UNIVERSITY OF SASKATCHEWAN
College of Medicine
DEPARTMENT OF PEDIATRICS
MEDICINE.USASK.CA

Royal University Hospital – Pediatric Respirology
103 Hospital Drive Saskatoon SK S7N 0W8 Canada
Phone: (306) 844-1275 Clinic Fax: (306) 844-1514

Saskatchewan Health Authority

February 14, 2020
To: The Patented Medicines Price Review Board (PMPRB)

To whom it may concern at the PMPRB,

I have been the Pediatric Cystic Fibrosis Clinical Nurse Coordinator at the Cystic Fibrosis Clinic in Saskatoon, Saskatchewan for 13 years. I have seen the effects of this progressive, life shortening disease on the child and on the family. We have many new treatments over the past decade that has resulted in improving the median age of survival, yet I have had children die of this terrible disease.

I need you to take pause and consider how the PMPRB can help Canadians living with cystic fibrosis (CF).

Trikafta is a game-changing drug that targets the basic defect of cystic fibrosis. It can treat up to 90% of Canadians with CF (which is still a small number of patients overall).

On October 21, 2019 the Food and Drug Administration (FDA) in the U.S. approved Trikafta for sale in the United States six months ahead of schedule. When the Washington Post wrote about 19 good things that happened in 2019 - #1 was the announcement of Trikafta.

Recent changes to the PMPRB could result in very large price reductions being imposed on patented medicines, even innovative, life-changing medicines like Trikafta. While this sounds like a success for the government, it may affect the number of companies that will approach Canada with rare drugs, including the company that makes Trikafta. I am very concerned that our patients will never receive this life saving and life changing medication. CF is a progressive, fatal disease and people with CF can't wait.

The federal government has committed to improving access to medicines for Canadians with rare disease by implementing a rare disease strategy. However, the changes proposed to the PMPRB will result in no new, innovative medicines for rare diseases being brought to Canada. **I ask that the PMPRB reforms be halted until their impact on drugs like Trikafta can be properly assessed and changes made to ensure that drugs such as this one are quickly made available to Canadians.**

Canadians with cystic fibrosis should not have to die because the Canadian drug system is broken. **Canadians with rare diseases need access to future medications to live productive lives.** Please put implementation of these changes on hold now.

Sincerely,

Lorna Kosteniuk

Lorna Kosteniuk, RN, BSN
Saskatoon, Sk.