tutorial here

Download template.



Sample Social Media Posts

Step up against #epilepsy #stigma this #InternationalEpilepsyDay Visit 50MillionSteps.org to be part of the change! #StepAgainstStigma #50MillionSteps

To raise awareness of #epilepsy #stigma we're asking you to help us walk #50MillionSteps \ Count your steps between 8 January and 12 February. Visit 50MillionSteps.org to take part.

In the 4 years since the #50MillionSteps campaign began, nearly 500,000,000 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 #StepAgainstStigma

I'm stepping up against #stigma Join me on my journey to walk #50MillionSteps to raise awareness of epilepsy stigma Learn more at 50MillionSteps.org #StepAgainstStigma

It's time to step up against epilepsy stigma! Visit 50MillionSteps.org to find out how you can make a difference ** #50MillionSteps

Every step counts 1 Lace up your shoes and join us as we #StepAgainStigma. Visit 50MillionSteps.org to learn more about the campaign! #50MillionSteps

Let's walk #50MillionSteps ahead of International #EpilepsyDay on 12 February ♥️ Visit 50MillionSteps.org

I'm taking strides on my #EpilepsyJourney with a mission to erase stigma. Walk beside me by joining the movement at 50MillionSteps.org 1

Let's unite to break down the barriers surrounding epilepsy Take the first step at 50MillionSteps.org. Together, we can make a difference! #StepAgainstStigma #50MillionSteps