

dravetCanada Request for Research Proposal -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.

With this rfrp, we want to receive sufficient information to make fair and responsible decisions regarding research funding, without making the process unnecessarily complicated and onerous on the part of the investigators or our reviewers.

Application deadline is January 5, 2018. Decisions will be announced March 26th.

2. Enquiries and Submissions

All enquiries related to this Request for Research Proposal (RFP), 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 Proposals

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. Proposal Guidelines

All proposals must include the following information

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.

Funding Contact: This is the person who represents the funding arm of the qualified donee as defined at section 149.1(1) of the Income Tax Act (Canada), the person who will manage transferring funds from us to the project.

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

(This section 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, 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.

8. Researcher Qualifications

Primary researchers should include current curricula vitae, lists of publications, affiliations, etc.; who is the lab staff heading the project “on the ground”; how many researchers and clinicians will be involved with this project, in what capacities, and what qualifications do you require of them.

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

We hereby submit this application for consideration of funding by dravetCanada

Primary Investigator

Administrative Lead

Signature

Signature

Name, affiliation, address, date:

Name, affiliation, address, date: