

TELL US YOUR STORY

The PARTNERS team are holding consultations in a face to face or virtual setting to understand the following:

- 1) What is important to patients and families affected by rare disease with respect to research and clinical care in Canada?
- 2) How would patients and families like to be engaged by the PARTNERS network in the effort to improve research and clinical care for rare disease in Canada?
- 3) What services can the PARTNERS network provide to help patients and families dealing with their rare disease?
- 4) What are the highest priorities for patients and families with respect to clinical care and research improvements in rare disease in Canada?

Complete our survey:

<https://www.surveygizmo.com/s3/2118051/PARTNERS-poster>



This project has been approved by the University of Calgary Conjoint Health Research Ethics Board (REB15-1606)

WHAT IS PARTNERS?

PARTNERS (Patient Assisted Research Transforming National Effectiveness in Rare Diseases) is a proposed SPOR (Strategy for Patient Oriented Research) Network in Chronic Disease that has a vision of working together with Canadian rare disease patients and their families to implement a clinical care and research strategy that will improve outcomes and reduce the burden of rare disease by the year 2021.

Canada's strategy for patient oriented research aims to ensure that all patients receive the interventions they need when they need them. The strategy aims to collaborate and engage the patient community to assist the development of innovative diagnostic and therapeutic approaches to improve the quality, accountability and accessibility of care.



ATTEND A GROUP INTERVIEW

A series of group interview sessions discussing rare disease patient, family, and caregiver experiences as well as discussing rare disease research and patient and family priorities for research will be held in communities across Canada. If you, or your family member or caregiver are interested to participate please register to attend your local session here:

Visit: <http://partnersnetwork.eventbrite.ca>

TO OBTAIN MORE
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