

NEWS RELEASE

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Canadian biotechnology companies championing treatments for rare diseases

OTTAWA – BIOTECanada supports the Canadian Organization for Rare Disorders in marking Rare Disease Day. These devastating, life-threatening and often terminal conditions affect 1 in 12 Canadians. This year, the European Organization for Rare Diseases member national alliances in 22 countries are combining their efforts to put the spotlight on *Rare Diseases and Health Inequalities*.

"Even though rare or orphan diseases affect only a very small portion of the population, the impact they have on patients and their families can be profound, isolating and life-altering. The need for access to safe and effective treatments for a rare disease is often urgent and overwhelming, and every day counts," says John Haslam, General Manager, Alexion Pharma Canada. "We invest in developing novel drug therapies for these rare medical conditions precisely because the need is so great. But our commitment to patients with rare diseases goes beyond innovation, to working with the medical community and governments to ensure that all those in need have access to these crucial therapies."

All Canadians deserve care. For the 3.2 million Canadians with one of 7,000 rare diseases we recommend the government take action to create a national Orphan Product Policy. Canada needs a national Orphan Product Policy to set a standard of equality for Canadians with rare and life-threatening conditions. Legislative changes must be introduced to define a rare disease, and provide the conditions for biotechnology companies to bring their research to market.

"Thanks to research being done by many companies, innovative treatments offer real hope for people living with rare disorders, however Canada's delay in implementing an orphan drug policy prevents many patients from the access to the innovative therapies they need. These vital medicines and the research involved in developing them will not come to Canada without a more welcoming environment," says Kevin Leshuk, General Manager, Celgene Inc.

While over 35 Canadian companies have had orphan products approved in the US, in Canada, the Common Drug Review has issued 'do not list' recommendations (to the provinces) for over 75% of rare disease therapeutics approved by Health Canada.

Biotechnology therapeutics offer new hope in treating rare disorders for Canadians. Due to the genetic nature of these conditions, scientists can identify specific variations in genes or cells linked to a condition. These biomarkers can be used to identify people with a particular disease, or those at risk of developing a disease. This insight helps guide the development of treatments.

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For further information

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