



June 8, 2021

Dr. Mitchell Levine
Chair and Deputy Head
Patented Medicine Prices Review Board
Box L40, Standard Life Centre
333 Laurier Avenue West, Suite 1400
Ottawa, Ontario
K1P 1C1

Posted on BMC's website

Dear Dr. Levine,

I am writing on behalf of the Best Medicines Coalition in my capacity as its volunteer Board Chair, in response to your letter dated June 2, 2021 in which you respond to issues raised in the Best Medicines Coalition letter dated May 28, 2021 to the Prime Minister regarding a Patented Medicine Prices Review Board (PMPRB) Communications Plan and related matters. We welcome receiving your perspectives directly and share your wish for us to have a more informed dialogue. Please be assured that all our concerns stem from a core belief that it is of critical importance that the federal government, including the PMPRB, operate in such a way that all concerns, constructive criticisms, and opportunities for improvement, can be expressed and are acknowledged respectfully.

We acknowledge that you express regret that patient advocacy communities have taken great offence to the PMPRB Communications Plan. We note that your letter confirms that the Communications Plan was requested by you, and was vetted and approved by you and other members of the Board.

That said, we stand by our position that the tone and content of this PMPRB document is profoundly disturbing, and in some instances erroneous, and we cannot ignore this malignment of patient voices. These issues must be addressed. The statements and tone put forth in your response of June 2, 2021 leaves the impression that the PMPRB still does not understand why the Best Medicines Coalition and its member patient organizations are deeply disturbed with how the PMPRB has unfairly and untruthfully framed our organization and others in your Communications Plan. We consider that the regret you express falls short of an apology.

We understand the legitimate purpose of communication plans in general, as you outline. However, our primary issue is that this specific document reflects an inherent and deliberate unwillingness to consider and respect concerns expressed and has denigrated the Best Medicines Coalition among others in an inappropriate and dishonest manner. Quite simply, this PMPRB Communications Plan disparages us in tone and content and specifically accuses us of disseminating disinformation. The PMPRB Plan and your letter of June 2, 2021 erroneously characterize legitimate efforts to share patient perspectives and concerns. Finally, the PMPRB allegation that we have aggressive public relations strategies is inaccurate. We are seeking clarifications on these inaccuracies and false allegations and your apology. We continue to support various investigations into how PMPRB is conducting itself, as outlined in our letter to the Prime Minister.

For the purposes of improved clarity, I will focus on the facts of how the Best Medicines Coalition, as a non-profit, national alliance of patient organizations, has engaged on these issues. Our work has involved sharing consensus-based positions from our member communities by participating in formal consultations and related discourse, often at the PMPRB's request, and in good faith. Our member organizations and the individuals who represent them, all with diverse experiences and concerns, share a passion for ensuring that patients in Canada get the best care possible with best possible outcomes. We are acutely aware that many patients struggle to pay for drugs, and some have unmet needs and wait in hope of new medicines. These realities are reflected in our core positions. We have consistently called for immediate implementation of the new basket of comparator countries to lower list prices, while expressing concerns that the proposed economic factors may have a negative impact on decisions to introduce or market drugs in Canada and so urge delay and further consideration of these elements.

In addition to formal PMPRB consultations, the Best Medicines Coalition has communicated positions in other ways, all of which are legitimate and in support of our mission and goals. For example, we have written letters outlining positions to government officials and have had follow up meetings to discuss positions. On social media, our Twitter account (@BMC_Patients) is used to notify of our positions, generally with links to our submissions on various topics including pricing reforms and to retweet items of interest. I can say unequivocally that BMC has not engaged in personal attacks on social media or participated in any campaign of disinformation. I say this to refute the false allegations in the PMPRB Communications Plan and in your letter dated June 2, 2021. In addition, while media coverage of these issues has been limited, there have been occasions where we have been asked by media to comment and, as Board Chair, I have shared Best Medicines Coalition positions.

The PMPRB Communications Plan includes unfounded statements which call into question the agency's impartiality, objectivity, and capability to receive diverse input and then productively move forward. The federal government must take steps to improve this situation. Again, it is of critical importance that the PMPRB operate in such a way that all perspectives can be expressed and received appropriately and respectfully even when there are differences of opinion and perspective, even to the point of opposition. This is so even when your Board and/or staff believe that claims or concerns are not supported by what you consider empirical evidence, as you wrote. As we have expressed previously, the Best Medicines Coalition hopes that the PMPRB and all stakeholders can come together to develop agreed upon research methods and evidence standards moving forward, including how the success or otherwise of the proposed regulatory changes take effect in the real world. We hope that in the face of the ill-advised Communications Plan, you, your Board and staff share our goal of rebuilding trust between the government, the PMPRB and its stakeholders, including the Best Medicines Coalition.

Given the seriousness of this situation, we request that you, as Board Chair, along with your Board colleagues, provide the following:

1. Immediate review by an independent third-party of the PMPRB's current approach to receiving and considering concerns and opposing views on its proposals. Is the current culture an acceptable reflection of appropriate consultation practices and inclusion of diverse voices? We request findings and details on how this situation will be addressed and rectified, including appropriate apologies.

2. Full clarification, including examples of how and where the Best Medicines Coalition has allegedly disseminated disinformation on access and impact on our patient constituencies. In addition, we request details of alleged aggressive public relations strategies put in place by the Best Medicines Coalition, including on social media, and where and when you believe the BMC has engaged in personal attacks.

We trust that these issues can be resolved by a focus on the truth so that the PMPRB and all stakeholders can move forward in a productive manner to better serve patients in Canada. We would be pleased to meet virtually to discuss these issues, as you suggest, and we also look forward to receiving a formal response from the PMPRB that reflects the urgency of the important matters and specific requests raised in this letter.

Sincerely,



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
- 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
- Karen Hogan, Auditor General of Canada
- Joe Friday, Public Sector Integrity Commissioner
- 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
- Paulette Eddy, Executive Director, Best Medicines Coalition



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