

**For Immediate Release  
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**CORD Urges Ministers of Health to Adopt Proven Model for Improved Access to  
Treatments for Rare Disorders**

***Local and international experts agree managed access program is the key to equity***

**TORONTO/BANFF, Sept. 24, 2014** – As provincial and territorial ministers of health prepare to gather for their fall meeting in Banff, Alberta, the Canadian Organization for Rare Disorders (CORD) is urging them to adopt the most viable solution to help the nearly three million Canadians with rare disorders benefit from life-extending and life-saving therapies.

Approximately half of the rare disease drugs available to patients in the U.S. or Europe have been approved in Canada and only half of these are funded by public drug plans. CORD is proposing a managed access program, a model involving multiple stakeholders which would provide patients with reimbursed access to new therapeutics, with ongoing monitoring for further evidence of safety, efficacy, and cost-effectiveness over time. CORD is not just bringing a moral and ethical request to the table – it is offering the health ministers a practical model to provide access based on the best international and Canadian experience, and overwhelmingly supported by the rare disease community.

“We have worked with Canadian and international experts, including patients, regulators, payers, industry and clinicians, to develop the best solution to provide Canadians with rare disorders timely and affordable treatments,” said Durhane Wong-Rieger, president of CORD. “We know with great certainty that managed access programs are working effectively in a number of disease areas and jurisdictions. We urge the provincial and territorial ministers of health to adopt this model and provide patients with rare disorders with appropriate, responsible and sustainable access, based on evidence and effective use of taxpayer dollars.”

This conclusion is the result of almost a decade of research and consultation with stakeholders that began in 2005. To gain consensus on how managed access programs would work for rare diseases in Canada, CORD held regional multi-stakeholder forums across Canada earlier this year. In July, a summit was convened by CORD of international managed access program and orphan drug experts from the UK, Italy, and Spain, and Canadian experts, including clinicians, patients, payers, and industry. Following the summit, Canadian stakeholders from all sectors strongly endorsed the managed access approach, with 80 per cent approval.

“My family has been fortunate to receive a new treatment for my daughter’s rare condition through a special access program, but the odds of getting access are like winning a lottery. There needs to be a better way that will ensure everyone can benefit,” said Cathy Evanochko, member of CORD’s board of directors, and mother of a patient with tuberous sclerosis complex, a condition that causes tumours to grow in vital organs. “It’s time for the provinces to act on this issue and adopt what we know to be a workable solution that will bring orphan drugs to patients, like my daughter, who are in need. It’s unacceptable that there are treatments available around the world that Canadians with rare disorders still can’t access.”

A Canadian solution to ensure access to orphan drugs is becoming increasingly important as hundreds of new therapies are currently in development and coming to market in the next decade.

“Canada continues to be a world leader in identifying the cause and developing new therapies for rare and ultra-rare disorders, yet Canadians do not have the same access to treatments as in Europe and the U.S.,” said Dr. Cheryl Rockman-Greenberg, professor in the Department of Pediatrics and Child Health, University of Manitoba. “Treatment advances are very exciting, but access remains a barrier we need to overcome so patients can benefit not only from existing therapies, but also from new ones as they become available.”

### **About Rare Disorders**

A rare disease is often defined as a disorder that affects fewer than one in 2,000 people. An ultra-rare disorder affects fewer than 20 people in a million. There are over 7,000 different types of rare diseases, many of which are life-threatening, chronically debilitating and progressive, including certain cancers, metabolic diseases and infections. An estimated one in 12 (eight per cent, or 2.8 million) Canadians are living with a rare disease. Half of these individuals are children.

### **About CORD**

CORD is Canada's national network for organizations representing all those with rare disorders. CORD provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders. CORD works with governments, researchers, clinicians and industry to promote research, diagnosis, treatment and services for all rare disorders in Canada.



Canadian Organization  
for Rare Disorders

**Media Contacts:**

**Durhane Wong-Rieger**

CORD President

Tel: 647.801.5176

Email: [durhane@sympatico.ca](mailto:durhane@sympatico.ca)

**Christine Beyaert**

Cohn & Wolfe

Tel: 647.259.3335

Email: [christine.beyaert@cohnwolfe.ca](mailto:christine.beyaert@cohnwolfe.ca)