



Canadian Organization  
for Rare Disorders

MYÉLOME  
CANADA



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November 29, 2018

Dr. Mitchell Levine  
Chairperson, Patented Medicines Prices Review Board  
[levinem@mcmaster.ca](mailto:levinem@mcmaster.ca)

Karen Reynolds  
Executive Director  
Office of Pharmaceuticals Management Strategies, Strategic Policy Branch, Health Canada  
[karen.reynolds@canada.ca](mailto:karen.reynolds@canada.ca)

Dear Dr. Levine and Ms. Reynolds,

This letter is being written on behalf of Myeloma Canada and the Canadian Organization for Rare Disorders in our role as Patient Representatives on the PMPRB Steering Committee on Modernization of Price Review Process Guidelines. Specifically, we are writing with respect to the CBC Second Opinion piece by Kelly Crowe of the CBC posted online on November 24, 2018. We would like to clarify some of the points raised in the above article which we feel do not accurately represent our views on this matter.

First, we would like to restate that we both, CORD and Myeloma Canada, are not opposed to Canada paying lower prices for prescription medicines. Our organizations as well as all patient groups that we know, strongly endorse the position that drug prices in Canada must be fair, reasonable, and sustainable. Indeed, we are not opposed to some form of regulatory price controls and benchmarking Canadian prices against those of countries with comparable GDP and drug usage.

Second, we noted that the article states that “patient groups are aligned with industry on most issues” and “[t]here’s not a lot of daylight between their two positions.” These comments are attributed by Ms. Crowe directly to Douglas Clark, executive director of PMRPB. Such statements not only malign our two patient organizations but all patient groups and advocates who work tirelessly in so many ways to represent, support, educate, care for, and raise funds for the patients and families that we serve. Our advocacy for access to the most appropriate medicines for patients is just one of the things we do, but it is a very important part of our mission.

Which brings us to the third point of contention. Perhaps Doug Clark was misquoted or quoted out of context by Ms. Crowe. If so, we very much need to know exactly what he did say and

indeed his actual perspectives on our patient groups and our participation the Steering Committee as well as his general perspective as to the independence and integrity of our opinions and actions. If indeed these are accurate reflections of his and PMPRB's true sentiments and perhaps those of the other stakeholders (public and private payers) on the "other side", then we must question why we are even at the table. Have we participated in such a way as to lose the "confidence" of the other members, or were we always there merely as tokens?

Fourth, we must point out that the patient representatives have adhered to the terms of reference of the Steering Committee, participating constructively and professionally and abiding by conditions of confidentiality and the Chatham House Rules (recited to us at the beginning of each meeting) respecting non-attribution of comments or positions provided during meetings. If indeed Doug did proffer the statements attributed to him, then we are profoundly disappointed and distressed. It is one thing to disagree with or challenge our views at the table; it is entirely another to put these differences into a public forum, especially in ways that malign our intentions and our integrity.

Finally, we would like to reiterate that the Steering Committee process has always intended to find the best pathway to achieve lower drug prices that would also not harm patient access and innovative medicines coming into Canada. Instead, the article states that the Steering Committee was the result of "industry uproar" and its role was only "to assist in developing an implementation roadmap." Now we understand why the Steering Committee was never allowed to consider alternative pathways but only allowed to consider "how" the proposed pathway could be done.

We are appealing to you as public officials providing oversight for the PMPRB to address and indeed redress these concerns. We request, at a minimum, the following actions. Note: these ask are likely never going to happen, so I suggest that we focus on what can:

1. Will the PMPRB and Health Canada clarify the quotes in the CBC article that were attributed to the Executive Director of the PMPRB Douglas Clark, and if indeed they were accurate, issue an apologize to Myeloma Canada and CORD?
2. If the executive director did indeed speak to Ms. Crowe about opinions and perspectives that were part of the confidential process of the Steering Committee, will you ensure that there is proper "discipline" imposed and steps to ensure that this will not happen again?

We request that these actions take place before our next schedule meeting on December 13<sup>th</sup>; at the very least we receive a response to this letter as soon as possible but no later than December 12<sup>th</sup> to ensure we can all participate in the Steering Committee in good faith.

Yours truly,



Durhane Wong-Rieger  
President, CORD



Martine Elias, Executive Director  
Myeloma Canada

Cc: Douglas Clark, Executive Director, PMPRB  
Simon Kennedy, Deputy Minister of Health  
Members of PMPRB Steering Committee