

Canada must ensure all orphan drugs are priced fairly to allow patient access

February 23 2015

In developing an orphan drug policy, Canada must ensure that all orphan drugs for rare diseases—both old and future drugs—should be priced fairly so that Canadians may access life-saving therapy, argue authors of an analysis published in *Canadian Medical Association Journal (CMAJ)*.

New orphan drugs often have very high prices, which companies justify based on costly research and development and a small number of patients. But for older orphan drugs, the justification for high prices is not clear. This study examines trientine, a life-saving therapy for Wilson disease. Trientine was developed in the 1960s and has been available for use since then. Last year, the manufacturer unexpectedly increased its price 13-fold, resulting in annual treatment costs of over \$150 000. Just as suddenly, the price increase was later rescinded in Canada.

New regulations for orphan drugs are expected soon in Canada, although the focus is on future drugs. The regulations must ensure that older orphan drugs remain accessible.

"An orphan drug framework should clarify that patient access to essential drugs should not be vulnerable to prices that reflect neither costs of production nor rewards for innovation," writes Dr. Eve Roberts, The Hospital for Sick Children (SickKids) and the University of Toronto, Ontario, and coauthors.

"All [orphan drugs](#) should be priced fairly," write the authors. "Fair pricing should be defined as what is fair for society and Canadian health

care systems, and fair given the contribution of the company to developing and producing the product."

More information: *Canadian Medical Association Journal* [DOI: 10.1503/cmaj.140308](https://doi.org/10.1503/cmaj.140308)

Provided by Canadian Medical Association Journal

Citation: Canada must ensure all orphan drugs are priced fairly to allow patient access (2015, February 23) retrieved 27 April 2024 from <https://medicalxpress.com/news/2015-02-canada-orphan-drugs-priced-patient.html>

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