



**FIGHTING
BLINDNESS
CANADA**

**VAINCRE
LA CÉCITÉ
CANADA**

**PROTECT
OUR** 
ACCESS

June 2, 2021

Hon. Justin Trudeau
Office of the Prime Minister
80 Wellington Street
Ottawa, ON K1A 0A2

Dear Prime Minister,

RE: Patient Groups concerns over actions of PMPRB

We are writing to you today to register our strong concern regarding plans made by the PMPRB to discredit patient groups who disagree with proposed changes the regulator has brought forward and to ask you to delay the implementation of those changes while a full investigation of the activities of the PMPRB can take place.

In an internal PMPRB document, obtained through an ATIP request, PMPRB staff allege that "opponents" of the PMPRB Guidelines reforms, including patient groups representing people living with rare diseases and the cystic fibrosis patient community, in particular, are spreading "disinformation" about the potential negative implications of these changes. This memo lays out a communications plan to discredit the stakeholder and patient community who oppose the reforms.

We want to be clear that the use of the word "disinformation" is both highly inflammatory and dangerous. "Disinformation" is defined as an intentional effort to mislead people. This was a deliberate vocabulary choice by PMPRB officials that should not be overlooked. Unfortunately, PMPRB took the inappropriate step of characterizing a policy disagreement as an intentional effort to mislead people and maligned the motives of patient groups working on behalf of all Canadians. These actions go far beyond disregarding the input of patient



**FIGHTING
BLINDNESS
CANADA** | **VAINCRE
LA CÉCITÉ
CANADA**

**PROTECT
OUR** 
ACCESS

organizations, which has been our concern with the PMPRB consultations for some time and instead seek to work against the patient community actively.

We cannot condemn this characterization and these actions strongly enough.

However, it is not simply inappropriate for a regulator to act in this manner; it is dangerous. Policy debate and disagreement is the hallmark of a healthy democracy. To malign and mischaracterize the actions of those that disagree with the PMPRB undermines our democratic values and calls into question the regulator's objectivity and fitness to fulfill its mandate.

Our view is that the PMPRB has operated with a lack of good faith throughout the consultation period and in the lead up to the coming into force of the revised guidelines. Rather than leading an open and transparent consultation process, where patient input was, at minimum, respected, the PMPRB ignored patient input, sidelined patient groups, and is now working to discredit them in the face of their continued concerns.

The actions of PMPRB demonstrate a flagrant abuse of power. Therefore, we are calling on the federal government to delay the implementation of the PMPRB changes while a full investigation of the activities of the PMPRB can occur.

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](#)



**FIGHTING
BLINDNESS
CANADA** | **VAINCRE
LA CÉCITÉ
CANADA**

**PROTECT
OUR** 
ACCESS

[Canadian Association of PNH Patients](#)
[Coalition Priorité Cancer au Québec](#)
[Colorectal Cancer Canada](#)
[Cure SMA Canada](#)
[Cystic Fibrosis Canada](#)
[Fighting Blindness Canada](#)
[Lung Health Foundation](#)
[MitoCanada](#)
[Ovarian Cancer Canada](#)
[PROCURE – The Force Against Prostate Cancer](#)
[Québec Breast Cancer Foundation](#)
[The Leukemia & Lymphoma Society of Canada](#)

Cc: Hon. Patty Hajdu, Minister of Health
Hon. Chrystia Freeland, Deputy Prime Minister and Minister of Finance
Hon. François-Philippe Champagne, Minister of Innovation, Science and Industry
Hon. Dominic LeBlanc, Minister of Intergovernmental Affairs
Members of the House of Commons Standing Committee on Health:
Mr. Ron McKinnon
Ms. Michelle Rempel Garner
Mr. Luc Theriault
Mr. John Barlow
Mr. Don Davies
Mr. Chris d'Entremont
Mr. Mike Kelloway
Mr. Larry Maguire
Ms. Jennifer O'Connell
Mr. Marcus Powlowski
Ms. Sonia Sidhu
Mr. Tony Van Bynen
Clerk of the Privy Council