

dravetCanada Request for Research Letter of Intent -2017

1. Summary and Background

dravetCanada is the Canadian Network for families, friends and caregivers of people with Dravet spectrum disorders and is registered in Canada as Charitable organization # 850807843RR0001.

dravetCanada receives and maintains funds and will apply all or part of the principal and income therefrom, from time to time, to qualified donees as defined at section 149.1(1) of the Income Tax Act (Canada).

The goal of our Network is to support individuals and families affected with this type of epilepsy and promote research so that one day there may be an effective treatment to prevent the disabilities associated with this disorder or perhaps a cure.

We are receiving Letters of Intent until October 13, 2017. We will be reviewing these letters of and will request complete applications from those short-listed during that process.

2. Enquiries and Submissions

All enquiries related to this Request for Research Letter of Intent (LOI), including any requests for information and clarification, are to be directed via email to research@dravet.ca. Queries will normally be responded to within 24 hours.

Delivery of LOI's

Proposals are to be submitted by mail or e-mail to:

dravetCanada – Research
6-2400 Dundas St. West, Suite 211
Mississauga, ON L5K 2R8
Email: research@dravet.ca

3. LOI Guidelines

All submissions must include as much of the following information as possible.

Principal Investigator: This is the owner of the project, the team leader who is responsible for all research, procedures and follow-up for this project. All proposals must be signed by the principal investigator.

Project Contact: This is the administrative lead, who we contact when we have questions.

Project Title: If the final title of the project has not been decided, supply the working title. This must be supplied in English and French.

Other partners: e.g. Suppliers of product to be used in Clinical Trial.

Other Funding Partners: Please include confirmed sponsors and funding you will wait on before beginning your project.

4. Project Purpose and Description

(Title and abstract must be submitted in English and French)

Project description:

dravetCanada is seeking to increase research into understanding, care, treatments and potential cures for Dravet spectrum disorders. We want to improve the lives of these patients and their families.

In a thousand words or less, in lay language, please include the type of research project (basic science, clinical trial, another purpose); if this is a long-term project, what stage it is in; please also include end points, population, controls, what is considered success; will participants maintain access to the medication after a trial has ended.

5. Project Scope

Will you be studying Dravet spectrum disorders specifically, an aspect of them, an aspect of a larger group of disorders? Please describe

Patient Engagement:

Describe your Patient Engagement Strategy for the life cycle of the research project (from study design to knowledge translation). E.g. for "clinical trials", access to medication at completion of trial; patient discussions before deciding endpoints.

In which institution(s) and clinic(s) will the research be conducted.

6. Request for Proposal and Project Timeline

Expected start date (when do you expect to have all permissions and funding in place to start)

Expected completion date (primary target date for first and other defined phases)

Length of the project (months/years)

7. Budget

Funding (sources, methods...)

Please specify funding Amount Requested, what percentage of the overall budget does this represent, how would these funds be utilized, and the estimated annual budget for each year of the project.

Will the project proceed before full funding is realized? If so, what percentage is necessary to begin each stage.

9. Proposal Evaluation Criteria

Oversight:

Please list Ethics Board and other human research approvals, fiduciary oversight committees, what safety and data monitoring will be in place throughout the project, will there be other independent committees reviewing the data as it is collected (e.g. Steering Committee).

Deliverables:

We require your agreement to provide us with copies of/access to forthcoming reports (e.g. quarterly reports submitted to dravetCanada Board of Directors) and acknowledgement of funding from dravetCanada in research articles and knowledge translation activities (such as presentations).

What other deliverables do you expect to generate, and when? E.g. publications, types, amount expected, open access, federally funded, grey literature, quarterly or other regular reporting periods. Which of these will you likely be able to share with us.

Please include as much of this information as possible and submit your application via email or mail to

dravetCanada – Research
6-2400 Dundas St. West, Suite 211
Mississauga, ON L5K 2R8
Or
research@dravet.ca

Thank you for your time and consideration.
Please feel free to forward to anyone who may be interested.

Patti Bryant,
Research Committee