



Network Charter

The network to advance research on rare diseases in Quebec (RARE.Qc)

Approved by network members on : August 15, 2025

Approved by Fonds de recherche du Québec – Santé on : (Date)

## **Table of Contents**

<b>1. Network Overview</b>	4
<b>1.1 Network Overview</b>	4
<b>1.2 The vision, mission and goals of the network</b>	4
1.2.1 Vision	4
1.2.2 Mission	4
1.2.3 Goals	4
<b>1.3 Strategic alignment to Quebec priorities</b>	5
<b>2. Network Management</b>	5
<b>2.1 Executive Committee</b>	5
2.1.1 Responsibilities of the Director	5
2.1.2 Responsibilities of the Co-directors	6
2.1.3 Procedures for the nomination, mandate term and renewal of the Director and Co-directors.	6
2.1.4 Resignation of a Director or Co-director	7
<b>2.2 Network Manager</b>	7
<b>3. Governance Structure</b>	8
<b>3.1 General Assembly</b>	8
3.2 Overview of governance structure	9
<b>3.3 Management Committee</b>	9
3.3.1 Composition	9
3.3.2 Mandate	10
3.3.3 Operation	10
<b>3.4 Scientific Committee (and Senior Advisors)</b>	10
3.4.1 Composition	10
3.4.2 Appointment of Scientific Committee Members and Pillar Leads	11
3.4.3 Mandate of the Scientific Committee	12
3.4.4 Operation of the Scientific Committee	12
<b>3.5 EDI Committee</b>	13
3.5.1 Composition	13
3.5.2 Mandate	13
3.5.3 Operation	13
<b>3.6 Student Committee</b>	13
3.6.1 Composition	13
3.6.2 Mandate	14
3.6.3 Operation	14

<b>3.7</b>	<b>Knowledge Mobilization Committee .....</b>	<b>14</b>
3.7.1	Composition.....	14
3.7.2	Mandate .....	14
3.7.3	Operation .....	15
<b>3.8</b>	<b>Commercialization Committee.....</b>	<b>15</b>
3.8.1	Composition.....	15
3.8.2	Mandate .....	15
3.8.3	Operation .....	16
<b>3.9</b>	<b>Other Network Committees.....</b>	<b>16</b>
3.9.1	Working group governance.....	16
<b>4.</b>	<b>Membership .....</b>	<b>17</b>
<b>4.1</b>	<b>Membership criteria.....</b>	<b>17</b>
<b>4.2</b>	<b>Eligibility criteria.....</b>	<b>17</b>
4.2.1	Regular members .....	17
4.2.2	Partner members .....	17
4.2.3	Student members.....	18
4.2.3.1	Regular student members.....	18
4.2.3.2	External student members.....	18
<b>4.3</b>	<b>Membership Adhesion and Renewal .....</b>	<b>18</b>
<b>4.4</b>	<b>Membership Responsibilities and Benefits.....</b>	<b>18</b>
<b>5.</b>	<b>Scientific Structure.....</b>	<b>19</b>
<b>5.1</b>	<b>Research Pillars .....</b>	<b>20</b>
<b>5.2</b>	<b>Infrastructure and resources .....</b>	<b>20</b>
<b>5.3</b>	<b>Network activities .....</b>	<b>21</b>
<b>6.</b>	<b>Annual Report .....</b>	<b>21</b>
<b>7.</b>	<b>Conflict Resolution .....</b>	<b>21</b>
<b>8.</b>	<b>Amendments to the Charter .....</b>	<b>22</b>
8.1	Process for Amendments.....	22
<b>9.</b>	<b>Appendices .....</b>	<b>23</b>
<b>9.1</b>	<b>Membership form .....</b>	<b>23</b>
<b>9.2</b>	<b>Member Code of Conduct.....</b>	<b>28</b>
<b>9.3</b>	<b>Committee Composition 2024-2028 .....</b>	<b>31</b>

# **1. Network Overview**

## **1.1 Network Overview**

The research network is officially named the “**R**éseau pour **A**vaner la **R**Echerche sur les maladies rares au Québec (**RARE.Qc**)” or translated to English as the “Network to advance research on rare diseases in Quebec”. It is further described as “RARE.Qc” or “The Network” in this document.

RARE.Qc was awarded as a Thematic Network by the Fond de recherche du Québec – Santé (**FRQS**) in February 2024. The thematic networks of the FRQS are concerted efforts to structure the vital forces of health research in Quebec. The thematic network program is one of the FRQS's research infrastructure grant programs. The very essence of the provincial network concept is to bring added value to collaborative work on priorities identified by the network, in strategic health themes involving all Quebec research resources.

The Networks are funded for a period of eight (8) years, at the end of which they may submit a new application.

The Coordinating institution of the RARE.Qc Network is based at the activity site of the current lead Director, which currently is the Research Institute of the McGill University Health Centre (**RI-MUHC**).

## **1.2 The vision, mission and goals of the network**

### **1.2.1 Vision**

The complex nature of rare diseases and their rarity call for an evolution in the model of care. Rather than isolated approaches, a "network" model, integrating research at every stage of care, is essential to transform the trajectory of people living with a rare disease (**RD**).

### **1.2.2 Mission**

This research network aims to complement the clinical roadmap developed by the *Comité consultatif québécois pour les maladies rares (CCQMR)* for the MSSS, by harnessing the expertise of all Quebec centers and developing a provincial network to foster peer-to-peer learning and the sharing of knowledge, resources and capabilities to strengthen healthcare systems for rare diseases. Ultimately, this network will make Quebec a beacon of innovation in the field of rare diseases.

### **1.2.3 Goals**

The general objectives of the network are:

- Develop a provincial RD network
- Unify the expertise of all of Quebec's RD specialists
- Define the epidemiology of RD in Quebec
- Share RD-specific data, materials, resources, and capacities

- Strategically align with RD initiatives across Quebec (i.e., CCQMR, Genome Québec, Montréal InVivo's Rare Disease Project Committee, National Institute of Excellence in Health and Social Services (INESSS))
- Foster the capacity for trans-disciplinary and multi-institutional transformative research

### 1.3 Strategic alignment to Quebec priorities

In June 2022, Quebec's Health Minister (MSSS) published their policy on RD, comprising 3 axes: While Axis 1 (*Awareness and training*) and Axis 2 (*Facilitated and equitable access to diagnosis, care and services*) are aligned with the health care purview of the MSSS, Axis 3 (*Promotion of research, innovation and data collection*) requires RD-specific research expertise, experience and infrastructure. RARE.Qc specifically addresses this latter need, by unifying the scientific expertise of all of Quebec's RD specialists and developing a provincial RD research network to define the epidemiology of RD in Quebec, share RD-specific data, materials, resources, and capacities, and foster the capacity for trans-disciplinary and multi-institutional transformative research.

## 2. Network Management

### 2.1 Executive Committee

The RARE.Qc network is led by the Executive Committee (EC), composed of one Director, at least one Co-director, and the network Manager, whose primary role is to provide the leadership necessary to ensure the vitality of the network and the scientific relevance and quality of its activities. As per FRQ recommendations, these individuals must demonstrate commitment and willingness to take on the role of managing a thematic network.

#### 2.1.1 Responsibilities of the Director

- Bring members (as defined in section 4 below) together and encourage them to network and collaborate
- To promote rare disease research in Quebec
- To act as an intermediary between researchers and the FRQS
- To establish, in conjunction with the Management Committee, a strategic development plan that meets the Network's objectives, as defined in this charter.
- Chair of the Management Committee and the General Assembly
- Ensure the administration of the Network, hire and direct the administrative staff
- Organize the Network's annual meeting
- Draft the annual reports and application for renewal of the FRQS Thematic Network grant, in concert with the members of the Management Committee and with the active participation of Network members.
- Ensure application of the Charter
- The position of the Network Director may not be combined with any other position within the Network.
- The term of office for the Director is generally four (4) years, renewable once.

### 2.1.2 Responsibilities of the Co-directors

- Bring members together and encourage them to network and collaborate
- To promote rare disease research in Quebec
- To establish, in conjunction with the Management Committee, a strategic development plan that meets the Network's objectives, as defined in this charter.
- Ensure the administration of the Network, hire and direct the administrative staff
- Organize the Network's annual meetings
- Draft the annual reports and application for renewal of the FRQS Thematic Network grant, in concert with the members of the Management Committee and with the active participation of Network members.
- Ensure application of the Charter
- The number of Co-Directors may be revised at the end of each term and is subject to approval by the Management Committee
- The term of office for the Co-director is generally four (4) years, renewable once.

### 2.1.3 Procedures for the nomination, mandate term and renewal of the Director and Co-directors.

If the Director or one of the current Co-directors does not seek a second term, an election process is set in motion.

1. Said Director or Co-director informs the FRQS Scientific Director in writing of his or her intention not to seek a new mandate before the call for candidates is launched.
2. The list of regular voting members is updated.
3. Selection by the Network Management Committee of an election advisory committee including at least two Network members who are not members of the Management Committee.
4. The call for candidates is initiated by the election advisory committee. The invitation is announced on the RARE.Qc website and by email/Newsletter to active members of the Network. The announcement includes the portrait of the candidate requested and a description of the opportunity.

#### 2.1.3.1 Candidate submissions (1 month)

Interested candidates are invited to submit (in PDF format, to the Network Manager) their CV (Common CV), their letter of intention and three letters of support from Network members. The Network Manager shares the candidacies without delay with the election advisory committee.

#### 2.1.3.2 Confirmation of candidates (two weeks)

The election advisory committee evaluates the eligibility of candidates.

The committee informs the Management committee of the retained candidacies by email or during a meeting.

Retained candidates are advised to provide the Network Manager with an electoral platform (1 page maximum), a biosketch (maximum 1 page) and a photo.

#### 2.1.3.3 Electoral period (two weeks)

The election advisory committee has the mandate to establish and organize the selection process.

#### 2.1.3.4 Voting period

The candidacy is approved by the Scientific Committee and the regular members of the network, either during the members' assembly or electronically, ensuring equity and transparency.

#### 2.1.3.5 Notification at the FRQS level

The nomination recommendation is sent to the Scientific Directorate of the FRQ, which then submits the file to the FRQ Board of Directors for approval. The file sent to the FRQ must include the curriculum vitae of the recommended candidate as well as an official letter from the network's Scientific Committee, signed by the current Director. This letter, addressed to the FRQ Scientific Directorate, must present the nomination recommendation and describe the selection process, specifying that the network members agree with the decision. The FRQ Scientific Directorate then informs the network leadership of the FRQ Board of Directors' decision.

#### 2.1.3.6 Conflict of interest declaration

A declaration regarding conflicts of interest by network Director or Co-directors is completed when the individual assumes their position. The Director or Co-director must also submit a new declaration each time a new situation renders their previous declaration inaccurate.

#### 2.1.4 Resignation of a Director or Co-director

In the event of the resignation of a Director or Co-director of the Network before the end of his or her term of office, the Management Committee may propose to its members a person to act as interim Director or Co-director if the unexpired portion of the term is less than two (2) years. If the unexpired portion of the term is more than two (2) years, a formal appointment process will be required.

## 2.2 Network Manager

The RARE.Qc Network Manager will support the network's Director, Co-directors and Management Committee in their missions, ensuring scientific and administrative coordination. The Manager cannot be both a salaried employee and a member of the network. Responsibilities include assisting with the preparation and follow-up of meetings, administrative and budgetary management, updating the website and disseminating information, contributing to the preparation of scientific reports and documentation, developing collaborations, and coordinating network activities and events.

### **3. Governance Structure**

#### **3.1 General Assembly**

The General Assembly Meeting is made up of all members (as defined in section 4 below) of the Network. All Network members may be invited to attend meetings, but only regular members have voting rights. A quorum is reached when half the regular members plus one are present, and decisions are taken by majority vote. Electronic voting may also be used to ratify decisions, with the active participation of at least half the members plus one.

The Management and Scientific Committees must hold a General Assembly of the members at least once a year to inform them of the scientific and administrative activities of the Network, discuss the main orientations and programs of the Network and have the nominations approved if necessary. The Charter or any modification thereto must be approved by the General Assembly of members.

Exceptionally, if required by two-thirds of the regular members, an unscheduled General Assembly Meeting may be convened by the members themselves.

Certain responsibilities fall to the General Assembly Meeting, including:

- Ratifying the recommendation of the Network Director or Co-director's candidacy in the event of a change in management;
- Approving the Network's major orientations and priority strategies on an annual basis, including major budgetary orientations;
- Ratifying the Charter's by-laws and regulations, as well as any amendments made thereto;
- Approving the Network's annual progress report, as presented at the Annual Meeting.

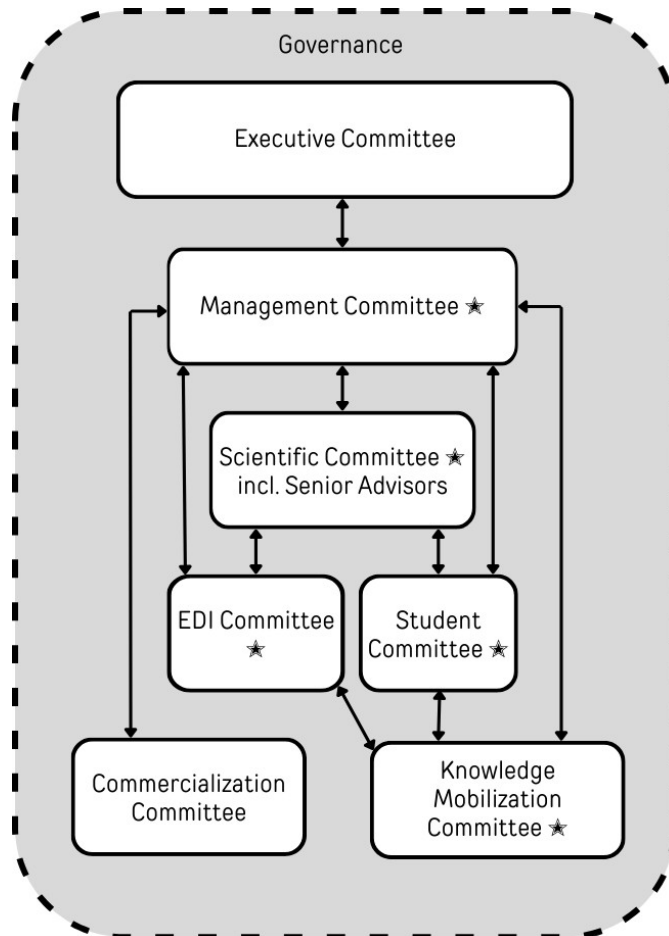


## 3.2 Overview of governance structure

The selection of members for all governance committees prioritizes diversity in professional, cultural, and social backgrounds in order to reflect the range of perspectives needed within the network.

**Figure 1.** Overview of the governance structure of the RARE.Qc Network

★ Involvement of patient partners on indicated committees



## 3.3 Management Committee

### 3.3.1 Composition

The Management Committee includes the network Director and Co-directors, at least one representative each from the Scientific Committee, the EDI committee, the Student Committee, the Commercialization Committee, and the Knowledge & Mobilization Committee, as well as the Manager, and a patient partner. Additional members may be included as needed. We recommend that members be appointed by the Director after approval by the network members (as defined in section 4 below). The composition of the Management Committee is appended (**Table 1**).

Depending on the size of the network, and at the discretion of the Director, a smaller committee may be set up to make quick decisions in the absence of the Management Committee.

### 3.3.2 Mandate

The Executive Committee in charge of the network is supported by the Management Committee, whose actions are aligned with the strategic objectives of the network and the FRQS.

The Management Committee ensures that the network operates fairly and transparently, and supports the Manager in the following areas:

- Network administration
- The selection and evaluation of axes and common resources, and the appointment of their leaders after consultation with the members
- Planning and reviewing activities to achieve strategic objectives
- Budget approval and monitoring of expenditures in accordance with the co-Directors' recommendations
- The biannual Network meeting and relevant RARE.Qc symposiums
- Periodic review of the Charter
- Sharing updates with members on network activities, available resources, and an annual report on scientific and administrative activities
- Convening the General Assembly with the Scientific Committee at least once a year
- Ensuring adherence to EDI (Equity, Diversity, and Inclusion) principles
- Ensure communication between pillars, committees and working groups

The term of office for Management Committee members is generally four (4) years, renewable once.

### 3.3.3 Operation

The committee determines the place (i.e., teleconference), dates and frequency of its meetings. Generally, the Management Committee meets once per month. Meetings must be announced at least two (2) weeks in advance. The quorum for meetings is half of the members of the Committee. Voting is taken by simple majority and the Director and Co-directors' votes. Except for the Network Manager, members of the Management Committee cannot be replaced at meetings. The Management Committee produces a final report which it presents to the general assembly and transmits to the FRQS.

## 3.4 Scientific Committee (and Senior Advisors)

### 3.4.1 Composition

The scientific committee includes, but is not limited to, network Director, Co-directors, senior advisors, at least four (4) regular network members (as defined in section 4 below), pillar leaders, RARE.Qc Knowledge Brokers, a patient-partner, a Student Committee representative and an EDI Committee representative. Additional researchers may be added as appropriate. The Committee is chaired by the Director or the co-Directors of the Network or any other

member of the Committee designated by him or her. A member of the Scientific Committee sits on the Management Committee.

#### 3.4.1.1 Senior Advisory Committee

The Senior Advisory Committee is made up of founding members or senior consultants with varied expertise deemed useful in the Network's progress. Members of the Senior Advisory Committee are appointed by the Director of the Network. The role of this committee is to assess the Network's direction and compliance with the Charter, to measure the Network's involvement in the local and international scientific community, and, if necessary, to forward its recommendations to the Management Committee.

#### 3.4.2 Appointment of Scientific Committee Members and Pillar Leads

Members of the Scientific Committee and Pillar Leads are appointed by the Director and Co-Directors, following approval by network members, either during the regular members' assembly or through electronic voting. If multiple candidates are being considered for a Pillar Lead position, a Co-Lead may be appointed by the Director and Co-Directors, with the approval of the network members. Vacant positions that need to be filled will follow the process outlined below:

- 1) The outgoing member of the Scientific Committee informs the network leadership in writing of their intention not to seek a new term before the call for applications is launched.
- 2) The network issues a call for applications to all regular members.
  - The nomination period for the vacant position is two weeks.
  - The call must be tailored to the specific role to be filled, based on the required expertise, and must promote equity and transparency.
- 3) The Scientific Committee selects a diverse pool of potential candidates, ensuring gender parity and reflecting a range of backgrounds, experiences, and perspectives, in line with EDI (Equity, Diversity, and Inclusion) principles.
- 4) If there are one or more candidates, an election process is carried out either during the regular members' assembly or electronically.
  - The vote takes place within fifteen days of the candidate list being shared. The candidate receiving the highest number of votes is elected.
- 5) The FRQ is notified of the change.
- 6) In the case of a prolonged absence (>6 months) of a person holding a position on the Scientific Committee, an "appointed representative" is temporarily designated by the Scientific Committee.
  - This individual must be a regular member of the network and have a profile aligned with the expertise required for the role.
  - The selection must respect gender parity and reflect diverse backgrounds, experiences, and perspectives, in accordance with EDI (Equity, Diversity, and Inclusion) principles.
  - If the absent member does not wish to resume their position, an election process will be initiated.

- The appointed individual holds voting rights during the absence of the person they are replacing.

### 3.4.3 Mandate of the Scientific Committee

The Scientific Committee is responsible for contributing to the planning and implementation of the strategic action plan. To ensure balanced participation, members of the Scientific Committee are separate from those of the Management Committee, with the exception of the Director and the co-Directors.

Among other things, the Scientific Committee is responsible for:

- Proposing the network's overall directions, strategic initiatives, and research priorities
- Ensuring compliance with the network's scientific orientations and priorities
- Providing the leadership to ensure the network's dynamism and vitality, active member participation, and the relevance, coordination, and scientific quality of activities, as stipulated in the FRQ regulations
- Encourage the creation of scientific activities and promote exchanges and collaboration within the network
- Participate in the scientific evaluation and monitoring of structuring initiatives and shared resources
- Convening the General Assembly with the Management Committee at least once a year
- Promoting equity, diversity, and inclusion within the network in collaboration with the EDI Committee
- Ensuring representation of the diverse members and disciplines involved in rare disease research
- Maintaining balance across all levels between basic, translational, clinical, health system, and other types of research related to rare diseases
- Encouraging the use of network resources among members
- Promoting open science, knowledge mobilization, as well as transdisciplinary and multi-institutional research.

The term of office for Scientific Committee members is generally four (4) years, renewable once.

### 3.4.4 Operation of the Scientific Committee

The Scientific Committee meets at least three (3) times per year, and the Director may convene additional meetings at any time. Meetings must be announced at least two (2) weeks in advance. The place (e.g., teleconference) and dates of the meetings are determined by the Committee. The quorum for meetings is half of the members of the Committee. Voting is taken by simple majority and the Director and Co-directors' votes.

## **3.5 EDI Committee**

### **3.5.1 Composition**

The EDI Committee will consist of at least four (4) regular members and one (1) student member representing different institutions in Quebec, and who are leaders in championing EDI and addressing questions of diversity and inclusion in their research, a patient partner, and partner members. Please see section 4 below for the definition of the different categories of members of RARE.Qc. During the initial formation of the EDI Committee, its members are selected by the Executive Committee following a call for applications circulated within educational institutions and the network. Subsequently, when a member leaves their position or completes their term, the EDI Committee appoints a new member. The network leadership is then informed. One member of the EDI Committee sits on the Scientific Committee, and one member of the EDI Committee sits on the Management Committee.

### **3.5.2 Mandate**

Its mandate is to ensure that EDI factors are implemented, measured, monitored and communicated in a manner that is inclusive, relevant, adapted and representative of the reality of its members and the rare disease research context in Quebec. The EDI Committee is an advisory committee and reports to the Scientific and Management Committees. The EDI Committee advises them on the EDI directions and activities of the Network. FRQS has published a [strategy](#) to strengthen the integration of these principles; members of the EDI Committee are expected to familiarize themselves with these principles and actively support their implementation.

### **3.5.3 Operation**

The EDI Committee meets at least four (4) times per year, and additionally on an *ad hoc* basis as needed. The committee determines the place (e.g., teleconference) and the dates of its meetings. Meetings must be announced at least two (2) weeks in advance. The quorum for meetings is half of the members of the Committee. Voting is taken by simple majority.

## **3.6 Student Committee**

### **3.6.1 Composition**

The Student Committee must constitute a credible voice for graduate and post-graduate students of the Network and serve as a privileged communication channel between the students and RARE.Qc management. The committee is open to any student member of the Network who is motivated to contribute to its vitality and has expertise in the field of rare diseases. This committee does not have a formally defined number of positions, but it is recommended to have two positions for each level of study (e.g., master's, doctoral, postdoctoral, and resident). One member of the Student Committee sits on the Scientific Committee, and one member of the Student Committee sits on the Management Committee. Members of the Student Committee shall, to the extent possible, represent a variety of RD research themes and institutions from across Quebec. When a position becomes available, it can be assigned to a

student member who has expressed interest in joining the committee to the network, either before or after a call for applications. If necessary, a vote is held among the members of the Student Committee. If multiple students apply, the one receiving the most votes is elected.

### 3.6.2 Mandate

Its mandate is to represent the student members (as defined in section 4 below) of the Network and to participate in its mission of training, dissemination and knowledge mobilization. The Student Committee is both an advisory and operational committee that reports to the Scientific Committee. The Student Committee organizes knowledge dissemination and mobilization activities (e.g., scientific communication events, science cafés, networking activities, activities with the citizen community). Members of the Student Committee gather information from student members of the network and communicate it to the Chair of the Student Committee.

The term of office for Student Committee members is generally two (2) years, renewable once.

### 3.6.3 Operation

The Student Committee meets at least four (4) times per year, and additionally on an *ad hoc* basis as needed. The committee determines the place (e.g., teleconference) and the dates of its meetings. Meetings must be announced at least two (2) weeks in advance. The quorum for meetings is half of the members of the Committee. Voting is taken by simple majority.

## 3.7 Knowledge Mobilization Committee

### 3.7.1 Composition

The Knowledge Mobilization Committee (KMC) will consist of at least four (4) regular members with success in moving evidence into practice and/or policy, a patient partner, and at least two (2) partner members. Please see section 4 below for definition of the different categories of members of RARE.Qc. During the initial formation of the KMC, its members are selected by the Executive Committee following a call for applications circulated within educational institutions and the network. Subsequently, when a member leaves their position or completes their term, the CMC appoints a new member. The network leadership is then informed. One member of the CMC sits on the Management Committee.

### 3.7.2 Mandate

Its mandate is to advise on the development, implementation and progress of the knowledge mobilization activities within the network. The KMC is an advisory committee and reports to the Management Committee. The KMC will:

- Establish, and update as necessary, a knowledge mobilization (KM) framework for the network;
- Advise on the KM activities, such that the research evidence generated by the network is appropriately mobilized into policy, practice and/or further research;
- Advise on KM activities in collaboration with Network committees and key stakeholders that will advance the goals of the Network;

- Advise the Management Committee on evaluation metrics for the Network; and
- Advise on the training of students in KM in the context of rare diseases.

The term of office for Knowledge Mobilization Committee members is generally four (4) years, renewable once.

### 3.7.3 Operation

The KMC meets at least four (4) times per year, and additionally on an *ad hoc* basis as needed. The committee determines the place (e.g., teleconference) and the dates of its meetings. Meetings must be announced at least two (2) weeks in advance. The quorum for meetings is half of the members of the Committee. Voting is taken by simple majority.

## 3.8 Commercialization Committee

### 3.8.1 Composition

The Commercialization Committee (CC) will consist of at least four (4) regular members and at least two (2) partner members (as defined in section 4 below). It is important that the overall composition of the Commercialization Committee provides a mix of financial, commercial, operating and marketing experience and expertise. During the initial formation of the CC, its members are selected by the Executive Committee following a call for applications circulated within educational institutions and the network. Subsequently, when a member leaves their position or completes their term, the CC appoints a new member. The network leadership is then informed. One member of the Commercialization Committee sits on the Management Committee.

### 3.8.2 Mandate

- The Commercialization Committee oversees the strategy and activities of the RARE.Qc Network in connection with the development, marketing and commercialization of the Network's research outputs. The CC is an advisory committee and reports to the Management Committee. The CC will: Advise on strategies for the development, commercialization, and protection of intellectual property
- Identify partnership opportunities with industry, technology transfer organizations, investors, and other key stakeholders
- Support the market launch of innovations stemming from research, in collaboration with researchers and partner institutions
- Evaluate the commercial potential of projects supported by the Network and recommend support or funding avenues to promote their maturation
- Promote a culture of innovation and entrepreneurship among Network members
- Advise on strategies for the development, commercialization, and protection of intellectual property
- Identify partnership opportunities with industry, technology transfer organizations, investors, and other key stakeholders

- Support the market launch of innovations stemming from research, in collaboration with researchers and partner institutions
- Evaluate the commercial potential of projects supported by the Network and recommend support or funding avenues to promote their maturation
- Promote a culture of innovation and entrepreneurship among Network members
- Ensure alignment between commercialization activities and the scientific mission of the Network.

### 3.8.3 Operation

The CC meets at least three (3) times per year, and additionally on an *ad hoc* basis as needed. The committee determines the place (e.g., teleconference) and the dates of its meetings. Meetings must be announced at least two (2) weeks in advance. The quorum for meetings is half of the members of the Committee. Voting is taken by simple majority.

## 3.9 Other Network Committees

The Management Committee may establish working groups as needed to address specific Network-related issues, which will include members (as defined in section 4 below) of the Network, and possibly other experts. The Management Committee has the overall responsibility of assessing and prioritizing the progress of the various working groups and other needed subcommittees of the working groups.

### 3.9.1 Working group governance

- Any Network member or group of Network members proposing a new working group will formally submit their written proposal to the Management Committee, using the Network's established template.
- The Management Committee will review proposals approximately every 4 months, with provisions for ad hoc review in cases of urgent network priorities or emerging societal or governmental needs.
- A formal majority vote of the Management Committee is needed to create a new working group.
- Volunteers for chair or co-chairs of the new working group will be solicited when the new working group is proposed. A formal majority vote of the Management Committee is needed to confirm the chair or co-chairs.
- Co-chairs are not required for all working groups but may be recommended by the Management Committee.
- Working group co-chairs may come from the same institution.
- In the absence of volunteers or if only one candidate emerges, the Management Committee may propose suitable member(s) for the working group. A designated Management Committee representative will then formally invite the recommended individual(s) to serve as chair.
- Any working group proposing to close will present their idea to the Management Committee. A formal vote of the Management Committee is needed to close a working group.



## 4. **Membership**

### 4.1 **Membership criteria**

FRQS thematic networks primarily target Quebec researchers, regardless of their institutional affiliation. They are made up of regular members, partners and students, offering an inclusive approach. Members' status is reviewed regularly, and their participation is required to maintain their membership. The FRQS may revoke membership for irresponsible research conduct.

Members of all types must have a demonstrated specialty in one or more rare diseases as defined by [Orphanet](#) or are in an early career stage with a great interest in studying rare diseases.

### 4.2 **Eligibility criteria**

#### 4.2.1 Regular members

A regular member is a researcher working in the network's thematic area and meeting the criteria of research statuses 1 to 4, detailed in the [FRQ Common General Rules](#). Regular members are actively involved in the network's scientific activities.

Status 1 – University researcher

Status 2 – Clinical university researcher

Status 3 – College researcher

Status 4 – Other research statuses:

- Researcher in a government institution recognized by the FRQ
- Researcher in a government-sector organization not recognized by the FRQ or in the private sector
- Practitioner
- Artist
- Individual contributor

#### 4.2.2 Partner members

A partner member is a person who is not a researcher, but who has expertise or experiential knowledge directly related to the network's activities, enabling him or her to make an active and significant contribution. Partner members can be knowledge generators, accelerators or users. Patient partners, decision-makers, government officials or community representatives are a few examples of people who might qualify as partner members. Partner members have the same obligations and privileges as regular members in network governance and are actively involved in network activities.

#### 4.2.3 Student members

##### 4.2.3.1 Regular student members

A regular student member is a person enrolled in a university training program at a Quebec university, or a person who qualifies as a postdoctoral research fellow, as described in the [FRQ Common General Rules](#), and who is training at a Quebec university. To be eligible for membership, the student must also be engaged in research activities.

##### 4.2.3.2 External student members

An external student member is a person not currently enrolled in a Quebec university, but who maintains significant ties to Quebec—such as having completed part or all of their academic training in the province and/or intending to pursue an academic or clinical career in Quebec. All other eligibility criteria applicable to regular student members shall also apply.

### 4.3 Membership Adhesion and Renewal

Eligible individuals may request to become a RARE.Qc member by completing the online form (Copy of the Membership form in appendix). Completed forms will be periodically reviewed by the RARE.Qc Manager or delegate.

The **status of each member is reviewed every two years** and the absence of any scientific activity or contribution within the Network for a period of two (2) years results in a change of status or terminates membership. However, if he or she resumes his or her research activities, he or she may again apply to join the Network. A member may also terminate their membership at any time.

The FRQ may require that a person's Network membership be revoked due to a confirmed breach of responsible research conduct.

In addition to the above, student members will be required to update their member profile on a yearly basis to ensure they meet the eligibility criteria as a student member.

### 4.4 Membership Responsibilities and Benefits

Regular and student members must contribute to the vitality of the Network by:

- Participating in the RARE.Qc governance as a committee member, working group member, and/or participant to one or more RARE.Qc initiatives
- Sharing valuable rare disease expertise (i.e., SOPs, technical guidance, training material, etc)
- Collaborating in the Network's planning and evaluation activities by providing the information requested by the Network, such as their updated publication list, CV, documentation on research grants awarded, progress reports and other data.
- Acknowledging the Network's contribution in their publications and communications when they receive support from the network.
- Agreeing to abide by the FRQ [Policy on Responsible Conduct in Research](#).

All members will benefit by:

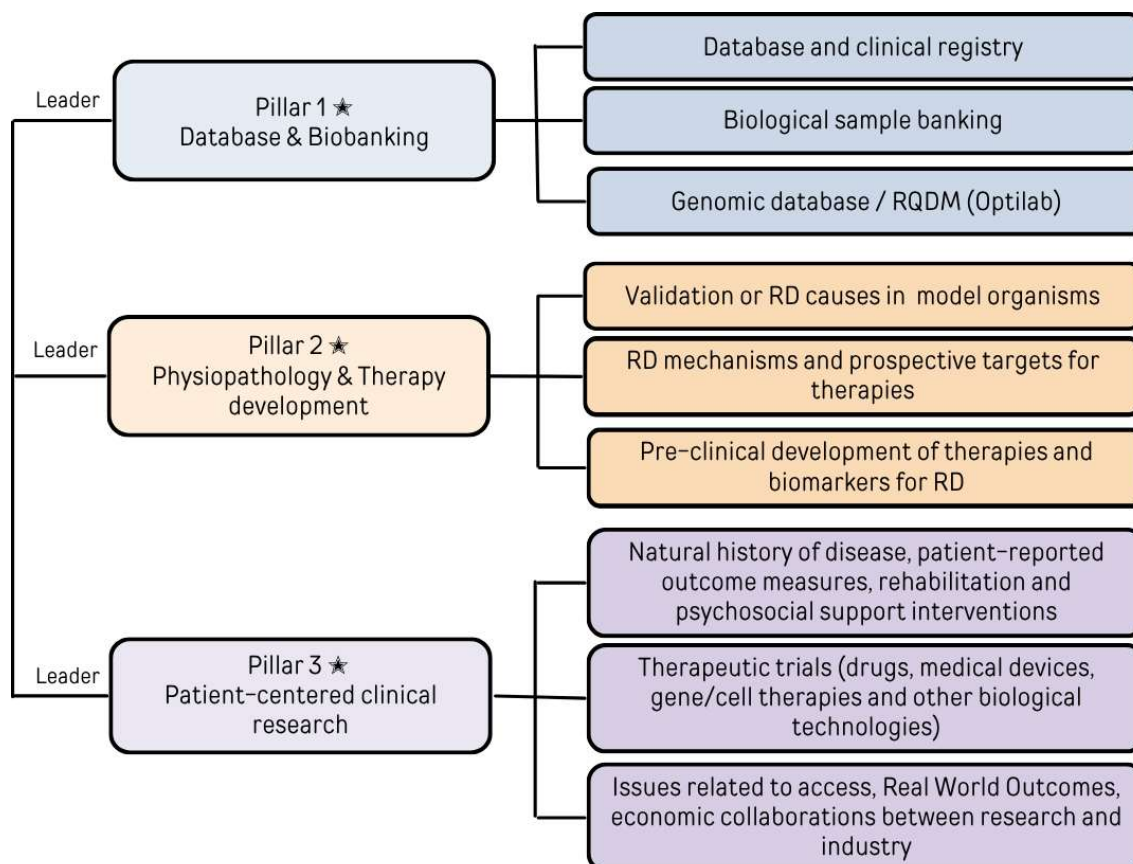
- Receiving communications from the Network (e.g., Newsletters)
- Be invited to participate in related events, annual conferences and workshops
- May assume administrative functions within the Network, such as sitting on the Management or Scientific Committee
- Having access to RD expertise through research resource sharing, networking and collaboration opportunities

Regular members are part of the General Assembly of members. They have, depending on availability, access to technical services and expertise from the Network. Other types of members can participate in the General Assembly of members, but do not have the right to vote.

## 5. Scientific Structure

Figure 2. Overview of the scientific structure of the RARE.Qc Network

★ Involvement of patient partners on indicated committees



## 5.1 Research Pillars

The Network organizes its core scientific activities through three defined research pillars, established by the Scientific Committee (illustrated above). Each pillar focuses on specialized research domains while actively promoting cross-network and multi-institutional collaboration. Although these pillars form the foundational pillars of our scientific work, researchers are strongly encouraged to:

- Engage with any research pillar aligned with their interests
- Pursue collaborative opportunities across all pillars
- Develop interdisciplinary partnerships network-wide

## 5.2 Infrastructure and resources

The Network acts as a driving force to organize, facilitate access to, and optimize utilization of shared RD-specific resources including: Data repositories; Biological materials; Research infrastructure; and Specialized expertise. By coordinating these assets across institutions, we enable and accelerate transformative, transdisciplinary RD research throughout Quebec.

To advance collaborative research across the Network, we will implement formal data and biomaterial sharing agreements, which will facilitate seamless resource exchange between partners while ensuring that all participating researchers receive appropriate authorship recognition for their contributions of data, materials, or expertise in resulting publications and academic outputs.

To facilitate information sharing among Network members, the Network provides a monthly newsletter featuring the latest news in rare disease research as well as member directory on its website outlining the available resources and data members can share with other members of the Network.

Author guidelines: Scientific collaboration is encouraged, and the Network operates under a collaborative authorship model, with multi-author outputs constituting the norm. Authors (first, middle, and senior) are determined by the type, scope and site of project. First author takes primary responsibility for the manuscript. Generally, it is expected that authors would make contributions to any or all of the following, including but not limited to, the concept, design, acquisition and analyses of data or included biological material, drafting of manuscript, editing, and revision of manuscript. The Network resolves all authorship disagreements, as detailed in Section 7.

RARE.Qc recognition and attribution policy: The RARE-Qc Network requires formal co-authorship as “Members of RARE.Qc” listed at the end of the author list on all academic products (publications, presentations, patents, etc.) generated from its activities when the following criteria are met: substantial contributions to the conception or design of the work, or to the acquisition, analysis, or interpretation of data for the work; AND drafting the work or critically revising it for important intellectual content; AND final approval of the version to be published; AND agreement to be accountable for all aspects of the work, ensuring that

questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

If the criteria for substantial contribution are met, formal co-authorship from RARE.Qc is requested in one or more of the following situations:

- Use of Network-shared data (>20% of included study data is derived from the Network)
- Use of Network-shared biological materials (>20% of included study material is derived from the Network)
- Utilization of Network core facilities
- Projects initiated through Network activities, including funding support generated from Network activities.

Researchers who share their data, biological materials, platforms, or other resources with the Network must be duly acknowledged, in accordance with the established sharing agreements (see section 5.2). Non-adherence with this policy may result in delayed publication approval, requirement for published corrections, and/or suspension of network privileges.

### **5.3 Network activities**

Beyond its core research mandate (detailed above), the Network also facilitates complementary activities, including (but are not limited to):

- Biannual general assembly and scientific day
- Organization and support of knowledge dissemination activities for the general public, the scientific community, and trainees.
- Active networking and coordination activities on the provincial and federal stage
- Training opportunities and scientific activities for students, including knowledge mobilization initiatives
- Other activities approved by the Scientific Committee.

## **6. Annual Report**

The RARE.Qc Networks must produce a financial and achievement report each year. It will demonstrate how the allocated grant has contributed to the Network's structuring effect, to the objectives of open science, equity, diversity and inclusion, sustainable health and knowledge mobilization.

## **7. Conflict Resolution**

Any conflict within the Network will be examined promptly by the Director with Co-directors who will receive the information from all relevant parties, review this information and detail, and take the necessary action. Depending on the seriousness of the situation, corrective measures may be proposed, or a special committee may be appointed to examine and recommend solutions to the Management Committee. The Management Committee decisions

are final. In the event of a conflict involving management, members may contact the FRQS Thematic Networks Program, which may refer the matter to another body if necessary.

## **8. Amendments to the Charter**

### **8.1 Process for Amendments**

In the event that amendments to the network charter are proposed, the amended charter must be submitted to the network members and by the Fonds de recherche du Québec for approval.

## 9. Appendices

### 9.1 Membership form

#### Global form

First Name: \_\_\_\_\_

Last Name: \_\_\_\_\_

Email address: \_\_\_\_\_

Preferred language:

- French
- English

Website: \_\_\_\_\_

What region do you work/live in?

- Abitibi-Témiscamingue
- Bas-Saint-Laurent
- Capitale Nationale
- Centre-du-Québec
- Chaudière-Appalaches
- Côte-Nord
- Estrie
- Gaspésie-Îles-de-la-Madeleine
- Lanaudière
- Laurentides
- Laval
- Mauricie
- Montérégie
- Montréal
- Nord-du-Québec
- Saguenay-Lac-Saint-Jean
- Outaouais
- Canadian providence outside of Québec
- Out of Canada

Postal address : \_\_\_\_\_

Upload your photo

Member type:

- Regular member: researchers, clinicians, members with recognized research statuses
- Partner member: expertise or experiential knowledge directly related to the network's activities, enabling him or her to make an active and significant contribution
- Student member: students with Quebec university affiliation or external student members (see definitions below)

## Regular Member Form

Status, as defined by the [FRQ Common General Rules](#):

- 1 – University researcher
- 2 – Clinical university researcher
- 3 – College researcher
- 4 – Other research statuses:
  - 4.a Researcher in a government institution recognized by the FRQ
  - 4.b Researcher in a government-sector organization not recognized by the FRQ or in the private sector
  - 4.c Practitioner
  - 4.d Artist
  - 4.e Individual contributor

Primary Affiliation: \_\_\_\_\_

Secondary Affiliation: \_\_\_\_\_

Your ORCID ID #: \_\_\_\_\_

Please be sure to update your ORCID profile with your latest published works, biography and keywords

Which of the following disease categories, as defined by the Ministry of Health and Social Services, do you most identify with?

- Dysmorphic or polymalformative syndromes
- Neurodevelopmental disorders
- Central nervous system conditions
- Heart diseases
- Autoimmune disorders
- Vascular diseases
- Liver diseases
- Neuromuscular diseases
- Dermatological diseases
- Endocrine diseases
- Inborn errors of metabolism
- Hematological conditions
- Cystic fibrosis
- Respiratory diseases



- Kidney diseases
- Connective tissue diseases
- Congenital deafness
- Eye diseases
- Head, neck, and dental diseases

Do you identify with multiple disease categories?

- Yes
- No

Do you have a clinical database of the rare disease patients you follow?

- Yes
- No
  - If Yes: Would you agree to share the metadata of your aforementioned data and/or banked samples as part of an academic collaboration agreement?
    - Yes
    - No

Do you have a human sample bank (biobank) of the rare disease patients you follow?

- Yes
- No
  - If Yes : Would you agree to share the metadata of your aforementioned data and/or banked samples as part of an academic collaboration agreement?
    - Yes
    - No

Your demonstrated specialty or great interest in one or more rare diseases as defined by [Orphanet](#) :

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I have read and agree to the RARE.Qc Code of Conduct

## Partner Member Form

Do you identify as one or more of the following:

- Patient partner
- Decision-maker in medical affairs
- Government official
- Community representative
- Other: \_\_\_\_\_

Primary Affiliation: \_\_\_\_\_

Secondary Affiliation: \_\_\_\_\_

Your demonstrated specialty or great interest in one or more rare diseases as defined by [Orphanet](#) :

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I have read and agree to the RARE.Qc Code of Conduct

## Student Member Form

Status:

1 – Regular student members, as defined by the [FRQ Common General Rules](#)

2 – External student members, as defined as : *a person not currently enrolled in a Quebec university, but who maintains significant ties to Quebec—such as having completed part or all their academic training in the province and/or intending to pursue an academic or clinical career in Quebec. All other eligibility criteria applicable to regular student members shall also apply.*

Primary Affiliation: \_\_\_\_\_

Current student status:

- Cégep
- Undergraduate
- Masters
- PhD
- PostDoc
- Clinical fellow involved in research

Estimated graduation year: \_\_\_\_\_

Your ORCID ID #: \_\_\_\_\_

Please be sure to update your ORCID profile with your latest published works, biography and keywords

Your demonstrated specialty or great interest in one or more rare diseases as defined by [Orphanet](#) :

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Do you have a Research Supervisor?

- Yes
- No
  - If Yes : Your Research Supervisor: \_\_\_\_\_

I have read and agree to the RARE.Qc Code of Conduct

## 9.2 Member Code of Conduct

This code of conduct outlines the expectations of the RARE.Qc Network for all its members.

It contains policies, behaviors, and consequences that aid in avoiding any conduct violations. It serves as a roadmap for all network members, helping them understand the conduct expected in the network and what constitutes a violation of the network's rules and policies. Establishing a code of conduct is a vital step for the RARE.Qc network to uphold ethics, professionalism, and foster a positive environment.

### Membership status

The status of each member is **reviewed every two years** and the absence of any scientific activity or contribution within the Network for a period of two (2) years results in a change of status or terminates membership. However, if he or she resumes his or her research activities, he or she may again apply to join the Network.

### Participation

Regular and student members must contribute to the vitality of the Network by:

- Participating in the RARE.Qc governance as a committee member, working group member, and/or participant to one or more RARE.Qc initiatives
- Sharing valuable rare disease expertise (i.e., SOPs, technical guidance, training material, etc)
- Collaborating in the Network's planning and evaluation activities by providing the information requested by the Network, such as their updated publication list, CV, documentation on research grants awarded, progress reports and other data.
- Acknowledging the Network's contribution in their publications and communications when they receive support from the network.
- Agreeing to abide by the FRQ [Policy on Responsible Conduct in Research](#).

Partner members must contribute to the vitality of the Network by:

- Participating in the RARE.Qc governance as a committee member, working group member, and/or participant to one or more RARE.Qc initiatives
- Connecting members to valuable rare disease expertise and/or funding opportunities to promote knowledge generation, acceleration and/or use.
- Agreeing to abide by the FRQ [Policy on Responsible Conduct in Research](#).

### Guiding Principles

1. Do not plagiarize.
2. Do not fabricate or falsify data, research procedures, or data analysis.
3. Do not use other people's unpublished writings, information, ideas, concepts, data, or biological samples that you may see as a result of processes such as peer review without permission of the author.
4. Do not make misrepresentations to editors and conference program chairs about the originality of papers you submit to them.

5. Give priority to the public interest, particularly when designing or implementing new information systems or other designed artifacts.
6. Respect the rights of research subjects, particularly their rights to information privacy, and to being informed about the nature of the research and the types of activities in which they will be asked to engage.
7. Do not abuse the authority and responsibility you have been given as an editor, reviewer or supervisor, and ensure that personal relationships do not interfere with your judgment.
8. Do not take or use published data or biological materials of other network members without acknowledgement; do not take or use unpublished data or biological materials without both permission and acknowledgement of the contributing network member(s).
9. Declare any material conflict of interest that might interfere with your ability to be objective and impartial when reviewing submissions, grant applications, software, or undertaking work from outside sources.
10. Acknowledge the substantive contributions of all research participants, whether colleagues or students, according to their intellectual contribution.
11. Use archival material, including any clinical data and biological samples, only in accordance with the rules of the RARE.Qc network.

**ADVICE:** The following suggestions are provided on how to protect yourself from authorship disputes, mis-steps, mistakes, and even legal action.

1. Keep the documentation and data necessary to validate your original authorship for each scholarly work with which you are connected.
2. Do not republish old ideas of your own as if they were a new intellectual contribution.
3. Settle data set ownership issues before data compilation.
4. Consult appropriate colleagues or the network Executive Committee if in doubt.

### **Acknowledgement of FRQS support in the common CV**

The FRQS recommends that network directors, pillar leaders and members receiving a network grant indicate this in their joint CV, in the “research funding” section. For other members, it is suggested that they indicate their network affiliation in the “Detailed contributions” document, in the “Activities and contributions” section.

### **Breach or violation of the Code of Conduct**

A breach or violation of code of conduct, is any action that goes against the network's established policies and guidelines, either intentionally or unintentionally. These violations can be categorized as workplace code of conduct violations and professional code of conduct violations, each with its own set of consequences. Recognizing and understanding these categories aids network members in complying with the network's code and upholding a professional work environment.

Violations of the above Code will be evaluated by the Management Committee. Potential outcomes of code of conduct violations may include verbal or written reprimand, suspension or dismissal from the network, and legal consequences. The FRQS may revoke membership for irresponsible research conduct.

By signing below, I have read and understood the RARE.Qc Code of Conduct.

_____	_____	_____
RARE.Qc member printed name	Signature	Date(DD-MM-YYYY)

### 9.3 Committee Composition 2024-2028

**TABLE 1. Composition of Network committees**

<b>Executive Committee</b>		
Name	Role	Institution
Donald Vinh	Director	RI-MUHC
Geneviève Bernard	Co-director	RI-MUHC
Philippe Campeau	Co-director	CHU SJ
Nicolas Pilon	Co-director	UQAM
Christine Yergeau	Manager	RI-MUHC

<b>Management Committee</b>		
Name	Role	Institution
Donald Vinh	Director	RI-MUHC
Geneviève Bernard	Co-director	RI-MUHC
Philippe Campeau	Co-director	CHU SJ
Nicolas Pilon	Co-director	UQAM
Christine Yergeau	Manager	RI-MUHC
Representative of Student Committee		
Representative of Scientific Committee		
Representative of Knowledge Mobilization Committee		
Representative of Commercialization Committee		
Representative of EDI Committee		
Patient Partner		

<b>Scientific Committee</b>		
Name	Role	Institution
Donald Vinh	Director	RI-MUHC
Geneviève Bernard	Co-director	RI-MUHC
Philippe Campeau	Co-director	CHU SJ
Nicolas Pilon	Co-director	UQAM
Vincent Ferretti	Pillar 1 leader	CHU SJ
Kessen Patten	Pillar 2 leader	INRS
John Mitchell	Pillar 3 leader	RI-MUHC
Gérald Cadet	RARE.Qc Knowledge Broker	RI-MUHC

RARE.Qc Knowledge Broker 2		
Patient Partner		
Representative of Student Committee		

Senior Advisors	
Name	Institution
Bernard Brais	RI-MUHC
Cynthia Gagnon	UdeS
Rachel Laframboise	CHU Laval
Jacques Michaud	CHU SJ
Suzanne Morin	RI-MUHC
Guy Rouleau	RI-MUHC

EDI Committee	
Name	Institution

Student Committee	
Name	Institution



Knowledge Mobilization Committee	
Name	Institution
Jade England	Student member, CHU SJ
Annie-Danielle Grenier	Patient partner

Commercialization Committee	
Name	Institution

## References

1. Office of Rare Disease Research – US Department of Health and Human Services. About ORDR. 2015; Available at <https://rarediseases.info.nih.gov/about-ordr/pages/30/about-ordr>.
2. Australian Institute of Health and Welfare. Incidence of type 1 diabetes in Australia 2000–2013. Vol Diabetes series no.23. Canberra: AIHW, 2015.
3. National Human Genome Research Institute. <https://www.genome.gov/27570902/april-13-rare-genetic-diseases/>.
4. HIV.gov. <https://www.hiv.gov/hiv-basics/overview/data-and-trends/global-statistics>.
5. Canadian Organization for Rare Disorders (CORD). <https://www.raredisorders.ca/about-cord/>.