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Elena Lungu
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Patented Medicine Prices Review Board (PMPRB)
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Dear Elena Lungu,

I am writing on behalf of the Expensive Drugs for Rare Diseases Advisory Committee both to thank you for the December 10, 2019 presentation on the Draft PMPRB Guidelines and to respond to your invitation to the committee to provide further feedback.

The Expensive Drugs for Rare Diseases Advisory Committee consists of fourteen members and includes specialist physicians, ethicists, pharmacists and pharmaco-economists. Our mandate is to provide expert evidence-informed advice to the Ministry of Health on the exceptional coverage of expensive drugs for rare diseases and related issues.

The committee strongly supports the aim of improving the current guidelines so that they more accurately reflect international pharmaceutical market prices and the value to patients of new medications. We applaud the sheer amount of work and creativity that has gone into these proposals to date and recognize that the next steps in your work will be equally demanding. We also want to acknowledge the openness you have exhibited in making presentations like this available to a wide audience.

As you know, these proposed changes are complex and will be challenged privately and publicly by interested companies who will be critical of the potential loss of revenue associated with these changes. Some companies may suggest these changes will cause them to reconsider whether they will seek a license for a new drug in Canada thereby depriving Canadian patients of innovative medications.

For this reason, we encourage PMPRB to develop a communications/public relations strategy directed to the Canadian public, and more specifically patients and providers, focusing on how the proposed changes are fair and of greater benefit to patients. It would be equally important to develop a separate communication strategy for specialist physicians who are more likely to be engaged in clinical trials and to prescribe new medications. Specialist physicians may be concerned about the potential for reduced access to innovative medications and threats of reduced funding for research to support innovation.

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We would also encourage PMPRB to work with the other federal agencies involved in drug development research, approval, evaluation and reimbursement so that none of the agencies are working in isolation. In particular, we feel that the guidelines under which Health Canada works need to be adjusted in order to maximize the potential benefits of the proposed changes to PMPRB guidelines. Current procedures (which involve Health Canada approving a drug before any evidence-based evaluation can be conducted) can hinder the success of pricing negotiations and nullify QALY-based thresholds for drug pricing proposed by the PMPRB resulting in less access for Canadians to expensive drugs for rare diseases rather than enhanced access to these drugs. Collaborations amongst the agencies are critical to providing access to drugs which the publicly funded system can afford in a timely fashion.

The committee also noted that while these draft guidelines are comprehensive and fair, they are not able to overcome a persistent problem in pharmaceutical pricing namely the lack of transparency around the cost of research and development. The fact that the information underlying the calculation of the Market Rebatable Price (MRP) is confidential will introduce additional obscurity into pharmaceutical prices which is unfortunate.

Finally, the committee recognizes that many issues associated with the cost of drugs lie beyond the scope of PMPRB as they reflect the international nature of the industry and will, therefore, require international solutions. We hope that Canada will be on the forefront of activities designed to address the increasingly serious issue of the cost of new medications.

In conclusion, we would like to thank you again for the presentation of this material and for the work of the PMPRB in this area. We would be happy to engage in further consultations should you need our input.

Sincerely,

Anne McFarlane
Chair
Expensive Drugs for Rare Diseases Advisory Committee

c: Dr. Maureen O'Donnell, Executive Vice President, Clinical Policy, Planning & Partnerships, Provincial Health Services Authority, BC
Eric Lun, Executive Director, Drug Intelligence Optimization Outcomes & Strategy, Pharmaceutical Services Division, Ministry of Health, BC