



May 28, 2021

The Right Honourable Justin Trudeau, P.C., M.P.
Office of the Prime Minister
80 Wellington Street
Ottawa, ON K1A 0A2
Via email: pm@pm.gc.ca

Dear Prime Minister Trudeau,

It has come to our attention that an agency of your government, the Patented Medicine Prices Review Board (PMPRB), has in an internal document accused the Best Medicines Coalition (BMC) and other patient organizations of disseminating disinformation on pricing and access to medicines, and furthermore, that the PMPRB has budgeted taxpayer dollars for a communications strategy to combat this. This is a disturbing development, and our organization cannot ignore this malignment. It is of critical importance that the PMPRB operate in such a way that all concerns, constructive criticisms, and opportunities for improvement can be expressed and are addressed.

It needs to be noted that our non-profit organization, a national alliance of patient organizations, has consistently called for efforts to improve access to and lower drug prices for patients and has participated in formal consultations conducted by the PMPRB and related discourse, in good faith. Our patient organization members are acutely aware that patients in Canada are too often unable to afford the medically necessary drugs and therapies they need, sometimes having to go without food to afford prescription medications, and we appreciate the steps your government has done to better understand and begin to address this issue.

The revelations in the internal PMPRB document, a Communications Plan made available as part of an [Access to Information Request](#) by Member of Parliament Tom Kmiec, are extremely distressing, revealing PMPRB's operating principles and core beliefs towards our organization and others while also questioning the independence of Members of Parliament who serve on the Standing Committee on Health. We believe that the content and tone seriously undermines your government's attempts to integrate patients' concerns into the new regulatory regime and creates an environment of distrust.

Statements expressed in the PMPRB's Communications Plan are false and hurtful, and the document makes conclusions that call into question the agency's impartiality, objectivity, and capability of carrying forward its responsibilities as a regulator and to conduct productive and necessary discussions with the patient groups we represent. At the heart of the matter, our concern is that the PMPRB is unduly focused on these constructs, be it a perceived alignment with the pharmaceutical industry on messaging or claims that our organization is undertaking aggressive public relations campaigns.

In fact, the BMC has engaged in sharing consensus-based positions from our patient organization community, often at the PMPRB's request, with the goal of working together to lower drug prices for patients in Canada and ensure that patients are able to access the medicines they need moving forward, again in good faith.

We ask that the government provide clarity on whether this apparent culture of distrust is acceptable and an appropriate reflection of the government's general approach to consultation and inclusion of diverse voices, and we request detail on how this will be addressed and rectified.

As it relates to the policy at hand - the government's regulations to reform the PMPRB's authorities - our organization has been consistent and clear: we continue to fully support the changes to comparator countries that establish maximum list prices for pharmaceutical drugs in Canada, thus lowering those prices. However, we remain concerned regarding other parts of the regulatory package, specifically the new economic factors where there remains a lack of clarity on if and how they will be used in practice and their impact. We have continued to seek data, information, and insights from the PMPRB about how the regulatory regime will impact specific types of patented medicines and related technologies (e.g., gene therapies) that may transform the lives of the patients we represent.

Furthermore, two court cases have made rulings that have effectively challenged the government's ability through PMPRB to move forward with the economic factors. We are unclear as to why the government continues to perpetuate this uncertainty by retaining the economic factors as part of the regulations. **With the further mistrust that has developed because of the PMPRB's actions, we are calling on the government to stay or otherwise cease the implementation of the economic factors prior to their planned implementation on July 1, 2021.**

Currently, the PMPRB has a consultation open to seek feedback on its self-monitoring and evaluation regime regarding the impacts of these regulations. Given the clear bias and perspective of the PMPRB on the feedback brought forward by patient groups, we do not believe that the PMPRB has the capacity and impartial knowledge to self-monitor and self-evaluate. Based on the PMPRB Communications Plan, we have lost confidence in the integrity of the PMPRB to behave properly as a regulator and to conduct an objective review of its own progress and impact in this regard. **We call on the Government to ensure a truly independent evaluation of the impact of these regulations, outside of the PMPRB.**

We support an immediate review of the PMPRB's activities, including investigations that have been called for by BMC member organizations, the Canadian Cystic Fibrosis Treatment Society and Cystic Fibrosis Canada, including by the Auditor General of Canada and the President of the Treasury Board. **We urge you to immediately and officially initiate investigations into the PMPRB's conduct as it has developed and implemented the regulatory regime, including regarding the PMPRB Communications Plan.**

We trust that the government understands and shares our primary objective of ensuring that patients have access to safe, effective, and affordable medications. To ensure that we can continue to move forward in good faith to achieve this shared objective, it is the government's responsibility to repair the trust that has been damaged. We look forward to hearing from you as leader of the government on how this will be achieved.

Sincerely,



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

CC:

- Katie Telford, Chief of Staff to the Prime Minister
- Janice Charette, Interim Clerk of the Privy Council
- Hon. Patty Hajdu, Minister of Health
- Jennifer O'Connell, Parliamentary Secretary to the Minister of Health
- Hon. Jean-Yves Duclos, President of the Treasury Board
- Greg Fergus, Parliamentary Secretary to the Prime Minister, to the President of the Treasury Board and to the Minister of Digital Government
- Members of the House of Commons Standing Committee on Health
- Erin O'Toole, Leader of the Official Opposition
- Michelle Rempel Garner, Conservative Shadow Minister of Health
- Jagmeet Singh, Leader of the NDP
- Don Davies, NDP Health Critic
- Yves-François Blanchet, Leader of the Bloc Québécois
- Luc Thériault, Bloc Québécois Health Critic
- Annamie Paul, Leader of the Green Party
- 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
- Douglas Clark, Executive Director, Patented Medicine Prices Review Board
- Dr. Mitchell Levine, Chairperson, Patented Medicine Prices Review Board
- Karen Hogan, Auditor General of Canada
- Chris MacLeod, Canadian Cystic Fibrosis Treatment Society
- Dr. Durhane Wong-Rieger, President & CEO, Canadian Organization for Rare Disorders
- Kelly Grover, President and CEO, Cystic Fibrosis Canada
- Beth Vanstone, Director, CF Get Loud



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
 Lymphoma Canada
 Medical Cannabis Canada
 Medicines Access Coalition - BC
 Millions Missing Canada
 Ovarian Cancer Canada
 Parkinson Canada