

Canada needs a policy for rare disease treatment

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Canada needs a national approach to funding drugs for rare diseases and can learn from other countries, states an analysis article in *CMAJ* (*Canadian Medical Association Journal*).

Due to relatively small markets, pharmaceutical companies may be reluctant to conduct research into new treatments or to manufacture drugs, and there is a constant risk that they may stop making these drugs. A partnership is needed between the federal government, pharmaceutical companies and the medical communities to ensure people with rare diseases can get treatment.

"In stark contrast to other developed nations and despite the fact that the number of rare diseases continues to increase along with the number of individuals affected, Canada does not have a policy framework connecting these three groups, and attempts to function with a relatively piecemeal approach," writes Dr. Chaim Bell, St. Michael's Hospital, Toronto and coauthor.

The paper outlines several elements that are part of rare disease policies in other jurisdictions such as the United States, the European Union, Japan and Australia. Two elements that Canada could incorporate in the short term would be to define rare diseases and to develop patient registries to track disease characteristics, treatments and health outcomes.

In the longer term, Canada needs to create formal rare disease drug

legislation, which could include incentives for [pharmaceutical companies](#) to invest in developing new drug treatments. The authors suggest an alternate economic evaluation to ensure there is public funding for these drugs.

"This funding would be rooted in the rule of rescue: the imperative that therapies should be provided to individuals suffering from life-threatening diseases in the absence of any other alternatives, irrespective of cost," state the authors. "In the context of treatment for rare diseases, adopting the rule would allow public funding of expensive drugs that would potentially help a very small number of Canadians." The rule of rescue is used to explain why expensive rescue missions are undertaken to rescue a single person lost at sea.

"It is time for Canada to take bold and decisive steps and develop a nation-wide and federally financed approach to [rare diseases](#) that ensures adequate health care for all Canadians," they conclude.

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