

FINDING THE MISSING PIECE

A VISION FOR RARE DISEASE CARE IN CANADA

While Canada is known for its world-class economy, education system, and high standard of living, we are well behind many other countries when it comes to caring for people with rare diseases.

However, with growing awareness and 2019 government funding commitments, Canada now has a unique opportunity to create one of the best health systems in the world to test for, diagnose and treat rare diseases.

All the foundational pieces exist:

Patient need

3 million Canadians have rare diseases. Two-thirds are childrenⁱ

Expertise

Canada has world-class doctors and researchers at the forefront of rare disease therapies and care

Societal imperative

Rare diseases take a tremendous toll on families, health systems, and society

Community leadership

CORDⁱⁱ is leading pan-Canadians efforts to improve diagnosis, care, and treatment

Experience

Global best-practices can help us create a world-class system in Canada

Funding

\$1.5 billion committed to fund national strategy for rare disease drugsⁱⁱⁱ

The missing piece

POLITICAL WILL

We need government action to implement rare disease strategies

RAREi'S VISION TO IMPROVE RARE DISEASE CARE IN CANADA

Better access to therapies



Design a special system for reviewing rare disease medicines

Improved care pathways



Create rare disease centres across Canada to provide specialized care and treatment

Focused on results for patients



Embrace value-based healthcare, which rewards quality (improved outcomes) rather than quantity (volume of services)

Visit [rarei.ca/vision](https://www.rarei.ca/vision) to learn more about RAREi's vision.

i. <https://www.raredisorders.ca/canadas-rare-disease-strategy/>

ii. Canadian Organization for Rare Disorders

iii. <https://www.canada.ca/en/health-canada/news/2023/03/government-of-canada-improves-access-to-affordable-and-effective-drugs-for-rare-diseases.html>