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June 2, 2021

Patty Hajdu
House of Commons
Ottawa, ON
K1A 0A6

Dear Minister Hajdu:

**RE: PMPRB and other cost-containment strategies
are putting Canadian lives at risk**

We are writing to you on behalf of Canadian patients and families concerned that their access to important life-changing medicines is at risk.

Since the changes to the Patented Medicines Pricing Review Board (PMPRB) regulations were first proposed in 2017, the patient community has consistently raised concerns that these changes will negatively impact access to new medicines and clinical trials for Canadians. However, these concerns have been largely overlooked, if not altogether dismissed by government and the PMPRB. We expressed these same concerns in our submission to Health Canada's consultations for their National Strategy for High-Cost Drugs for Rare Diseases. We strongly believe that the PMPRB changes, as they currently stand, and any other policies that focus solely on cost-containment impede patients from achieving fair and quick access to the medicines they need.

This is not only un-Canadian, but it puts the lives of millions of Canadians at risk. Government must reconsider these changes before it is too late.

Our collective organizations and the patients we represent support efforts to lower the cost of prescription drugs for Canadians. We expect pharmaceutical manufacturers to bring their products to market at a responsible price, but we



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also expect the government to ensure that the regulatory environment in Canada does not unnecessarily limit our ability to quickly and fairly access new therapies that hold promise to improve the health of Canadians.

Efforts to lower drug prices must be balanced in a way that encourages ongoing innovation and the launch and uptake of new medicines, including drugs for rare disorders, into the Canadian market. However, we are concerned that the current emphasis by government on cost-containment – over access and seeing patients benefit from scientific innovation – will greatly disadvantage millions of Canadians who are waiting for new therapies.

New regulations have already created a chilling regulatory, review and reimbursement environment in the Canadian market. For instance, Canadians living with cystic fibrosis have [died waiting for access](#) to a new therapy that could have saved their life, but which is still not available in Canada because the [manufacturer delayed bringing the drug to Canada](#) as a result of the proposed regulatory changes – and there are other patients living with other diseases across Canada that are similarly struggling to access therapies currently available in other countries.

The lack of incentives for manufacturers to conduct clinical trials or commercialize new drugs, including drugs for rare diseases in Canada, has ultimately resulted in access issues. Right now, it is estimated that [only 60% of the drugs approved](#) by the US FDA are available in Canada and most that are get approved up to six years later than in the US or Europe. As a result, Canadian patients are not only being left behind; their lives are being put at risk.

Despite claims to the contrary, government knows the proposed changes will delay access to new therapies, which is why it exempted COVID-19 vaccines and treatments from its new regulatory regime. In doing so, it has



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implicitly acknowledged that the proposed changes will delay access to new medicines for Canadians.

We appreciate and support the need to expedite access to these lifesaving COVID-19 vaccines and therapeutics, but there are millions of Canadians living with life-threatening conditions or who may benefit from transformational treatments which also need fast access to new medicines and for whom time is running out. But no such exemptions exist for them. Canadians deserve fast and equitable access to all new medicines, not just when it comes to COVID-19.

Canadians value fairness and equity. It is the very foundation of universal healthcare. Canada does not apply a monetary cap to each patient's healthcare services, nor would governments ever suggest that needed, potentially life-saving services should be withheld from a Canadian because it is expensive. Yet, this is precisely what is being proposed when we reduce drugs, particularly those for rare diseases, to their cost.

We call on the government to reconsider these changes before it is too late and ensure that patients, families, and the organizations who represent them are meaningfully engaged and truly listened to. Now that policies such as the PMPRB and Strategy for High-Cost Drugs for Rare Diseases will weigh in on the economic value of patient lives, patients need to be at the table and weigh in on the value of their lives.



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We look forward to hearing back from you regarding your plans to ensure that Canadian patients receive early and timely access to the medicines they so desperately need.

Sincerely,



Doug Earle

President & CEO, Fighting Blindness Canada | Vaincre la cécité Canada

On behalf of:

[ALS Society of Canada](#)

[Canadian Cancer Survivor Network](#)

[Canadian Hospice Palliative Care Association](#)

[Canadian Association of PNH Patients](#)

[Coalition Priorité Cancer au Québec](#)

[Colorectal Cancer Canada](#)

[Cure SMA Canada](#)

[Cystic Fibrosis Canada](#)

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[Lung Health Foundation](#)

[MitoCanada](#)

[Ovarian Cancer Canada](#)

[PROCURE – The Force Against Prostate Cancer](#)

[Québec Breast Cancer Foundation](#)

[The Leukemia & Lymphoma Society of Canada](#)

Cc: Rt Hon. Justin Trudeau, Prime Minister

Hon. Chrystia Freeland, Deputy Prime Minister and Minister of Finance

Hon. François-Philippe Champagne, Minister of Innovation, Science and Industry



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