April 9, 2021

Dr. Mitchell Levine, Chairperson
Mr. Douglas Clark, Executive Director
Patented Medicine Prices Review Board
Standard Life Centre
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Ottawa, Ontario
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Via email:
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Dear Dr. Levine and Mr. Clark,

The Best Medicines Coalition has been following recent communications from the PMPRB with interest, including proceedings at the House of Commons Standing Committee on Health, the February 2021 newsletter, exchanges on Twitter, a podcast featuring Mr. Clark, and the March 23, 2021 PMPRB background document relating to Gap medicines. Flowing from these communications, questions have come to light about which we write to seek clarification from the PMPRB to further understand the path forward and inform our patient organization members.

We appreciate the efforts of the PMPRB to highlight component recommendations of our submissions to the PMPRB. To reiterate, it is our view that the PMPRB (and the federal government) should move forward with the new basket of comparator countries immediately and formally pause on the economic factors until there is more clarity of legality and evidence to remove any uncertainty around their impacts on drug access for patients. In fact, regarding the most recent delay of the effective date of the regulations to July 1, 2021, those patients who pay directly for drugs are the most impacted by the now $600 million which those patients would have saved by applying the new basket of comparator countries, as estimated by Mr. Clark in the podcast.

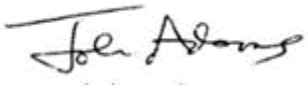
It is clear from those recent communications, though, that the PMPRB wishes to pursue implementing the economic factors and – publicly – it is unclear yet if and how the PMPRB will do so. It is this sort of uncertainty that needs to be avoided and addressed. ***The Best Medicines Coalition requests that the PMPRB immediately establish a clear process on if and how the economic factors could be implemented, transparency around that process and how patients and patient organizations will be engaged in that process.***

Further, it was acknowledged in Mr. Clark's recent podcast comments that the PMPRB is developing a monitoring and evaluation regime of the new regulations and guidelines in advance of July 1, 2021. This is a process that we would like to support, however, at this point we have not received adequate communication from PMPRB on the development and implementation of this system, and specifically, how patients will be engaged and involved. At its core, any decision that PMPRB takes will have an impact on patient access to medicines. We have seen conflicting data and interpretation of data with respect to possible impact on patient access to medications and the potential for this in a monitoring plan must be minimized. ***The Best Medicines Coalition and our members need to better understand how this regime will focus on evaluating and monitoring the impact to patient access to medicines resulting from these regulatory changes and so we again are calling on the PMPRB to formally engage patients and the organizations that represent them in the co-development of the monitoring and evaluation regime.***

Finally, we must address with the PMPRB how our coalition was referenced in the March 23 PMPRB-released background on its decision relating to the definition of Gap medicines and the timeline for information reporting compliance. The BMC did not provide a submission to this consultation, nor did the BMC take a position on either technical policy change.

While we do appreciate knowing our correspondence has been reviewed, it came as surprise to be referenced as a reason for a technical policy change that the PMPRB made on something about which BMC does not have the technical capability to provide advice. As the backgrounder is written, we think it misleads about BMC's role and position in this consultation. ***Therefore, the Best Medicines Coalition requests that the PMPRB make it clear that the BMC did not make a submission to this specific consultation, and as such, include this letter alongside the letter previously published on the PMPRB website as part of the consultation background and recognize in the background information that BMC did not take a position on the definition of Gap medicines and the timeline for information reporting compliance.*** We believe that when the PMPRB engages BMC and our members more regularly, the PMPRB will benefit from a better understanding of patients' perspectives.

Thank you for your consideration. We look forward to your response to the three requests highlighted above, and as always, we would be pleased to discuss any of the aforementioned questions and recommendations with you at any time.



John Adams
Chair of the Board of Directors
Best Medicines Coalition
(President & C.E.O, Canadian PKU and Allied Disorders)

CC:
The Right Honourable Justin Trudeau, Prime Minister of Canada
The Honourable Patty Hajdu, Minister of Health
Members of the House of Commons Standing Committee on Health
Dr. Stephen Lucas, Deputy Minister, Health Canada
Kendal Weber, Assistant Deputy Minister, Health Canada
Rick Theis, Director of Policy and Cabinet Affairs, Prime Minister's Office
Sabina Saini, Chief of Staff, Health Minister's Office
Kathryn Nowers, Director of Policy, Health Minister's Office

About the Best Medicines Coalition

The Best Medicines Coalition is a national alliance of patient organizations, together representing millions of patients, with a shared goal of equitable, timely and consistent access for all Canadians to safe and effective medicines that improve patient outcomes. The BMC's areas of interest include drug approval, assessment, and reimbursement, as well as patient safety and supply issues. As an important aspect of its work, the BMC strives to ensure that Canadian patients have a voice and are meaningful participants in health policy development, specifically regarding pharmaceutical care. The BMC's core activities involve issue education, consensus building, planning and advocacy, making certain that patient-driven positions are communicated to decision makers and other stakeholders. The BMC was formed in 2002 as a grassroots alliance of patient advocates. In 2012, the BMC was registered under the federal Not-for-profit Corporations Act.

Alliance for Access to Psychiatric Medications
Asthma Canada
Brain Tumour Foundation of Canada
Canadian Arthritis Patient Alliance
Canadian Association of Psoriasis Patients
Canadian Breast Cancer Network
Canadian Cancer Survivor Network
Canadian Council of the Blind
Canadian Cystic Fibrosis Treatment Society
Canadian Epilepsy Alliance
Canadian Hemophilia Society
Canadian PKU & Allied Disorders
Canadian Psoriasis Network
Canadian Skin Patient Alliance
Canadian Spondylitis Association
CanCertainty
Crohn's and Colitis Canada
Cystic Fibrosis Canada
Fighting Blindness Canada
Health Coalition of Alberta
Huntington Society of Canada
Kidney Cancer Canada
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Medical Cannabis Canada
Medicines Access Coalition - BC
Millions Missing Canada
Ovarian Cancer Canada
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