



# Frequently Asked Questions (FAQs)

## 1. What is the Global Epilepsy Needs Study (GENS)?

The Global Epilepsy Needs Study (GENS) is a research study led by the International Bureau for Epilepsy (IBE) aimed at understanding the diverse needs and challenges faced by individuals living with epilepsy worldwide.

## 2. Who is conducting the GENS study?

GENS is conducted by the International Bureau for Epilepsy (IBE) in partnership with a patient research organization, MediPaCe and 19 of IBE's member organizations (national epilepsy support groups).

## 3. Which countries are participating in GENS?

Our 15 focus countries include:

Canada, USA, Argentina, Brazil, Bosnia & Herzegovina, Croatia, Denmark, Spain, Tunisia, The Gambia, Uganda, India, China and Hong Kong SAR, Korea and Australia!

This includes working with 19 national epilepsy patient groups across these countries to deliver this study on the ground including:

### Argentina

- [Fundación Espacio Epilepsia](#) (Argentina)
- [Fundación de Hemisferectomía FundHemi](#) (Argentina)

**Australia** - [Epilepsy Foundation](#)

**China** - [Chinese Association Against Epilepsy](#) (CAAP)

**Tunisia** - Tunisian Association Against Epilepsy

**USA** - [Epilepsy Foundation of America](#)

**Bosnia & Herzegovina** - [Centar Against Epilepsy](#)

**Brazil** - [Associação Brasileira Epilepsia - ABE - Brazil](#)

**Croatia** - [Croatian Association for Epilepsy](#)

**India**

- [Indian Epilepsy Association](#)
- [Indian Epilepsy Foundation](#)

**Korea** - Korea Bureau for Epilepsy

**The Gambia** - [Foundation for Epilepsy and Stigma Support - Gambia](#)

**Uganda** - [Purple Bench Initiative](#)

**Uganda** - [Epilepsy Support Association Uganda](#)

**Spain** - [Federación Española de Epilepsia](#)

**Canada** - [Canadian Epilepsy Alliance](#)

**Denmark** - [Epilepsiforeningen](#)

**Hong Kong SAR** - [Hong Kong Epilepsy Association](#)

### 3. What is the goal of the Global Epilepsy Needs Study ?

The goal of the study is to collect detailed information and insights from people with epilepsy and their caregivers to better understand their experiences, challenges, and needs. This information will be used to drive meaningful change in global policy, research, and healthcare programs to improve the lives of people with epilepsy.

### 4. How can I participate in the study?

People with epilepsy and their caregivers can take part in the study by completing the GENS survey.

As this is a global research project we're launching the survey in three phases. This will make analysing the results easier. Here's more information on when the GENS survey will launch in your country.

Phase	Country	When can I expect the survey to launch and close in my country? *
Phase 1	<ul style="list-style-type: none"><li>• USA</li><li>• Argentina</li><li>• Tunisia</li><li>• China</li><li>• Australia</li></ul>	<b>Launch:</b> Week beginning 19th August <b>Close:</b> Before 22nd September

Phase 2	<ul style="list-style-type: none"> <li>● Bosnia &amp; Herzegovina</li> <li>● Brazil</li> <li>● Croatia</li> <li>● India</li> <li>● Republic of Korea (South)</li> </ul>	<p><b>Launch:</b> Week beginning 26th August</p> <p><b>Close:</b> Before 29th September</p>
Phase 3	<ul style="list-style-type: none"> <li>● Spain</li> <li>● Canada</li> <li>● Denmark</li> <li>● Hong Kong</li> <li>● Uganda</li> <li>● The Gambia</li> </ul>	<p><b>Launch:</b> Week beginning 2nd September</p> <p><b>Close:</b> Tuesday 1st October</p>
Phase 3a	Global – all other countries invited to participate	<p><b>Launch:</b> Week beginning 2nd September</p> <p><b>Close:</b> Tuesday 1st October</p>

*\*All launch dates are subject to national ethics approval*

**5. Is my participation in the study confidential?**

Yes, your participation in the GENS survey is confidential. All responses will be anonymised (you won't be able to be identified) and data stored securely.

**6. How long does it take to complete the GENS survey?**

The GENS survey takes approximately 30 minutes to complete.

**7. Are there any eligibility criteria to participate in the GENS survey?**

Yes, participants should be 18 years or older and either an individual living with epilepsy or a caregiver of an individual with epilepsy.

Caregivers can complete the survey on behalf of a person with epilepsy under 18.

## **8. Can caregivers or family members of individuals with epilepsy participate in the study?**

Yes, caregivers and family members of individuals with epilepsy are encouraged to participate in the GENS survey to share their valuable insights.

## **9. Is the GENS survey available in multiple languages?**

Yes, the GENS survey is available in multiple languages to ensure inclusivity and accessibility for participants from different regions. The survey is available in:

- English
- Spanish
- French
- Arabic
- Simple Chinese
- Danish
- Croatian
- Portuguese
- Luganda
- Hindi
- Kannad
- Telugu
- Korean
- Bosnian

## **10. How will the data collected from the GENS survey be used?**

Our goal is to improve the quality of life for individuals with epilepsy. The data collected from the study will be used to create a scientific publication and a global policy advocacy report.

These will influence global and national policy for epilepsy as well as epilepsy research, and healthcare programs. This project will also help national epilepsy support groups to better support their communities.

## **11. When will the results of the study be available?**

The results of the study will be compiled and published in a scientific publication early in 2025. An IBE report on Global Epilepsy Needs is expected to be launched before May 2025.

If you would like to be kept updated with the results of GENS, [please sign up here](#).

## **12. Who can I contact if I have further questions about GENS?**

If you have any questions about getting involved in GENS, please get in touch at [engagement@ibe-epilepsy.org](mailto:engagement@ibe-epilepsy.org).

If you are having trouble completing the survey, please contact [gens@medipace.com](mailto:gens@medipace.com)

## **13. Can I share information about the GENS study with others?**

Yes, please feel free to share information about this important study with anyone who might be interested in participating or learning more about epilepsy needs and challenges. Your support in spreading the word is greatly appreciated!