

MEDIA RELEASE

Minister Hajdu, PMPRB: Your drug pricing approach is DEAD Wrong for Patients!

October 16, 2020 (Toronto, Ontario) The Patented Medicine Prices Review Board (PMPRB) abruptly cancelled the October 15 release and media briefing of its FINAL guidelines on new pricing restrictions for patented medicines with absolutely no explanation or rescheduled release date. The delay should not be interpreted as offering a reprieve for Canadian patients who have been at risk of losing access to important new medicines as a result of these draconian pricing reductions.

“While these policies will have a negative effect on all innovative medicines, rare disease drugs have been in the bulls-eye of these pricing policies since they were floated last year. The PMPRB and the federal government have displayed wanton disregard for the impact on the lives of Canadians with rare diseases,” said Durhane Wong-Rieger, President and CEO of the Canadian Organization for Rare Disorders (CORD).

Frankly, the PMPRB decision to deny patient attendance at the briefing on the guidelines was an affirmation of the abandonment of duty, betrayal of trust, and lack of accountability that they demonstrated throughout the consultation process. We can only hope that they will use the intervening time to correct this egregious error although we have little expectation that they will address the fundamental flaws in the guidelines given their wrongheaded intransigence to date.

The federal government’s proposed approach to pricing has no basis in scientific or economic evidence or experience. They have not been endorsed by any other country and have been questioned by key economic and policy institutions in Canada and elsewhere.

“No one cares more about affordable drug prices than the patients, but with the currently proposed pricing scheme, the PMPRB and the federal government have guaranteed that Canadians will be among the last patients in the developed world to access new, innovative, life-saving, and life-altering therapies,” added Wong-Rieger.

If no substantive changes are made to the FINAL guidelines prior to their release next week, this whole consultation process will have been nothing more than a smokescreen. As well, moving forward with an unchanged approach will pre-empt and undercut the government's commitment in the recent Throne Speech to implementing a national rare disease strategy, just as CORD is launching consultations to set up Canada's Rare Disease Drug framework, promised in the 2019 budget and reaffirmed in the Throne Speech. It begs the question of why bother with such a framework if no new rare disease medicines will come to the Canadian market because of the PMPRB changes.

According to Wong-Rieger, "As we all struggle through COVID-19, the biggest health emergency in a century, we need to ensure Canadians are taken care of, and not left behind. There is still time to get this right, so let's put in place a system that can work for patients."

About Canadian Organization for Rare Disorders (CORD)

CORD is Canada's national network for organizations representing all those with rare disorders. CORD provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders. CORD works with governments, researchers, clinicians and industry to promote research, diagnosis, treatment and services for all rare disorders in Canada. For more information, visit www.raredisorders.ca

About www.fightforourlives.ca:

CORD has been at the forefront in raising awareness regarding the PMPRB changes and the impact on patients and invite all Canadians to engage and learn more about this issue at www.fightforourlives.ca and by following @fight_4_lives #FightForOurLives and #Canada4Rare

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