



Program

Priority #1 : The patient!

Zebinars 2025

- February 1st at 12 p.m.: Launch of the Month of Zebra 2025 and the RQMO #Showyourzebra campaign, presented by Jonathan Pratt, Executive Director of the RQMO. (Webinar in French)
- February 3rd at 12 p.m.: Testimony : LIVING in Diagnostic Wandering, presented by Elsa Chouinard, patient and administrator of the RQMO Board of Directors. (Webinar in French)
- February 7th at 12 p.m.: Psychological Support Program for Adults with Rare Diseases, presented by Cécile Bardon, Professor in the Department of Psychology at UQAM. (Webinar in French)
- February 12th at 12 p.m.: The Quebec Action Plan for Rare Diseases, Jade Falardeau, Coordinator of the Quebec Action Plan for Rare Diseases. (Webinar in French)
- February 14th at 12:00 p.m.: Presentation of a research project on ARSACS: A collaborative model, presented by Benoît Gentil, professor at McGill University and Sonia Gobeil, co-founder of the ARSACS Foundation. (Webinar in French)
- February 17 at 12:00 p.m.: Patients and researchers: an essential partnership to advance research, presented by Diana Zidarov, researcher (IURDPM) and Michèle Forget, patient-partner. (Webinar in French)
- February 19 at 12:00 p.m.: The Network to Advance Research on Rare Diseases in Quebec : 1 year later!, presented by Michelle Canac-Marquis, network coordinator, Dr Vincent Ferretti, Leader of Axis 1 of the network (Database & Biobanking), Dr. Philippe Campeau and Prof. Nicolas Pilon, network co-directors. (Webinar in French)
- February 21 at 12:00 PM: C-BIG: A project focused on patient partnership and open science, presented by the C-BIG team (Nicolas Ferry, Jason Karamchandani, Amina Boulid) and Linda Lafontaine, patient partner.
- February 24 at 12:00 PM: The Canadian Rare Disease Network (CRDN): Who, What, Why?, presented by Svenja Espenhahn, CRDN Director, François Bernier, Leader of the CRDN steering committee, Leanne Ward, Pillar 2 Leader (Advanced Therapies), Ian Stedman, Pillar 3 Leader (Care, Support and Empowerment) *This webinar will be presented in English.

March 1st - RQMO 2025 International Rare Disease Day

Theme of the day: Care for rare diseases

To celebrate the International Rare Disease Day, RQMO is organizing an event on March 1st, 2025 at the Hôtel Sandman, located at 999, rue de Sérigny in Longueuil. The event will run from 10 a.m to 3 p.m, and will be followed by a networking cocktail from 3 p.m to 5 p.m.

The event will be presented as a hybrid, so you'll have the option of attending in person or on zoom. We look forward to welcoming you with a special announcement during the cocktail party!

Details of the day's program will be available soon! (Event in French; Simultaneous translation will be available on zoom)

[Link to register](#)



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