

CORD: Assuring Affordability and Sustainable of Access to Orphan Drugs

Key Points: June 25, 2015

With regard to the cost of orphan drugs, it is important to remember that the only acceptable solutions are those that assure rare disease patients get access to the right drugs in a timely fashion.

- CORD believes there are workable solutions. We have consistently called for affordable and sustainable access to rare disease drugs, recognizing the small patient population, the lack of effective alternative therapies, and the overall budget impact as well as per-patient cost.
- CORD has (repeatedly) proposed a responsible “managed access” pathway, starting only those patients who meet “evidence-informed” start criteria and maintaining those who continue to meet “treatment milestones” or show net benefits. This approach has been used in Canada for rare and common drugs and is increasingly used in the European Union. Health Ministers have not agreed to meet with CORD and the patient community.
- In October 2014, provincial and territorial Health Ministers announced formation of a Working Group to develop a national (panCanadian) reimbursement pathway specifically for rare disease drugs. CORD has asked that patients be included in the Working Group. We are still awaiting response from the Health Ministers. There is no indication the Working Group has been formed, even though they are due to report back in January 2016.
- CORD takes no position with regard to the appropriateness of the price of any specific drug, rare or common.
- CORD supports the need for fair and value-based pricing. The price and other financial incentives (reduced or no filing fees, data protection, and risk sharing) should be perceived as fair and compatible with international benchmarks to ensure companies will want to bring drugs to Canada and Canadians have access at the same time as other developed countries (which doesn’t always happen now).
- CORD believes transparency in all steps of the review and reimbursement process is important. We must be consistent with international practice but we can also show leadership by adopting an ethical and inclusive approach.

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