



April 2, 2020

The Honourable Patty Hajdu, P.C. M.P.
Minister of Health
70 Colombine Driveway Tunney's Pasture
Postal Location: 0906C
Ottawa, Ontario K1A 0K9

Subject: COVID-19 and request to pause federal PMPRB regulation changes

Dear Minister Hajdu,

I am writing in support of the March 23, 2020 letter sent to you by the Health Charities Coalition of Canada, Canadian Organization for Rare Disorders, Best Medicines Coalition, Alliance des patients pour la santé, and Regroupement Québécois des maladies orphelines/Quebec Coalition of Orphan Diseases with an urgent request that you and your Cabinet colleagues pause implementation of changes to the price control regulations of the Patented Medicines Prices Review Board (PMPRB) set to come into force on July 1, 2020.

We recognize the government's goal of lowering pharmaceutical drug prices and appreciate your commitment to listen to patient input on the PMPRB changes. In the ALS Society of Canada's February 13 submission to the PMPRB we identified the strong likelihood that the proposed reforms could result in fewer innovative therapies coming to Canada, limiting access for patient populations with an unmet need. **The real impact of the proposed PMPRB changes on Canadians can only be understood when the experiences of the patient populations are considered, and our organization, like so many others, is consumed with assessing and responding to the needs of our community during the COVID-19 crisis.**

Efforts to improve affordable access to therapies must be done in a way that ensures Canadians' swift access to innovative treatments and clinical trials of new medicines and is representative of the needs, experiences and perspectives of all Canadians. This is particularly relevant to the ALS community as a population facing a terminal diagnosis, with the majority of people dying within five years while experiencing progressive paralysis. While there are two approved therapies for ALS, more treatments are desperately needed to significantly improve the lives of Canadians diagnosed with the disease. We see promise in the Phase 2 and Phase 3 clinical trials currently underway, making it essential that tomorrow's proven ALS therapies be accessible to Canadians in a timely, equitable and affordable way.

Appropriate time must be given to consult with all stakeholders, including patient representatives to make sure that any changes to Canada's drug access pathway – including the PMPRB – are flexible and responsive to the needs of Canadians and encourage more proven therapies to be developed, sold, and reimbursed in Canada.

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We commend you on your role in addressing and mitigating the significant impact of the COVID-19 crisis. Thank you for your tremendous leadership during this challenging time and for considering this request.

Sincerely,

A handwritten signature in black ink, appearing to read 'Tammy Moore', with a long horizontal flourish extending to the right.

Tammy Moore, CEO

Enclosure

Cc:

The Right Honourable Justin Trudeau, Prime Minister of Canada

The Honourable Jean-Yves Duclos, President of the Treasury Board

The Honourable Chrystia Freeland, Deputy Prime Minister and Minister of Intergovernmental Affairs

The Honourable Bill Blair, Minister of Public Safety

Dr. Stephen Lucas, Deputy Minister of Health

Dr. Theresa Tam, Chief Public Health Officer of Canada



Canadian Organization
for Rare Disorders



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Subject: COVID-19 and request to pause federal PMPRB regulations

Dear Minister Hajdu,

We are writing to urgently request, in light of the COVID-19 pandemic health crisis, that you and your Cabinet colleagues pause implementation of changes to the price control regulations of the Patented Medicines Prices Review Board (PMPRB) set to come into force on July 1, 2020. We are signing this letter on behalf of national patient organizations, including health charities and not-for-profits, which are part of Alliance des patients pour la santé, Best Medicines Coalition, Canadian Organization for Rare Disorders, Health Charities Coalition of Canada, and Regroupement québécois des maladies orphelines/Quebec Coalition of Orphan Diseases. Together, we represent millions of Canadian patients with all types of illness, conditions and unmet therapeutic needs.

We fully recognize the significant challenges in addressing and mitigating the impact of the COVID-19 crisis to save lives, including communicating national efforts, and we commend you on your role in this vital work. We greatly appreciated the work to ensure the flow of life-saving medicines given the partial closure of the USA-Canada border. We fully support Prime Minister Justin Trudeau's statement today that it is time for all hands on deck. This effort must involve national leaders along with all stakeholders, including patient organizations that are a vital link and support to patients and indeed all Canadians. The COVID-19 crisis requires full, sustained and undivided attention.

Therefore, together we fully support and jointly urge you to put implementation of the PMPRB regulations on hold in the spirit of reprioritizing/postponement of other national and provincial initiatives including, for example, Ontario healthcare restructuring plans. We believe this is necessary to allow for a singular focus on COVID-19 countermeasures and to continue further review and consultations on the PMPRB implementation. For our part, we need to focus on helping our patient members through the COVID-19 crisis. We respect your commitment, expressed at the House of Commons Health Committee on March 11, to listen to patient input on the PMPRB changes, especially considering the PMPRB's own listening session to be held March 18 was cancelled due to COVID-19. We wish to to prepare additional input as suggested by the PMPRB in its announcement of the cancellation of the session, but of course we need time to prepare this which is extremely challenging currently.

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Given these extenuating circumstances, we ask that that you and Cabinet pause the changes and provide public notification to this effect in order to ensure there is time to appropriately consult all stakeholders, including patient representatives, and for government to complete a comprehensive review. We look forward to your leadership and prompt action on this crucial issue for the sake of Canadian patients and our health system. Thank you in advance for your consideration and continued support.

Sincerely,

Alliance des patients pour la santé

Jérôme Di Giovanni, President and Founder

Best Medicines Coalition

John Adams, Chair, Board of Directors

Canadian Organization for Rare Disorders

Durhane Wong-Rieger, President and Chief Executive Officer

Health Charities Coalition of Canada

Connie Côté, Chief Executive Officer

Regroupement québécois des maladies orphelines/Quebec Coalition of Orphan Diseases

Gail Ouellette, President and Founder

c.c.: The Right Honourable Justin Trudeau, Prime Minister of Canada
The Honourable Jean-Yves Duclos, President of the Treasury Board
The Honourable Chrystia Freeland, Deputy Prime Minister and Minister of Intergovernmental Affairs
The Honourable Bill Blair, Minister of Public Safety
Dr. Stephen Lucas, Deputy Minister of Health
Dr. Theresa Tam, Chief Public Health Officer of Canada