Provincial Health Services Authority
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August 4, 2020

Elena Lungu
Manager of Policy Development
Patented Medicine Prices Review Board (PMPRB)
Box L40
Standard Life Centre
333 Laurier Avenue West
Suite 1400
Ottawa, Ontario
K1P 1C1

Dear Elena Lungu,

I am writing on behalf of the Expensive Drugs for Rare Diseases Advisory Committee to provide comments on the newly circulated Revised PMPRB Guidelines.

As we indicated in our letter of December 30, 2019, the Expensive Drugs for Rare Diseases Advisory Committee consists of fourteen members and includes specialist physicians, pharmacists and individuals with expertise in ethics and pharmacoeconomics. Our mandate is to provide expert evidence-informed advice to the Ministry of Health on the exceptional coverage of expensive drugs for patients with rare diseases and related issues.

Having reviewed the revised guidelines, we feel that comments made in our first letter still stand. We are supportive of these new guidelines and believe they can result in prices which both encourage innovation and are justifiable in terms of the health and healthcare benefits they can provide.

We would observe that the revised guidelines are complex and, as such, it will be difficult for the PMPRB to explain the guidelines and to justify guideline-based decisions to the public. When the new guidelines come into effect, we suggest the PMPRB develop communication tools to explain to the public and to physicians, pharmacists and other healthcare providers how the new rules will affect drug prices and how these rules are justifiable in terms of international price comparisons, comparative benefit vis-a-vis other healthcare interventions and improvements in quality of life.

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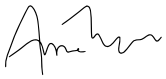
We note the new guidelines do not address the lack of transparency in drug pricing. The fact that the costs of research and development are not known means there can be no assessment of a reasonable return on investment and no assessment of the contribution that public support for research through post-secondary institutions has had on development costs. If there were more transparency with respect to costs of development and production, the calculation of a reasonable price would be clearer and more defensible to the public.

Thank you for the opportunity to respond to these new guidelines.

Sincerely,



Anne McFarlane, Chair
Expensive Drugs for Rare Diseases Advisory Committee

c: Mitch Moneo, Assistant Deputy Minister,
Pharmaceutical Services Division, Ministry of Health
Tijana Fazlagic, Executive Director,
Drug Intelligence, Outcomes and Strategy, Ministry of Health
Dr. Maureen O'Donnell, Executive Vice-President,
Clinical Policy, Planning & Partnerships, Provincial Health Services Authority