FOR IMMEDIATE RELEASE

Canadian Organization for Rare Disorders Welcomes Announcement of Orphan Drug Framework

Toronto, Ontario – October 3, 2012 - The Canadian Organization for Rare Disorders, on behalf of the 2.8 million Canadians with rare disorders, welcomes Health Minister Aglukkaq’s announcement of the “first ever Canadian framework to increase access to new treatments and information” and the launch of Orphanet-Canada. The highly anticipated regulatory framework is a major step forward, opening the way for research and development of new drugs for “orphan” indications and improving access to existing therapies.

The announcement reverses a 16-year-old Health Canada policy denying the need for an Orphan Drug Policy in Canada and comes nearly 30 years after the USA passed the world’s first Orphan Drug Act and 12 years after the European Union did the same for its 27 member countries.

“We are extremely grateful to Minister Aglukkaq, to the Members of Parliament, and to Health Canada for responding to the patients and families who have been writing letters, sending petitions, and traveling to Ottawa year after year,” said Durhane Wong-Rieger, President of CORD. “We were very pleased to have taken part in the consultations and hope that the regulations will be enacted quickly.”

There are between 6,000 and 8,000 rare diseases, and these affect 1 in 12 Canadians. In the decade before 1980, there were only 10 new drugs for rare diseases but since the 1983 US Orphan Drug Act, there have been more than 300 new drugs. Unfortunately, up to now, Canadians have had access to only about half of these and usually several years later.

“We hope this announcement will stimulate the provinces to work together to develop a national program to review and fund drugs for rare diseases,” said Maureen Smith, a patient with a rare disorder and secretary of CORD.

Currently, the Common Drug Review and most provinces routinely deny funding for drugs for rare diseases, even after they are approved by Health Canada. And while Ontario, British Columbia and Alberta have “special pathways” for rare disease drugs, there is no consistency, so patients in one province may receive treatment while their relatives in another province will be denied. What is needed is something similar to the “risk-pooling” scheme announced by the private drug plans earlier this year that will significantly benefit rare disease and other patients requiring high-cost innovative therapies.

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The Orphan Drug Policy, along with Orphanet, also opens the way for a Canadian Plan for Rare Diseases, including guidelines for newborn screening, diagnosis, and the creation of Centres of Reference.

According to Stephen McElroy, treasurer of CORD, “Canada has the scientists, the clinical expertise, the industry support, and the patient community to become a leader in research, drug development, and treatment for rare diseases.”

Canada may be a bit late to the party, but we are dressed and ready for action.

**About the Canadian Organization for Rare Disorders (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.

Information about the Canadian Organization for Rare Disorders can be found at www.raredisorders.ca

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