

## **COORDINATOR, SPECIAL PROJECTS AND INITIATIVES - JOB DESCRIPTION**

### **About the Organization**

Canadian Society for Mucopolysaccharide and Related Diseases Inc., is a national not for profit organization, serving all Canadians affected by MPS and related diseases through support, education, advocacy and by advancing research.

The Coordinator, Special Projects and Initiatives, works with INFORM RARE and our partners in the Canadian Inherited Metabolic Diseases Research Network (CIM-DRN) in co-designing a Canadian patient oriented MPS registry and MPS newborn screening advocacy campaign in Canada.

### **Job Description**

The Coordinator, Special Projects and Initiatives assists the Executive Director in managing, coordinating, developing, and mobilizing various activities related to the Newborn Screening Advocacy Campaign and National MPS Registry.

### **Responsibilities:**

- Conduct literature reviews, analyze and summarize information for use by decision makers
- Develop and manage relationship with key stakeholders in the Canadian healthcare policy research and rare disease area
- Collaborate with team members, and analyze issues/programs from a policy perspective and perform, coordinate, and oversee project-dependent activities.
- Facilitate connections between Canadian MPS Society, INFORM RARE, CIMDRN, patients, caregivers, rare disease advocates and policy makers
- Identify areas of unmet patient need and design collaborative solutions with the professional community.
- Work collaboratively with team members and community partners to carry out project plans, provide strategic support and achieve objectives related to the project.
- Project monitoring of all activities.
- Represent activities of Canadian MPS Society externally
- Other duties, as assigned

**Ideal candidate will have:**

- Demonstrated knowledge and understanding of Canadian healthcare policy and healthcare system
- Relevant experience or education in rare diseases
- Excellent digital skills (i.e., MS Word, MS Excel, MS Outlook)
- Ability to multitask and excellent verbal, written, and presentation skills
- Ability to take initiative and work independently
- Currently enrolled in a Graduate program in healthy policy management, public health, or related Health Sciences Program
- Bilingual (French and English)

Remote, Part-time, 16-week contract with possibility of extension.

This position is funded by Biotalent Canada's Student Work Placement Program. Only students enrolled part time / full time in a university program and are Canadian citizens, permanent residents and/ or conferred refugee status can be considered for the position.

Please forward CV with covering letter (PDF files preferred) by **November 15, 2020** to:

Kim Angel, Executive Director  
**[kimangel@mpsociety.ca](mailto:kimangel@mpsociety.ca)**

Note: We thank all candidates for their interests. However, only those selected for interviews will be contacted. No telephone calls please.