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## **CIHR Team Grant : Pediatric Rare Disease Clinical Network**

### **Sponsor**

Canadian Institutes of Health Research (CIHR), under the scientific leadership of the CIHR Institute of Genetics, and in partnership with the Government of Canada's National Strategy for Drugs for Rare Diseases

### **Program**

[Team Grant : Pediatric Rare Disease Clinical Network](#) [1]

### **Description**

This new funding opportunity will support the creation of a Pediatric Rare Disease Clinical Network. Every year, 14,000 Canadian children under the age of 15 die from a rare disease and many rare diseases can take up to five years to diagnose. This network will help streamline rare diseases clinical research across Canada and improve health outcomes for people living with rare diseases.

This Network will maximize synergies to advance discovery across the rare disease continuum from prevention to diagnosis through to treatment and survivorship to improve health outcomes for children and adolescents affected by rare diseases. The aim is to support national and international clinical trials to rapidly advance discoveries to support rare diseases patients and their families across Canada. It will maximize the impact of the Government of Canada's efforts deployed in the regulatory modernization for health products, improve Canada's standing globally and attract industry dollars for future investments and sustainability.

CIHR recognizes that a broad range of partners may be relevant to this opportunity, and it is expected that applicant(s) describe the role of all [applicant partners](#) [2] and how/if they will contribute to research-related activities. Any consideration of risk and/or conflict of interest should also be explained, as appropriate.

### **Objectives**

The specific objectives of this funding opportunity are to:

- Develop a platform to support pediatric rare disease clinical trials in Canada in an accessible manner, for both the profit and not-for-profit sectors, to maximize the impact and benefit of the research for clinical practice, policy and future research;

- Increase the capacity to perform rare disease clinical trials in Canada by offering training and mentorship opportunities for researchers, patients, clinicians and other relevant stakeholders;
- Attract international clinical trials, increasing investments in Canada and providing earlier access to innovative therapies to people living in Canada;
- Foster diversity and inclusion in and improve access to clinical trials;
- Implement processes to acquire data from clinical trials, real world registries, health economics evaluation, and post-marketing surveillance to inform assessment reviews throughout the whole drug/therapy cycle; and,
- Increase the number of new rare disease drug submissions for authorization of commercialization to Health Canada.

## Eligibility

For an application to be eligible, all the requirements stated below must be met:

1. The Nominated Principal Applicant (NPA) must be:
  1. an [independent researcher](#) [3] affiliated with a Canadian postsecondary institution and/or its affiliated institutions (including hospitals, research institutes and other non-profit organizations with a mandate for health research and/or knowledge translation).  
OR
  2. an individual affiliated with an Indigenous non-governmental organization in Canada with a research and/or knowledge translation mandate.  
OR
  3. an Indigenous non-governmental organization in Canada with a research and/or knowledge translation mandate.
2. The NPA must have their [substantive role in Canada](#) [4] for the duration of the requested grant term.
3. The Institution Paid must be [authorized to administer CIHR funds](#) [5] before the funding can be released (see [Administration of Funds](#) [6]).
4. The research team must include an [Early Career Researcher \(ECR\)](#) [7] identified as a Principal Applicant (PA).
5. At least one project participant must be a [knowledge user](#) [8] (including but not limited to [decision makers](#) [9], policy-makers, clinician scientists, health professionals) identified as Principal Knowledge User (PKU) or Knowledge User (KU).
6. In addition to the Nominated Principal Applicant and Knowledge User, at least one Co-Applicant must be a [patient](#) [10].
7. The applicant team must include at least one applicant who self-identifies as Indigenous (First Nations, Inuit or Métis) and/or provides evidence of having [meaningful and culturally safe](#) [11] involvement with Indigenous Peoples.
8. The applicant team must have a [Sex and Gender Champion](#) [12] and an [Equity, Diversity and Inclusion \(EDI\) Champion](#) [13] :
  - Combined, the champions must have experience in (i) sex- and gender-based analysis (SGBA) or with gender diversity in the community; (ii) fostering EDI in research and/or applied settings (e.g., promoting equitable access to research participation or inclusion of typically underrepresented population groups in decision making), and (iii) creating Sex and Gender and EDI plans for diversity of

- team composition;
  - These individuals may hold other roles within the team in addition to standing as the team's Sex and Gender and EDI champions;
  - The Sex and Gender and EDI champion roles may be served by the same individual or different individuals.
9. The applicant team must include representation from a [minimum of five provinces/territories](#) [6]

## Funding Availability

CIHR and partner(s) financial contributions for this initiative are subject to availability of funds. Should CIHR or partner(s) funding levels not be available or are decreased due to unforeseen circumstances, CIHR and partner(s) reserve the right to [reduce, defer or suspend financial contributions](#) [14] to grants received as a result of this funding opportunity.

- The total amount available for this funding opportunity is \$20,000,000 enough to fund one (1) grant over 5 years. This amount may increase if additional funding partners participate.
- The \$20,000,000 will be available according to the following profile:
  - Year 1: \$6,867,188
  - Year 2: \$4,281,250
  - Year 3: \$4,000,000
  - Year 4: \$3,882,813
  - Year 5: \$968,750
- For more information on the appropriate use of funds, refer to [Allowable Costs](#) [15].

## Deadlines

**If College-level review is required, your College will communicate its earlier internal deadlines.**

| Type                     | Date                            | Notes   |
|--------------------------|---------------------------------|---|
| <b>External Deadline</b> | Tuesday, June 27, 2023 - 8:00pm | Note that this task is mandatory to be eligible to submit a Full application as the Nominated Principal Applicant (NPA).  |
|                          |                                 | <ul style="list-style-type: none"><li>• Applicants interested in submitting, participating in and/or joining an application to this call must email an Expression of Interest (EOI) to <a href="mailto:support-soutien@cihr-irsc.gc.ca">support-soutien@cihr-irsc.gc.ca</a> [16] by 8:00 pm (EDT) on June 27th,</li></ul> |

| Type | Date | Notes  |
|------|------|--|
|      |      | <p>2023.</p> <ul style="list-style-type: none"><li>• The email must include contact information (email address and telephone numbers) as well as an area of expertise. The email subject line must be "EOI: National Pediatric Rare Disease Clinical Trials and Treatment Network".</li><li>• Email submission of the EOI also affirms your consent for CIHR to coordinate a Collaboration Call with other applicants to explore collaborations across teams.</li><li>• Please copy Kristin Zimmermann (<a href="mailto:kristin5@uoguelph">kristin5@uoguelph</a>) from RSO on the EOI email to CIHR. If invited to submit a full-proposal at Step 3, applicant will need to submit a copy of the application (PDF) and OR-5 to RSO (<a href="mailto:research.services@uoguelph.ca">research.services@uoguelph.ca</a>) one week prior to the full application deadline.</li></ul> |

## How to Apply

- The application process for this funding opportunity is comprised of three steps: Expression of Interest, Collaboration Call, and Full Application.
- All participants listed, with the exception of Collaborators, are required to:
  - Have/obtain a [CIHR PIN](#) [17]
  - Complete the [Equity, Diversity and Inclusion Self-identification Questionnaire](#) [18] .

## Step 1 – Expression of Interest (EOI)

The objective of the EOI is to enable applicants to signal interest in submitting, participating and/or joining applications to this call. It will also facilitate participation in the Collaboration Call and subsequent stages of this competition. While there will only be one grant awarded, collaboration is highly encouraged.

Note that this task is mandatory to be eligible to submit a Full application as the Nominated Principal Applicant (NPA).

- Applicants interested in submitting, participating in and/or joining an application to this call must email an Expression of Interest (EOI) to [support-soutien@cihr-irsc.gc.ca](mailto:support-soutien@cihr-irsc.gc.ca) [16] by 8:00 pm (EDT) on June 27th, 2023.
- The email must include contact information (email address and telephone numbers) as well as an area of expertise. The email subject line must be "EOI: National Pediatric Rare Disease Clinical Trials and Treatment Network".
- Email submission of the EOI also affirms your consent for CIHR to coordinate a Collaboration Call with other applicants to explore collaborations across teams.

## Step 2 – Collaboration Call

- CIHR will schedule a Collaboration Call for July 6, 2023, 1pm EDT with those who submitted an EOI to: (1) support participants with the requirements of this funding opportunity; (2) allow participations to explore potential collaboration across teams prior to the submission of the Full application; and (3) answer questions. It is mandatory for those who have submitted an EOI to attend this meeting to be eligible to submit a Full application as a Nominated Principal Applicant.
- A formal meeting invite will be sent by email following the EOI deadline.

## Step 3 – Full Application

- To complete your Full Application, follow the instructions listed in the [Grants – Application Guidelines](#) [19], along with any additional instructions below found under "specific instructions"
- All participants listed on the application, with the exception of Collaborators, are required to:
  - Have/Obtain a [CIHR PIN](#) [17];
  - Complete the [Equity, Diversity and Inclusion Self-Identification Questionnaire](#) [20].
- Organizations applying as Nominated Principal Applicants for the first time must contact CIHR's [Contact Centre](#) [21] for guidance in creating a ResearchNet account and registering for a CIHR PIN.
- When completing the application, applicants must protect the privacy and confidentiality of all team members. How an individual self-identifies is personal and confidential information, which should not be disclosed without consent.

## Information For Co-applicants

If you need to meet a deadline set by the lead institution for this opportunity, please ensure that you provide the Office of Research with at least five days in advance of the lead institution's deadline to review the application, or your proposed component of the project. Please be in touch with the Office of Research (contact information below) ahead of the deadline if it looks like it will be difficult for you to submit all the required documentation on time (i.e. budget, proposal, OR-5 Form).

For Questions, please contact

### CIHR

CIHR Contact Centre

Telephone: 613-954-1968

Toll Free: 1-888-603-4178

Email: [support-soutien@cihr-irsc.gc.ca](mailto:support-soutien@cihr-irsc.gc.ca) [16]

### Office of Research

Kristin Zimmermann, Senior Grants & Contracts Specialist

Research Services Office

519-824-4120 x56257

[kristin5@uoguelph.ca](mailto:kristin5@uoguelph.ca) [22]

Alert Classifications **Category:**

Funding Opportunities and Sponsor News

### Disciplines:

Health and Life Sciences

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### Source

**URL:** <https://www-research.uoguelph.ca/research/alerts/content/cihr-team-grant-pediatric-rare-disease-clinical-network>

### Links

[1] <https://www.researchnet-recherchenet.ca/rnr16/vwOpprntnyDtIs.do?prog=3920&view=currentOpps&org=CIHR&type=EXACT&resultCount=25&sort=program&next=1&all=1&masterList=true>

[2] <https://cihr-irsc.gc.ca/e/34190.html#p1>

[3] <https://cihr-irsc.gc.ca/e/34190.html#r6>

[4] <https://cihr-irsc.gc.ca/e/51197.html>

[5] <https://cihr-irsc.gc.ca/e/50805.html#g-4>

[6] <https://www.researchnet-recherchenet.ca/rnr16/vwOpprntnyDtIs.do?prog=3920&view=search&terms=rare+disease&org=CIHR&type=EXACT&resultCount=25&next=1#moreinformation>

[7] <https://cihr-irsc.gc.ca/e/34190.html#r14>

[8] <http://www.cihr-irsc.gc.ca/e/34190.html#k4>

- [9] <https://cihr-irsc.gc.ca/e/34190.html#d4>
- [10] <https://cihr-irsc.gc.ca/e/48952.html#p1>
- [11] <http://www.cihr-irsc.gc.ca/e/50340.html>
- [12] <http://www.cihr-irsc.gc.ca/e/50652.html>
- [13] <https://www.researchnet-recherchenet.ca/rnr16/vwOpprtntyDtls.do?next=1&prog=3734&resultCount=25&terms=THINC&type=EXACT&view=search&language=E#definitions>
- [14] [https://www.nserc-crsng.gc.ca/InterAgency-Interorganismes/TAFA-AFTO/guide-guide\\_eng.asp#17](https://www.nserc-crsng.gc.ca/InterAgency-Interorganismes/TAFA-AFTO/guide-guide_eng.asp#17)
- [15] <https://www.researchnet-recherchenet.ca/rnr16/vwOpprtntyDtls.do?prog=3920&view=search&terms=rare+disease&org=CIHR&type=EXACT&resultCount=25&next=1#guidelines>
- [16] <mailto:support-soutien@cihr-irsc.gc.ca>
- [17] <http://www.cihr-irsc.gc.ca/e/38201.html>
- [18] <http://www.cihr-irsc.gc.ca/e/50959.html>
- [19] <https://cihr-irsc.gc.ca/e/50454.html>
- [20] <http://www.cihr-irsc.gc.ca/f/50959.html>
- [21] <https://www.researchnet-recherchenet.ca/rnr16/vwOpprtntyDtls.do?prog=3920&view=search&terms=rare+disease&org=CIHR&type=EXACT&resultCount=25&next=1#contactinformation>
- [22] <mailto:kristin5@uoguelph.ca>