Epilepsy Priority Setting Partnership

Pick your priorities!

What are the most important questions for future epilepsy research to answer?

What is this survey for?

We recently conducted a survey that asked people to submit their unanswered questions about epilepsy and seizures. We want to use this information to guide future research and make sure researchers focus on the most urgent needs of people affected by epilepsy.

Approximately 500 Canadians submitted almost 1900 questions about the diagnosis, treatment, social repercussions and management of epilepsy and its co-existing conditions. Our research team reviewed each submission, summarized into research questions and removed any questions that have already been answered by previous research. Please note that these answered questions will be used in different ways, such as public education campaigns, and will not be lost.

We have turned the remaining unanswered responses into research questions. Now we need to know which ones are most important to you for research to address in this second survey.

Who should take part in this second survey?

This survey is open to people living with epilepsy or people who experience seizures as part of a co-existing disorder, their families, their caregivers, and healthcare professionals working with people with epilepsy. We are looking to receive at least 500 responses.

What do I need to do?

We are asking you to select **up to ten (10)** questions that matter to you the most from the list of 43 questions. Simply check the box next to the questions that you would like to select.

Once you have selected your questions, you will be asked to provide some information about yourself so we can understand who has responded to the survey.

There are no risks to taking part in this survey. You may get a little tired reading through 43 questions, so you may wish to take a break as you make your selections. If you choose to take a break, please keep the browser tab with the survey open – if you exit the browser tab, your progress will be lost and you will have to restart.

What happens next?

The final stage of this project will occur in March 2021, when we will hold a virtual workshop that brings together a representative group of patients, caregivers and clinicians from across Canada. Based on the responses from this survey, they will discuss the most popular questions in more detail and agree on the top ten questions that need researching. 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.

If you would like to attend this workshop, please complete the online **Expression of Interest** form (add hyperlink) and email it to Carla Southward, JLA Project Team, at csouthward@braininstitute.ca

Will my answers be kept confidential?

- ✓ Yes, 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 anonymous and stored in facilities with high-level security. No names or identifying information will be included. For more information about Brain-CODE, visit http://www.braininstitute.ca.
- ✓ Participation in all parts of the survey are voluntary and you may skip questions without any consequence. Although participating in this survey is voluntary, once you hit “submit”, you will not be able to withdraw your responses.
- ✓ The JLA Project Team – Rebecca Woelfle, Carla Southward and Rachel Chepesiuk – will be responsible for monitoring responses as they come in to drive appropriate survey promotions.

Who can I contact for more information?

If you would like more information about the JLA survey, please go to braininstitute.ca/epilepsy-psp or contact:

Rebecca Woelfle, JLA Project Coordinator
Email: **rwoelfle@eplink.ca**
Phone: (519) 494-8817

If you would like more information about your rights as a participant, please contact the Community Research Ethics Office at 1-888-411-2736.

If you are in emotional distress and need someone to talk to, please contact the Canada Suicide Prevention Service: toll-free 1-833-456-4566, French and English, available 24/7 or find local crisis support here.

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

Section 1

Please select **a maximum of 10** questions from the list of 43 potential research questions below that you think are the most important for researchers to answer. Please do this based on your own experience.

#	Question	Select	#	Question	Select
1	Can genetic markers be used to diagnose and treat epilepsy and seizure disorders?		23	How can people who experience seizures and their caregivers or care partners manage fear associated with seizures?	
2	What causes memory problems associated with seizures? Can these memory problems improve over time and what are the best treatment options for memory loss in people who experience seizures?		24	Is there a relationship between hormonal changes (e.g. puberty, menopause, pregnancy) and seizure onset and/or frequency, and what are the effects of seizures during pregnancy?	
3	What are the impacts of long-term use of anti-seizure drugs, the causes of side-effects of these treatments and how we can prevent the side effects?		25	Are there any exposures in a person's surroundings (e.g., chemicals, pesticides, pollution etc.) that are associated with an increased risk of seizures?	
4	What are the brain changes, on a cellular level, that lead to seizure development?		26	What is the best protocol for screening seizure patients for common comorbidities?	
5	What are the best ways to support people who experience seizures secure and perform in employment (e.g., through accommodations) and what interventions can reduce workplace discrimination?		27	Aside from EEG and videoEEG, what monitoring devices can be used to reduce safety risks/complications related to seizures?	
6	Are cannabis products (e.g. Marijuana, CBD oil) a safe and effective treatment for seizures alone or in combination with standard treatments (e.g. anti-seizure drugs)?		28	How does understanding where seizures originate affect the outcome of treatment?	

7	What is the most effective testing protocol for determining causes of seizures and/or a diagnosis of epilepsy or other seizure disorders and reduce time to diagnosis?		29	Why and how does abnormal brain organization (i.e. cortical dysplasia, enlarged ventricles) cause seizures?	
8	What non-drug lifestyle treatments (e.g., cardiovascular exercise, yoga) are effective for controlling seizure frequency with or without standard treatments (e.g., anti-seizure drugs)?		30	In addition to medication adherence, what causes seizures to change in presentation and/or severity?	
9	Do dietary changes alone or in combination with standard treatments (e.g. anti-seizure drugs) provide increased seizure control?		31	Why do some seizure disorders resolve?	
10	Apart from monotherapy (e.g., being prescribed a single drug, using the keto diet without drugs), how can we personalize treatment options to combat a specific type of seizure or syndrome (i.e. specific drugs, combination of pharmacological and non-pharmacological treatment)?		32	What is the efficacy (i.e. the effectiveness of reducing seizures) of adding a second antiseizure medication compared to changing to a different antiseizure medication? How can we determine which combination of anti-seizure drugs are effective?	
11	How can healthcare professionals communicate diagnostic information and collaborate with each other and people who experience seizures to ensure quality care?		33	How can access to resources/supports for people who experience seizures be optimized?	
12	What are the impacts of common non-drug treatments (e.g., surgery, diet changes etc.) on a person’s overall health and development?		34	Are there lifestyle factors (e.g. diet, vitamin deficiency, amount of exercise) associated with an increased risk of seizures?	
13	Is it safe to wean a person who has experienced seizures off of anti-seizure drugs and if so, when is the right time to wean off anti-seizure drugs?		35	What are the best methods to provide information about seizures to patients and their caregivers?	
14	What is the relationship between age and seizure onset?		36	Do environmental factors (e.g., changes in weather patterns, moon phases, and seasons) affect the frequency of seizures?	
15	What barriers prevent the general population from understanding the challenges facing people who have seizures?		37	What is the relationship between seizures and the human gut/microbiome?	

16	What barriers prevent healthcare providers from understanding the lived experience of their patients who have seizures?		38	Apart from anterior thalamic and responsive neurostimulation, does deep brain stimulation prevent seizures?	
17	How effective is surgical treatment for adults and children who experience seizures/epilepsy?		39	Are sleep disorders linked to developing seizures and are people who experience seizures at an increased risk of sleep disorders?	
18	Aside from anti-seizure drugs and some brain lesions, what causes behavioural changes in people who experience seizures? What is the best way to treat behavioral issues?		40	How can sleep quality be monitored for people who experience seizures?	
19	How do seizures impact the mood of people who experience them and what are the best methods to manage mood swings?		41	How can the risk of SUDEP be reduced in people with epilepsy?	
20	What primary and secondary prevention measures can be used for epilepsy/seizure disorders?		42	Are vaccinations safe and effective while one is taking anti-seizure drugs? Can vaccinations cause seizure disorders?	
21	What are the long-term impacts of seizures on a person's brain, and overall health and development?		43	Are people who experience seizures at an increased risk of developing autoimmune diseases?	
22	Is vagus nerve stimulation (VNS) an effective treatment for reducing seizure frequency, and how effective is it in people where anti-seizure drug therapy has failed?				

Section 2

Please use this section 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

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 therapist, midwife)
    - Other

3. What is your age?
    - Under 18
    - 18-35
    - 36-49
    - 50-69
    - 70 +
    - Prefer not to say

4. Please indicate your gender:
    - Female
    - Male
    - Prefer not to say
    - I self-identify as ___________________________

5. What is your ethnic/cultural background? (Check all that apply)
    - Indigenous/First Nations/Métis/Inuit
    - Arab
    - Black
    - Caucasian
    - Chinese
    - Filipino
    - Japanese
    - Korean
    - Latin American
    - Pacific Islander
    - South Asian
    - Southeast Asian
    - West Asian
    - Other (Please Specify) ____
    - Prefer not to say

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

Thank you! Please share the link to this survey:

https://braininstitute.ca/epilepsy-PSP