

The Quebec Policy and Action Plan for Rare Diseases & the RQMO's iRARE Centre

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Canadian Organization for Rare Disorders' Fall Conference

November 2023

REGROUPEMENT QUÉBÉCOIS DES MALADIES ORPHELINES / QUEBEC COALITION OF ORPHAN DISEASES



MISSION

Inform & support

Awareness

Disseminate
information

Facilitate research

POUR UNE MEILLEURE RECONNAISSANCE ET PRISE EN CHARGE DES PERSONNES ATTEINTES DE MALADIES RARES

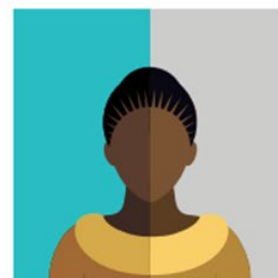
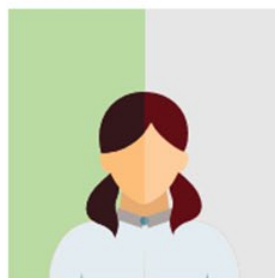
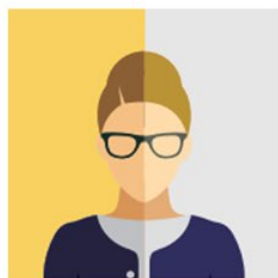
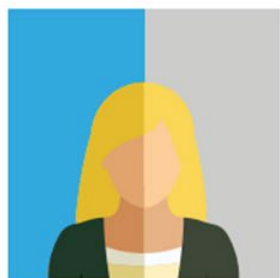
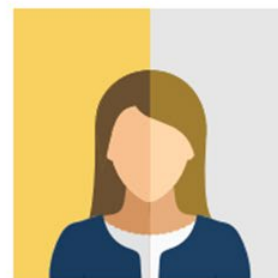
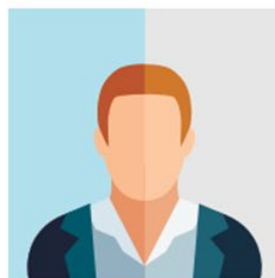
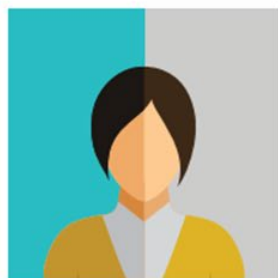
POLITIQUE QUÉBÉCOISE

POUR LES MALADIES RARES

QUEBEC'S POLICY FOR RARE DISEASES

Québec 

June 2022



POUR UNE MEILLEURE RECONNAISSANCE ET PRISE EN CHARGE DES PERSONNES ATTEINTES DE MALADIES RARES

POLITIQUE QUÉBÉCOISE

POUR LES MALADIES RARES

QUEBEC'S POLICY FOR RARE DISEASES

#1

Raising awareness
and training of
doctors & health
professionals

#2

Easy and
equitable access
to diagnosis, care,
and services

#3

Promotion of
research,
innovation, and
data collection

#1

Raising awareness and training of doctors & health professionals

- Raise awareness about RDs in medical milieu
- Encourage knowledge transfer
 - Encourage partnerships between the health network and patient-partners/patient organizations
- Improve training of doctors and other health professionals
- Support the development of clinical tools
- Facilitate access to information



#2

Easy and equitable access to diagnosis, care, and services

- **Reduce delay in diagnosis by improving and developing screening and diagnosis of RDs**
 - Preconception, newborn, and prenatal screening
 - Access to preimplantation diagnostic tests
 - Support the development of genomic medicine
 - Support the development of other screening or diagnostic tools
- **Better access to care and services**
 - Prioritization and connection (rapprochement) of services
 - Designate centres of reference and regional centres
 - Increase services
 - Increase access to dental care (\$)
 - Improve access to pharmaceutical services (Food Bank, blood products)

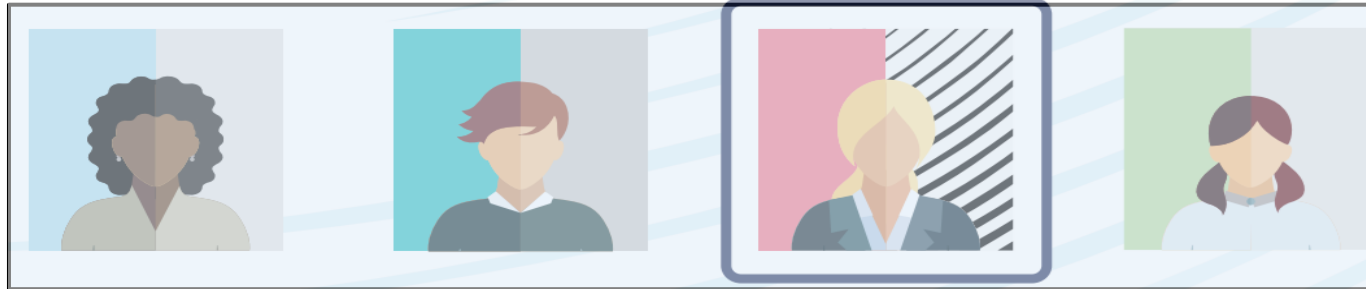


#3

Promotion of research, innovation, and data collection

- Establish a rare disease patient registry
- Promote fundamental, translational, and clinical research to better screen and understand RDs
- Facilitate knowledge transfer between researchers, clinicians, and patients
- Accelerate therapeutic innovation





Quebec Rare Disease Action Plan

May 2023

- Réseau national de navigation clinique pour MR (Navi-Nat)
- RD dental care program (\$)
- Increase services
- Add diseases to the Quebec Newborn Screening Program
- Deployment of the Réseau québécois de diagnostic moléculaire (RQDM)
- Reimbursement of fees for preimplantation diagnosis
- Development of a Quebec research network for RDs
- Creation of a RD patient registry

2023-2027
\$17,2 million



The RQMO's iRARE Centre



- Free
- Bilingual
- Professional



iRARE
centre

i NFORMATION
R ESOURCES
A ID
R EFERENCES
E DUCATION

For any rare or undiagnosed disease

*Open also to Canadians
outside of Quebec
for information on any
rare disease.*

INFORMATION AND SUPPORT are the keys to a better management of your disease.

INFORMATION



Articles in lay language, practice guidelines



Rare disease experts and specialized clinics



Orphan drugs, on the market or in development



Research projects and clinical trials



Basic genetic counselling



Patient registries and biobanks

SUPPORT



Matching

Matching with individuals/families with the same or similar rare disease



Listening



Referral to

- Patient organizations
- Support groups



Medical, government and community resources



IMPLEMENTATION OF A DIGITAL PLATFORM TO BRING TOGETHER RARE COMMUNITIES



Funded by the
Government of Canada's
Community Services Recovery Fund



**Community Services
Recovery Fund**



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DES MALADIES ORPHELINES



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