**Rare Disease Registry Funding**

**Letter of Intent Application**

Contract: C-242506400

Please complete this application and submit it to [contracts@cda-amc.ca](mailto:contracts@cda-amc.ca) before the application deadline of **April 16, 2025,** by 11:59 P.M. (ET). Save the file as a document (.docx) or portable document format (.pdf). Only 1 application per organization. Refer to RFP Section 3 and 4 for more information.

1. **Applicant Information**

| **Registry name** | **Name** |
| --- | --- |
| **Legal organization name**  **Mailing address**  **Contact information**  (email, phone number, and website) | Details of legal organization or host institution with authority to execute a contract and receive funds from CDA-AMC. |
| **Lead applicant** | Name: Name  Credentials: E.g., PhD, MD.  Job title: Title, Institution  Relevant experience and expertise of team (75 words): Experience in supporting registry improvements. |
| **Co-applicant 1** | Name: Name.  Credentials: E.g., PhD, MD.  Job title: Title, Institution |
| **Co-applicant 2** | Name: Name.  Credentials: E.g., PhD, MD.  Job title: Title, Institution |
| **Funds** | Is the registry receiving funds in 2025–2026 from another component of the National Strategy for Drugs for Rare Diseases?  No  Yes, specify: Name of funding source or project and $ |

1. **Registry Information**

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| --- | --- |
| **Domain** | **Information** |
| **Definition** | What classification is being used to determine whether the diseases(s) captured by registry is (are) rare?  FDA or National Organization for Rare Disorders (NORD)  European Medicines Agency (EMA)  Other (specify): Specify unmet need of disease if not listed in existing rare disease classifications. |
| **Overview** | Number of patients: Enter approximate #  Coverage in Canada: Which provinces, territories, and clinical sites?  Affiliations: Clinical groups, other registries, patient groups, or other connected networks.  Types of data collected by the registry (select all that apply)  Clinical  Demographic  Patient or caregiver reported  Treatment  Other, specify: Provide info |
| **Other relevant information** | Is there any other aspect of the registry that will be important for CDA-AMC to know:  Add Information |

1. **Drugs for Rare Diseases of Focus**

|  |  |
| --- | --- |
| **Data collection** | Does the registry have capacity or capability to address evidence gaps related to specific drugs for rare diseases (DRD) (select only 1):  Yes  No, but proposing to build capacity  No, explain circumstance: Details |
| **Specific DRD 1** | **DRD name:** Add Information.  Indication: Add Information.  DRD prioritization level (refer to RFP): Select level.  Current status Provide description, E.g. Active review at pCPA. |
| **Specific DRD 2** If a registry is focusing initiatives on more than 2 drugs, please add information following the entry for DRD 2 | **DRD name:** Add Information.  Indication: Add Information.  DRD prioritization level (refer to RFP): l: Select Level.  Current status Provide description, E.g. Active review at pCPA. |

1. **Proposed Initiatives**

Describe a summary of proposed improvement initiatives for your registry and how they could aim to help address evidence uncertainties for specific DRDs – maximum 300 words.

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| Add narrative details, may include bullet points – max 300 words |

1. **Declarations**

By submitting this LOI application to CDA-AMC, you confirm that the information provided is accurate and complete to the best of your knowledge.

You acknowledge that should this LOI advance to the next stage of the application, you will be required to submit a detailed proposal.

You acknowledge that should you be awarded a contract though this RFP, the funding will be administered via a contractual agreement, and not a grant. You will be required to comply with the conditions of the agreement and the payment will be in receipt of deliverables as per the contract.

Name: Click or tap here to enter text.

Date: Click or tap here to enter text.