



RARE DISEASE DAY WEBINAR

February 24, 2022 @ 12 pm EST

It's the Year of the Tiger! Join CORD for Rare Disease Day 2022 when we launch a Year of Action to bring Canada's Rare Drug Strategy from Vision to Reality. For the past two years, YOU, the rare disease community, have engaged with CORD in over two dozen roundtables and forums to forge a "working consensus" on the vision, framework, key components, and recommended actions and to a collective call for implementation in 2022.

Agenda

How We Got Here and How Do We Get to Where We Want to Go

- Why does Canada need a national Rare Disease Drug Strategy?
- What is Status Quo; what has gotten better and what are priority challenges?
- What case examples of current and emerging rare therapy challenges?
- What is a "Smarter Way Forward?"

Vision and Actions

- Five-, Three-, and One-Year Vision and Objectives
- Three Essential Pillars of Action: Infrastructure, Drug Supply, and Patient Engagement

Roundtable of Stakeholders

- **Who:** Participants representing different sectors
- **What Now:** Assessment of "prototypical" innovative rare disease drug using current agencies, tools, hand-offs, and trade-offs
- **What Next:** Reimagining a better way forward to address uncertainties (outcomes, eligibility, system capacity, data management), adjust timelines relative to urgency, and promote sustainability (valuation, funding, budget impact)
- **Recommended Priority Actions:** Investments in changes that have impact today, next three years, and in five years