

MEDIA ADVISORY / INVITATION TO PRESS CONFERENCE

Canadian Organization for Rare Disorders reports at halfway point of first three-year phase of Canada's Rare Disease Strategy

- *The federal 2024–27 strategy has improved provincial drug coverage, helping patients get drug treatments they need, but a new national survey reveals that diagnosing rare diseases still takes far too long, consuming significant health resources and delaying care and treatment for patients*
- *It's time for the federal government to prioritize efforts to improve screening and diagnostics and commit to funding next phase of the strategy after March 2027*

Preliminary results of a national Ipsos survey of Canadians with rare disorders will be released, showing the impact on patients, caregivers and society

WHEN: Tuesday, November 25, 2025, 9:30 a.m.

WHERE: Ottawa National Press Theater, 180 Wellington Street, Ottawa

WHO:

- **Dr. Durhane Wong-Rieger, PhD**, President and CEO, Canadian Organization for Rare Disorders (CORD)
- **Dr. Jida El Hajjar, PhD**, Chair CORD Board of Directors and Executive Director of the Loeys-Dietz Syndrome Foundation Canada
- **Dr. Rebecca Marsh, PhD**, Senior Director of Strategy, Innovation, and Outreach, Institute of Health Economics
- **Dr. Jennifer Adams, MD**, Ottawa family physician, Primary Hyperoxaluria Canada advocate and mother of a daughter with the rare disorder primary hyperoxaluria type 1 (PH1) now benefiting from drug treatment

VIDEO FEED / REMOTE QUESTIONS: *Participation in the question and answer portion of this event is in person or via Zoom, and is for accredited members of the Press Gallery only. Media who are not members of the Press Gallery may contact pressres2@parl.gc.ca for temporary access.*

For further information: For interviews and media enquiries: Don Sancton on behalf of CORD, (514) 206-1191, dsancton@3sixtypublicaffairs.com