

DO YOU HAVE UNANSWERED QUESTIONS ABOUT EPILEPSY OR SEIZURES?

We need your voice to shape the future of epilepsy research!



HAVE YOUR SAY on

EPILEPSY RESEARCH



Epilepsy is a common brain disease that is characterized by **recurrent, unpredictable seizures** and the effects these seizures may have on the individual's health and well-being. This Priority Setting Partnership brings together patients, caregivers and clinicians to identify unanswered questions about epilepsy. We are looking for questions about **diagnosis, treatment, management or day-to-day life** that could be answered by research. This information will help us to identify future research studies that could benefit people living with epilepsy.

Why we need your help: We're asking Canadians to submit their most pressing questions around epilepsy or seizures. This survey is the first step in collecting your questions, and it will be open until January 2020. It will be followed by a second survey to prioritize the questions that are received. We will share the final "Top 10" list of questions directly with researchers and research funders to encourage them to focus on the most urgent needs of people living with seizures. This final report will be available on the Ontario Brain Institute and Eplink websites.

What do we mean by unanswered questions? An unanswered question is any uncertainty related to epilepsy that could benefit from research. You do not need to know whether or not the question is actually unanswered. You may also skip questions. Our team will collect your questions and check them against published research. Some examples of questions include:

- *Will I pass my epilepsy onto my children?*
- *Why do seizures stop?*
- *How does epilepsy impact mental health?*
- *Is the ketogenic diet or is vagus nerve stimulation more effective in reducing seizures in people with drug-resistant epilepsy?*

Will my answers be kept confidential?

✓ Absolutely! Your responses will be stored electronically in Brain-CODE, a highly secure database developed and maintained by the Ontario Brain Institute.

✓ Brain-CODE, which has been designated a Privacy by Design ambassador by the Information and Privacy Commissioner of Ontario, is an open-access database, which means that other researchers from Canada and around the world can request access to the survey data. By combining these responses with data from other participants, we can gain a better understanding of brain disorders. Responses will be stored indefinitely.

✓ All data made available on Brain-CODE will be stored in facilities with high-level security. No names or other identifying information will be included. For more information about Brain-CODE, visit www.braininstitute.ca

✓ Although participating in this survey is voluntary, once you hit "submit", you will not be able to withdraw your responses.

✓ Only the Informational Specialist will have access to all survey information. The PSP Steering Committee will have access to the combined responses to ensure fair representation from all stakeholders across the country and to inform promotional strategy.

Please complete:

I confirm that I understand the requirements of participating in this survey as stated in this form and consent to participate in this survey: YES NO

To learn more about the **PSP survey**, please visit braininstitute.ca/epilepsy-psp or contact: Rebecca Woelfle, JLA Project Coordinator ✉ rwoelfle@eplink.ca ☎ 416-978-6381

To learn more about **epilepsy support services**, please visit: www.canadianepilepsyalliance.org/

To learn more about **your rights as a participant**, please contact the Community Research Ethics Office at 1-888-411-2736.

SECTION 1

1 What question(s) do you still have about the **cause or diagnosis** of epilepsy and seizures?

2 What question(s) do you still have about the **treatment** of epilepsy and seizures?

3 What question(s) do you still have about **managing day-to-day life** with epilepsy and seizures? (Examples include life at work or school, memory problems, fear, stigma, or suicidal thoughts)

4 What question(s) do you still have about **managing the co-existing conditions** related to epilepsy and seizures? (Examples include depression, anxiety, behavioural issues, or developmental disorders)

Please use Section 2 to provide some information about yourself to help us understand who is responding to the survey.

SECTION 2

1 Which of the following best describes you?

- Person with epilepsy or seizures
- Caregiver/former caregiver of someone with epilepsy or seizures
- Friend/family member of someone with epilepsy or seizures
- Health care provider
- Representative of a Community Epilepsy Agency
- Other

2 If you are a health care provider, please indicate your profession:

- Family doctor
- Specialist
- Nurse or nurse practitioner
- Pharmacist
- Allied health professional (e.g. physician assistant, social worker, psychologist, occupational or physical therapies, midwife)

3 What is your age?

- Under 18
- 18-35
- 36-49
- 50-69
- 70 +
- Prefer not to say

4 Please indicate your gender:

- Male
- Female
- Prefer not to say
- I self-identify as: _____

5 What is your ethnic/cultural background? (Check all that apply)

- Arab
- Black
- Caucasian
- Chinese
- Filipino
- Indigenous
- Japanese
- Korean
- Latin American
- Pacific Islander
- South Asian
- Southeast Asian
- West Asian
- Prefer not to say
- Other (please specify):

6 For location purposes, please provide the first 3 digits of your postal code:

Thank you! Please share the online link to this survey:

<http://www.braininstitute.ca/epilepsy-ppsp>

Please complete and keep this copy for your records.

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