

December 11, 2023

Patented Medicine Prices Review Board

Standard Life Centre, Box L40

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Ottawa, ON K1P 1C1

Submitted electronically to: PMPRB.Consultations.CEPMB@pmprb-cepmb.gc.caRe: [Scoping paper for the consultations on the Board's Guidelines.](#)

Thank you for inviting written comments in addition to those provided at the roundtable on December 6.

The GI Society is a national charity formed in 2008 on the groundwork of its partner organization, the Canadian Society of Intestinal Research (CSIR), which was founded in Vancouver in 1976. We receive national and international attention, simply because we have earned the respect of both the gastrointestinal medical community and Canadians who battle GI and liver issues daily.

I was one of only three patient group representatives on the PMPRB steering committee back in 2018 during modernizing attempts. We were not treated well, so I do hope that you find value in what patient groups offer now.

I will not make it too easy for you by going in the order for the questions you asked, as they are not all applicable to our perspective.

One of my concerns is the open comparison of Canadian maximum list prices to other countries' list prices when we all know that the public coverage price is way below this and there is a trend for private payers to also pay way less than the PMPRB price. To me, this does not seem like a sincere effort to really discuss drug pricing in Canada.

There have been so many consultations since 2018 and we are no further ahead. We should have agreed to changing the basket of comparator countries and then moved forward without wasting so much money.

While we do want our voices heard, it is a deep financial burden for patient groups to respond to all of your requests when we don't get funding for this. We're in the midst of the three big Cs, the **C**limate crises, **C**COVID and world **C**onflict that take huge tolls on patients in Canada and on patient groups. We are living through difficult times and most individuals are donating less to charities.

The patients themselves are not getting the medications they need due to processes downstream from PMPRB, such as pCPA that take so long and, despite letters of intent, sadly, results in disparity across the country and for Indigenous populations. Is it time for PMPRB to navel-gaze to see how valuable it really is now, because other agencies are in place now that did not exist in 1987.

Medications serve a purpose for us. I urge caution that the wall you put between us and a treatment that will make us well or save our lives, is not undoing your intent.

We should have a respectful working committee that values input from patient groups so we can fully access the experts you have available, at no cost to us, and provide feedback from the end users, which really should be the object of the exercise.

Yours sincerely,



Gail Attara, President & Chief Executive Officer

Gastrointestinal Society

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