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**VIA EMAIL:** [pm@pm.gc.ca](mailto:pm@pm.gc.ca) and [hcmister.ministresc@canada.ca](mailto:hcmister.ministresc@canada.ca)

May 27, 2021

The Right Honourable Justin Trudeau, PC, MP  
Prime Minister of Canada  
80 Wellington St.  
Ottawa, Ontario K1A 0A2

The Honourable Patty Hajdu, PC, MP  
Minister of Health  
Brooke Claxton Building, Tunney's Pasture  
Ottawa, Ontario K1A 0K9

Dear Prime Minister Trudeau and Health Minister Hajdu

**Subject: PMPRB Campaign to Discredit Patients and Others Who Do Not Agree with Them**

This is a direct appeal to the Prime Minister and Minister of Health on behalf of the Canadian Organization for Rare Disorders (CORD), which represents over 100 rare disease patient groups and hundreds of thousands of patients and their families.

Frankly, the rare disease community has been truly baffled and dismayed by the open contempt that the Patented Medicine Prices Review Board (PMPRB) has displayed toward patients and patient organizations. Now, with the PMPRB Communications Plan dated 19 February 2021 that was revealed through Access to Information, we have confirmation that the PMPRB's tactic all along was to deliberately denigrate and diminish the voice of the patients and all others who disagreed with their "new direction." Now it is clear why all of the data, analyses, and expert opinions that we brought to discussions of the regulatory changes were ignored and had negligible impact on the PMPRB's positions or their plans to roll out the regulations.<sup>1</sup>

Worse, we as patients were told outright that we had no idea what we were talking about, that our examples and analyses were flawed, and that we were "in the pocket" of "big pharma" and just parroting the industry's perspectives. We raised this issue directly with the PMPRB and Health Canada in 2018 when the PMPRB's Executive Director made these same comments to the media, leading to his removal as Chair of the Steering Committee and banning of further attendance.<sup>2</sup> Unfortunately, even without his presence, the Steering Committee was never allowed to do any genuine analysis of the potential impact of the regulatory changes and prohibited from exploring alternative pathways to address drug prices, affordability and access.

Every developed country is grappling with these same issues and no other country has proposed measures like the PMPRB changes because of their very serious negative impact on patients. Indeed, CORD has brought many European experts to the table and to our various forums with alternative proposals but these have never been considered by the PMPRB.

As patients who will be seriously affected by the regulations if they are implemented, we request that you take executive action to put an immediate halt to the implementation of the new guidelines, still scheduled for July 1, 2021, until there have been real consultations.

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<sup>1</sup> PMPRB February 9, 2021 Communications Plan released through Access to Information Request and posted online here: [bit.ly/3vgqmky](http://bit.ly/3vgqmky)

<sup>2</sup> <http://www.raredisorders.ca/content/uploads/MC-CORD-Letter-PMPRB-and-HC-with-logo-2.pdf>

We all agree that there is much room for improvement in terms of how medicines are adopted and funded in Canada. But there is a swelling outcry from healthcare providers and researchers who concur that the proposed PMPRB changes will be disastrous for Canadians with rare disorders and more common conditions who depend on medicines to survive.

### **Final consideration**

On behalf of the rare disease community, I reiterate our gratitude for the federal government's support to set up in Canada what could be the world's best rare disease drug program to provide timely, appropriate, and cost-effective medicines to all patients. We have been engaged actively in consultations toward the design and implementation in collaboration with Health Canada, CIHR, CADTH, INESSS, and the drug programs. But it will be a hollow vehicle if we do not have access to the best innovative medicines, by attracting clinical trials and timely submissions as well as supporting Canadian research and development.

It is imperative that changes to the pricing regulations have the same degree of multistakeholder consultation and engagement.

As always, I welcome the opportunity to discuss these important matters with you at earliest opportunity.

Sincerely,



Durhane Wong-Rieger  
President & CEO  
Canadian Organization for Rare Disorders  
151 Bloor Street West, Suite 600  
Toronto, Ontario M5S 1S4  
p: 416-969-7435  
m: 647-801-5176  
[durhane@sympatico.ca](mailto:durhane@sympatico.ca)  
[www.raredisorders.ca](http://www.raredisorders.ca)