James Lind Alliance
Priority Setting Partnerships

EPLINK
THE EPILEPSY RESEARCH PROGRAM
OF THE ONTARIO BRAIN INSTITUTE

ONTARIO BRAIN INSTITUTE
INSTITUT ONTARIEN DU CERVEAU

[Date]

Pick Your Priorities for Epilepsy Research

Dear X,

Thank you for helping us disseminate the first survey as part of the Epilepsy Priority Setting Partnership.

This partnership is committed to learning how research can best serve those living with epilepsy or experiencing seizures, their families, friends, caregivers, and healthcare professionals. With your help, we received responses from over 500 people across Canada.

We are inviting you to join us in the second phase of the partnership. Please help us disseminate the next online survey to your network to ensure that we give as many people as possible a chance to pick their top priorities for research on epilepsy and seizures. We are hoping again for 500+ responses.

From the first survey responses, a team of information specialists checked the questions submitted by the epilepsy community against existing research evidence. Our specialists identified a set of “uncertainties” - questions that do not currently have sufficient answers. We now ask the epilepsy community to pick which questions are the most important to be answered by research. The results of this **second survey** will inform the **“Top 10”** list to be compiled in the final phase of the partnership, which will be published and shared with funding organizations and researchers to initiate research into the topics identified through this process. This research study has been approved by the Community Research Ethics Office.

Below is a Communications Guide for you to help disseminate the **second survey**. Your involvement will help ensure that future research focuses on the needs of your community members. Participation in the survey is voluntary and should not affect your members’ relationship to your organization.

To learn more, please feel free to contact us or visit http://www.braininstitute.ca/epilepsy-psp.

Sincerely,

The Epilepsy Priority Setting Partnership Steering Committee

Priority Setting Partnership Contact:
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Ontario Brain Institute

The Ontario Brain Institute is a provincially-funded, not-for-profit research institution seeking to maximize the impact of neuroscience and establish Ontario as a world leader in brain research, commercialization and care. Convergent partnerships are created between researchers, clinicians, industry, patients, and their advocates to foster discovery and deliver innovative products and services that improve the lives of those living with brain disorders.

The James Lind Alliance

The James Lind Alliance is a non-profit making initiative funded by the National Institute of Health Research (www.nihr.ac.uk). Its aim is to provide an infrastructure and process to help patients and clinicians work together to agree which are the most important treatment questions affecting their particular interest, in order to influence the prioritisation of future research.

EpLink

EpLink is a partner research program of OBI that brings together patients and their families, researchers and clinicians, focusing on finding new ways to diagnose, treat and improve the lives of people living with drug-resistant epilepsy. EpLink’s research covers areas such as drug therapy, diet therapy, surgical procedures, finding novel treatment options, and other programs to improve cognition, mood and quality of life for people living with uncontrolled seizures.

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The Epilepsy Priority Setting Partnership

Communications Guide

Key Information:

Survey open date: January 7, 2021

Survey end date: March 7, 2021

Co-existing conditions related to epilepsy include:

- Rett Syndrome
- Cerebral Palsy
- Down Syndrome
- Tuberous Sclerosis
- Depression, anxiety and other mood or behavioural disorders
- Neurodevelopmental disorders

Home Base

Website: **http://www.braininstitute.ca/epilepsy-psp**
or JLA site: http://www.jla.nihr.ac.uk/priority-setting-partnerships/epilepsy-canada/

Direct Survey Link: **http://www.braininstitute.ca/epilepsysurvey**

Contact:
Rebecca Woelfle, MSc
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Toronto, Ontario M5S 1A8
Phone: (519) 494-8817

Email: rwoelfle@eplink.ca

Graphics

JPGs of the graphics and printed copies are available on request.

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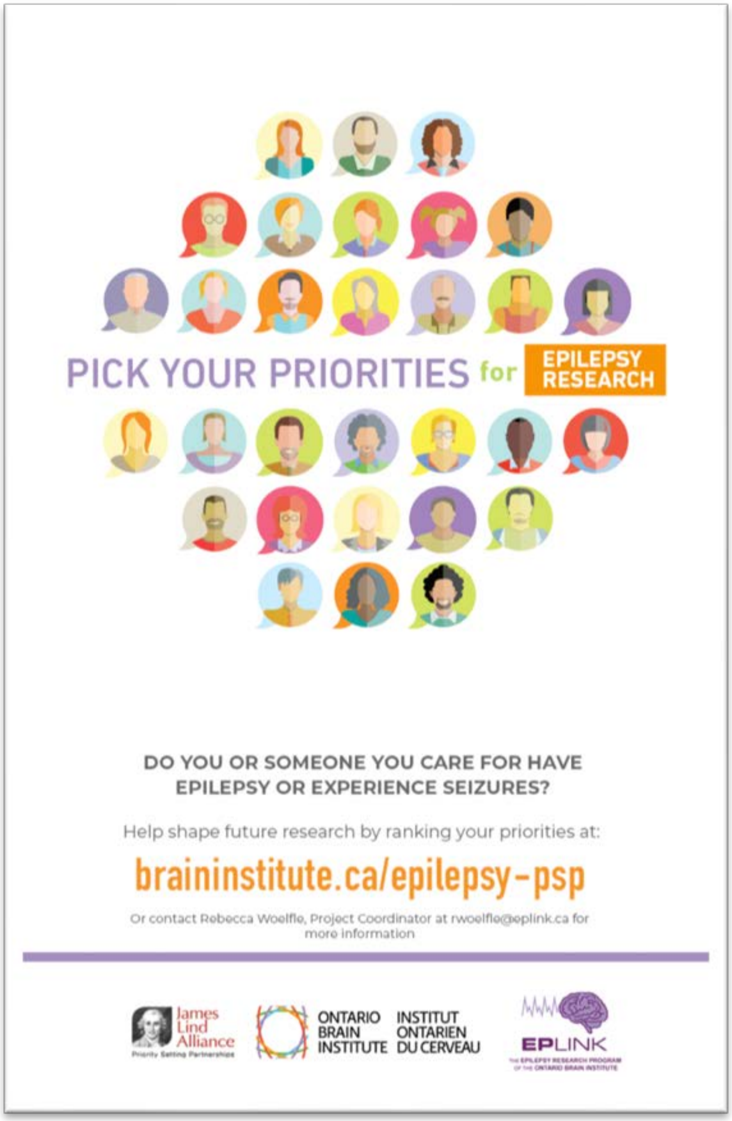
ONTARIO BRAIN INSTITUTE INSTITUT ONTARIEN DU CERVEAU


PICK YOUR PRIORITIES for EPILEPSY RESEARCH


PICK YOUR PRIORITIES for EPILEPSY RESEARCH

Leaderboard: for webpage banners, email signatures; can be printed for bookmarks


PICK YOUR PRIORITIES for EPILEPSY RESEARCH

DO YOU OR SOMEONE YOU CARE FOR HAVE EPILEPSY OR EXPERIENCE SEIZURES?

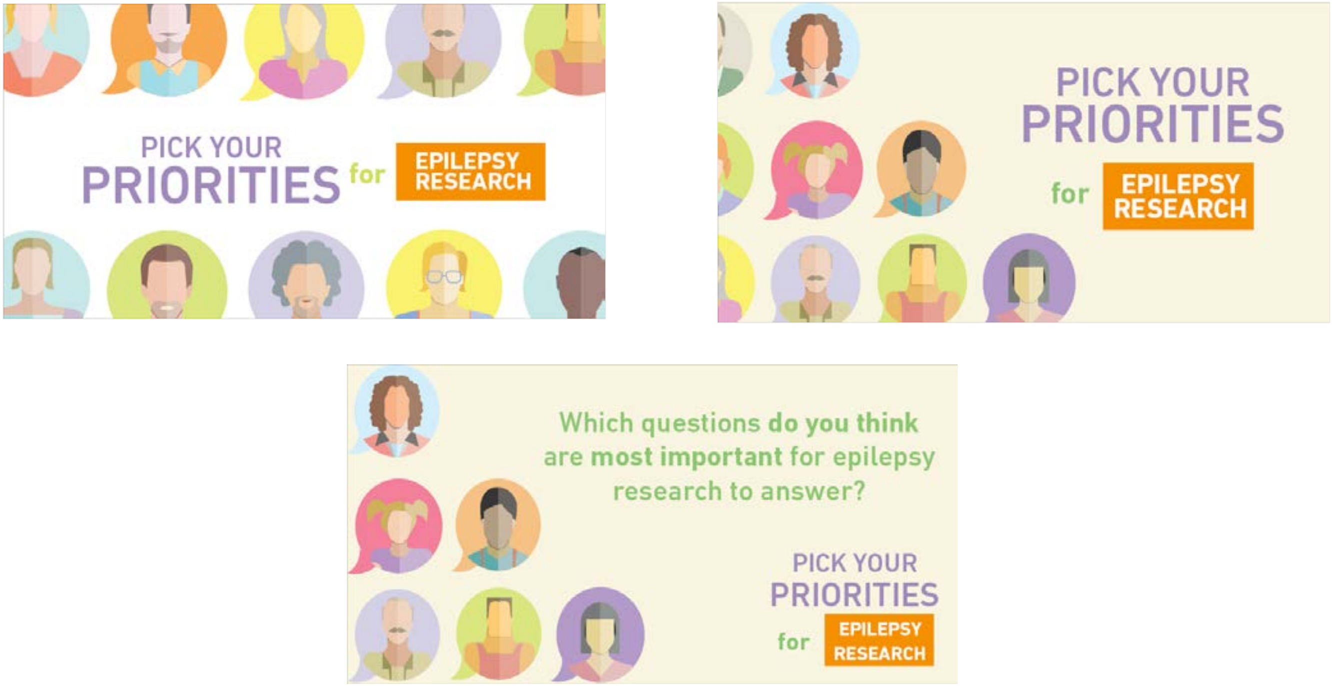
Help shape future research by ranking your priorities at:

braininstitute.ca/epilepsy-psp

Or contact Rebecca Woelfle, Project Coordinator at rwoelfle@eplink.ca for more information

James Lind Alliance Priority Setting Partnerships · ONTARIO BRAIN INSTITUTE INSTITUT ONTARIEN DU CERVEAU · EPLINK THE EPILEPSY RESEARCH PROGRAM OF THE ONTARIO BRAIN INSTITUTE

Poster: can be used as a graphic on webpages, or printed for distribution; poster with pull-off tabs also available by request



Twitter graphics

Social Media

Twitter

Tweets should include:

- Direct link to survey: http://www.braininstitute.ca/epilepsysurvey
    - **OR,** link to webpage: http://www.braininstitute.ca/epilepsy-psp
- Graphic
- Partner organizations:
    - James Lind Alliance: @LindAlliance
    - EpLink: @EpLinkON
    - Ontario Brain Institute: @OntarioBrain
    - And your own organization’s Twitter handle
- Hashtag: #epilepsypriorities

Additional guidance:

- Use additional hashtags such as #epilepsyresearch, #epilepsy, #seizures
- Encourage sharing by including “Please RT”

Suggested tweets (max 280 characters):

Timeline: early to midway through survey opening

We received over 1000 questions about epilepsy and seizures in our first survey! We checked which questions still need answers, now we want you to pick which ones are most important to address. Take the survey today: [link]

Time to rank! We gathered your questions on epilepsy and seizures, now which questions should take priority for research to address? Pick your priorities here: [link] #epilepsypriorities

We heard what questions you want epilepsy research to answer, now it's time to pick which ones are most important! Take the second survey to pick your priorities: [link] #epilepsypriorities

You can help shape the future of epilepsy research in Canada! What should be the research priorities for #epilepsy or #seizures? Pick your priorities here: [link] #epilepsypriorities

We heard your questions on epilepsy and seizures. Which ones should future #epilepsy and #seizure research in Canada focus on? Pick your top priorities today: [link] #epilepsypriorities

Do you provide care for people living with #epilepsy or #seizures? Pick which priorities matter most to you for research to address: [link] #epilepsypriorities

[Healthcare providers:]What matters most to you in providing care to people with #epilepsy and #seizures? Have your say in picking the top #epilepsypriorities for research today: [link]

[Healthcare providers:]What should #epilepsy and #seizure research prioritize to improve clinical care? Pick your top #epilepsypriorities today: [link]

Are you a healthcare provider for people with epilepsy or seizures? We want your vote in picking the top priorities for epilepsy research! [link] #epilepsypriorities

Do you work with people who have epilepsy or seizures? What do you think is most important for epilepsy research to address? Pick your top research priorities today: [link]

Want to influence the future of #epilepsy and #seizure research in Canada? Pick your top #epilepsypriorities that you think research should address today: [link]

Have your say in shaping the future of #epilepsyresearch in Canada! Pick which questions you think epilepsy and seizure research should address: [link] #epilepsypriorities

People who experience seizures, their caregivers and healthcare providers have important insights for what #epilepsy and #seizure research should focus on. Pick your top research priorities today: [link] #epilepsypriorities

What matters to you for epilepsy research to answer? Pick which questions identified by the community should be a priority for future research in #epilepsy and #seizures: [link]

Help shape the future of #epilepsyresearch in Canada! Pick the #epilepsy research priorities that matter most to you here: [link] #epilepsypriorities

Timeline: near survey closing

Closing soon! 2 weeks left to pick which #epilepsypriorities matter most to you for research to address: [link]

Have you picked your which priorities you want #epilepsy and #seizure researchers to focus on? Survey closes in 1 week – have your say today!: [link] #epilepsypriorities

Don't miss out on the chance to have your say in shaping the future of #epilepsy research in Canada! Pick your top priorities today: [link] #epilepsypriorities

Last chance to have your say in helping shape the future of #epilepsyresearch in Canada! Choose your top #epilepsypriorities today: [link]

Facebook

Posts should include:

- Link to survey: [insert link when ready]
- Graphic
- Brief message (the suggested tweets can be used here, as well)

Additional guidance:

Be strategic about your use of hashtags. One hashtag per post should be sufficient.

You are welcome to modify the tweets to make them relevant to your organization! We are looking for consistent messaging, however we want to make sure the messaging is salient to all our intended audiences.

Email/E-newsletter suggested text:

The content body can be used either for the body of an email inviting a partner to disseminate the survey, or to be included in a partner's newsletter. You can optionally include a copy of the Twitter graphic, poster, or both.

Subject line examples:

- Pick your priorities for the future of Epilepsy Research
- Have your say in the future of epilepsy research [include timeframe of survey window, e.g., "two weeks left!"]
- We want to hear from you: Pick your top priorities for [epilepsy]/[seizure] research

Content body (when emailing a general audience)

[Dear [X],]

The Ontario Brain Institute's (OBI) epilepsy research program (EpLink) wants the input of Canadians living with or caring for people with epilepsy or seizures to set the priorities for epilepsy research in Canada.

If you have epilepsy or experience seizures, or if you care for or work with someone who does, we want your help in setting the priorities for epilepsy research by picking your top research priorities in a short survey.

Your rankings in this survey will help direct researchers and research funding organizations to the answer the questions that are most important to people living with epilepsy and/or seizures when planning future research projects.

This priority setting process follows the methods of the James Lind Alliance (UK) and is being funded by OBI. It is led by a Steering Committee that includes patient advocates, patient advocacy group representatives, clinicians, and healthcare professionals working with persons who have epilepsy and/or seizures.

This is an opportunity for you to lend your own personal/professional expertise and have your say in setting epilepsy research priorities. We are looking to receive 500+ responses.

Please complete this short questionnaire at: **http://www.braininstitute.ca/epilepsy-psp** (also available in French)

This survey is open from January 7, 2021 to March 7, 2021 – pick your priorities today.

This study has been reviewed by the Community Research Ethics Board. For more information, please contact Rebecca Woelfle, JLA Project Coordinator at **rwoelfle@eplink.ca** or 519-494-8817.

Thank you for your help,

[+ your name and organizational affiliation(s)]

Content body (when emailing healthcare professionals)

[Dear [X],]

The Ontario Brain Institute's (OBI) epilepsy research program (EpLink) is looking to gather the input of Canadians caring for people with epilepsy or seizures to set the priorities for epilepsy research in Canada. The project aims to identify a top ten list of questions that people living with epilepsy, their family and friends, and healthcare professionals (HCPs) jointly agree are the most important for research to address.

To inform this top ten list, we are inviting you to participate in a short survey. The survey should take approximately 5-10 minutes to complete, where you can select up to 10 research questions you feel are most important to address that will improve your practice and your patients' lives.

Your rankings to this survey will help researchers and research funding organizations better identify what is important to people living with epilepsy and/or seizures as well as their care providers and incorporate their priorities when planning future research projects.

You can take the survey here: **http://www.braininstitute.ca/epilepsysurvey**

It would be greatly appreciated if you could support this initiative. Here are some ways you can help:

1. Take part by completing the survey: **http://www.braininstitute.ca/epilepsysurvey**
2. Share the survey with your team/colleagues and other HCPs.
3. Share the survey with support groups or professional groups you might have connections with. We are looking to receive at least 500 responses, so all sharing is appreciated.
4. Raise awareness via newsletters/webpages/blogs/social media - please follow the Twitter accounts @EpLinkON, @OntarioBrain, @LindAlliance

The survey is open from January 7, 2021 to March 7, 2020 – pick your priorities today.

This study has been reviewed by the Community Research Ethics Board. For more information, please contact Rebecca Woelfle, JLA Project Coordinator at **rwoelfle@eplink.ca** or 519-494-8817.

Background on the survey:

The research questions in the above survey are the result of a first survey of the epilepsy community, i.e., people living with epilepsy, their family and friends, and HCPs, which received over responses from over 500 people across Canada. All submissions were summarized and checked against evidence to determine which questions are currently unanswered by research.

The rankings in this survey will inform a short list of the most picked questions will then go into our final workshop for people living with epilepsy, their families, and HCPs to jointly agree on the top 10.

Thank you for your help,

[+ your name and organizational affiliation(s)]

Another version (slightly longer):

[Dear [X],]

The Ontario Brain Institute's (OBI) epilepsy research program (EpLink) is looking to gather the input of Canadians caring for people with epilepsy or seizures to set the priorities for epilepsy research in Canada. The project aims to identify a top ten list of questions that people living with epilepsy, their family and friends, and healthcare professionals (HCPs) jointly agree are the most important.

Your rankings to this survey will help researchers and research funding organizations better identify what is important to people living with epilepsy and/or seizures and incorporate their priorities when planning future research projects.

Our project has three stages which, importantly, need the views and experiences of people living with epilepsy, their family and friends, and HCPs.

Firstly, people who represent these groups submitted their questions about epilepsy and seizures in a survey, and over 500 submissions were received. From these, we identified a long list of questions which remain unanswered by research.

We are now in the second stage and **we are inviting people to pick the questions from the long list which they feel are most important in a short survey**. A shortlist of the most picked questions will then go into our final workshop for people living with epilepsy, their families, and HCPs to jointly agree on the top 10.

It would be greatly appreciated if you could support this initiative. Here are some ways you can help:

1. Take part by completing the survey: **http://www.braininstitute.ca/epilepsysurvey**
2. Share the survey with your team/colleagues and other HCPs.
3. Share the survey with support groups or professional groups you might have connections with. We are looking to receive at least 500 responses, so all sharing is appreciated.
4. Raise awareness via newsletters/webpages/blogs/social media - please follow the Twitter accounts @EpLinkON, @OntarioBrain, @LindAlliance

The survey is open from January 7, 2021 to March 7, 2021 –pick your priorities today.

This study has been reviewed by the Community Research Ethics Board. For more information, please contact Rebecca Woelfle, JLA Project Coordinator at **rwoelfle@eplink.ca** or 519-494-8817.

Thank you for your help,

[+ your name and organizational affiliation(s)]