

## VISION

**Innovative care and research in Canada so that all patients and families affected by a rare disease are empowered to live their full potential.**

## MISSION

Establish a growing network that builds connections across geographies and disease boundaries to enable timely diagnosis, screening, and access to treatment, and facilitate best care, support and empowerment, and global sharing of best practices for patients and their families in Canada, ultimately enhancing their quality of life.

## VALUES

Patients and Families First  
 Collaboration and Inclusivity  
 Equity  
 Innovation  
 Excellence  
 Solidarity and Mutual Respect  
 Empowerment



### PILLAR 1: DIAGNOSTICS AND REGISTRIES

**Goal 1.1:** All RD patients will receive the right diagnostic test at the right time regardless of where they live in Canada.

**Goal 1.2:** Genetic diagnostic laboratories across Canada will integrate resources and best practice guidelines to ensure high-quality GWS for patients.

**Goal 1.3:** All families with diagnosed and undiagnosed RD will have access to relevant registries for secondary research and re-contact.

**Goal 1.4:** RD diagnostics and research will be a political priority and sustainably funded.

**Goal 1.5:** Canada will be a world leader in RD mechanism discovery and translation of new technologies into the clinic.



### PILLAR 2: INNOVATIVE THERAPIES

**Goal 2.1:** Canada will lead in the discovery and validation of novel therapeutic targets and treatments for RD patients.

**Goal 2.2:** All RD patients, regardless of their age, location, or social context, will have equitable access to clinical trials and innovative therapies.

**Goal 2.3:** Innovative therapies will be readily integrated into clinical practice to improve patient care and outcomes.

**Goal 2.4:** Canada will be recognized globally for its RD clinical trials potential and as an attractive hub for investment and partnerships.



### PILLAR 3: CARE, SUPPORT, AND EMPOWERMENT

**Goal 3.1:** All RD patients, along with their families and caregivers, will be aware of and have equitable access to the resources and supports they need.

**Goal 3.2:** All individuals affected by RD will have the opportunity to be empowered and engaged in meaningful opportunities in research and beyond.

**Goal 3.3:** All RD patients and their families will receive the mental health and wellbeing support they need regardless of their location or social determinants of health.

**Goal 3.4:** Canada will have a unified RD community that strengthens comprehensive care and support systems for RD patients and their families.



### PILLAR 4: NATIONAL AND GLOBAL COLLABORATION

**Goal 4.1:** Canada will have a unified national approach to RD that drives innovation and improves care for all RD patients.

**Goal 4.2:** Canada will be recognized as a key global player in RD research, innovation, and knowledge exchange, benefiting patients worldwide.