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The Canadian Pulmonary Fibrosis Foundation (CPFF) is pleased to respond to the PMPRB's Phase 2 Consultations on New Guidelines.

CPFF's comments will focus on Topic 1 (Price level within the PMPRB11 to be used), Topic 4 (individuals/groups permitted to submit a complaint) and Topic 7 (Future role of the Human Drug Advisory Panel). Our comments will also be briefly directed to the comments in the Discussion Guide issues the PMPRB indicates fall outside its statutory authority, namely the feedback received from patient groups concerning access to medicines and the need for meaningful stakeholder engagement with patient groups.

Topics Beyond PMPRB's Decision-Making Authority

Access to medicines

Though patient groups "raised concerns about the impact of PMPRB processes on access to new medicines, particularly in the context of drugs for rare diseases", the Board "observed that access to medicines is not a factor the Board is directed to consider". Though this may be true, CPFF strongly encourages and agrees with the PMPRB to use its administrative authority to make every effort to simplify the review of drugs for rare diseases. CPFF agrees with the Canadian Organization for Rare Disorders (CORD) that "Rare diseases tend to be severe, progressive, and life-threatening. About 95% have no approved therapies, so a new rare disease drug is often the first effective treatment for that condition. Patients should have access as soon as possible."

Patient perspectives

CPFF agrees that PMPRB engagement with patient groups is essential, and that some mechanism be in place to solicit their input, consult and collaborate with them, and learn more about the lived experiences of the people they represent. As a patient group focused on supporting people living with and caring for people with pulmonary fibrosis, the CPFF routinely surveys patients, their families, oxygen providers and healthcare providers across the country. The feedback CPFF receives from these surveys is shared with and often requested by provincial health authorities as they seek to develop good public health policy. We encourage the PMPRB to avail itself of the myriad reports developed by the CPFF that provide decision-makers with the information they need to understand the barriers faced by people living with pulmonary fibrosis, including access to medicines and other forms of treatment such as pulmonary rehabilitation. Please visit https://cpff.ca/understanding-pf/treatment-and-care/cpff-oxygen-access-canada-reports/.

Topic 1: Price level within the PMPRB11 to be used in the initial and post-initial price review

CPFF believes that regardless of the price level chosen, the PMPRB should take steps to ensure patient access to affordable medicines is protected while supporting rights holders' ability to bring new treatments to market. As we stated in our December 2022 submission, CPFF's primary concern is the impact on Canada's rights holders and our global competitiveness and ability to be seen as a destination for continued investment into new drug development. The median international price or the midpoint between the highest and the median prices offer a balanced approach; these options lend themselves to

fair pricing while maintaining incentives for the rights holder to continue bringing valuable treatments to the market.

Topic 4: The individuals/groups permitted to submit a complaint

As a patient-focused organization, CPFF believes generally that anyone affected by excessive pricing be permitted to submit a complaint. As the Discussion Guide states, this would allow for fair treatment of all affected parties and ensure the broadest range of complaints.

Topic 7: Future role of the Human Drug Advisory Panel (HDAP)

As a patient-focused organization, our primary concern is ensuring that the scientific review process for new drugs is rigorous, transparent, and prioritizes patient safety and access to effective treatments.

CPFF would encourage continued use of the HDAP in its traditional role, as this ensures consistency, expertise, and transparency in the evaluation process. Additionally, we would suggest that the PMPRB retains the option to use the HDAP on an ad hoc basis in exceptional circumstances, particularly for evaluating breakthrough or highly innovative therapies where a more tailored approach might be beneficial.

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