



The Canadian Pulmonary Fibrosis Foundation (CPFF) appreciates the opportunity to share its views on the 2022 proposed updates to the Patented Medicine Prices Review Board (PMPRB) guidelines.

The CPFF is a registered Canadian Charitable Foundation established in 2009 to provide answers, hope and support for people affected by pulmonary fibrosis (PF). It educates and raises awareness about PF; raises funds to invest in research; and represents Canadians affected by PF to governments, healthcare professionals, the media and the public. PF is a chronic lung disease that makes it progressively harder to breathe. There is no cure, and the prognosis is worse than many types of cancer (with a median survival as low as 5 years). PF is a rare disease.

The CPFF's views on the proposed updates to the PMPRB are focused on the impact they will have on the patients we serve and the business and regulatory environment in which new drugs are brought to market in Canada.

Rare disease drugs already face a funnel of uncertainty in Canada, and the CPFF is concerned that the proposed updates to the PMPRB guidelines will do little more than limit access by PF patients to new and innovative treatments by discouraging new investments into R&D and clinical trials by drug manufacturers. The guidelines and their focus on the triggers of an investigations – rather than actual price tests – create business uncertainty at a time when companies must be both encouraged and enabled to innovate. We are concerned the new guidelines will do the opposite.

The proposed approach adds additional business risk where our small patient population already implies challenges in developing new treatments for smaller returns. It constitutes an additional reason for biopharma companies to de-prioritize developing drugs to meet the significant needs of PF patients, and to deprioritize bringing those treatments to Canada

The CPFF is also concerned with the impact on Canada's competitiveness and its ability to be seen as a destination for continued investment into new drug development. It will be those jurisdictions that create favourable environments for business investments and protect consumers from excessive prices that will succeed. Unfortunately, the guidelines as proposed will, we believe, hamper Canada's reputations as a destination for investment.

The CPFF also believes the proposed guidelines are inconsistent with the goals of a national pharma care program as well as a host of court rulings which have favoured the arguments put forth by industry that they stifle innovation and therefore create a barrier to equitable access to life saving treatments.

Innovative therapies save lives, they limit progression of rare diseases, and improve quality of life. The research also tells us there is a significant return in terms of patient lives, the health care system, recurring costs, hospital and other medical care, and the return to society, when new and innovative drugs are allowed to be developed. However, the new guidelines make PMPRB more focused on punitive measures and less on encouraging the development of new drugs.

The CPFF recommends:

- A sector wide approach that brings all stakeholders (patients, clinicians, payers) together to develop pricing guidelines that work for all
- A commitment to conducting a much-needed impact assessment to determine how any changes to the guidelines can protect consumers while encouraging innovation and limit business uncertainty

The CPFF would be pleased to answer any questions or provide additional information. Please do not hesitate to contact Sharon Lee, Executive Director, CPFF at sharon@cpff.ca or at 416-903-6925.