

July 19, 2023

Ms. Marilyne Picard

Parliamentary Assistant to the Minister Responsible for Seniors

Email: [Marilyne.Picard.SOUL@assnat.qc.ca](mailto:Marilyne.Picard.SOUL@assnat.qc.ca)

Dear Ms. Picard:

I am writing to congratulate your government on the release of the 2023-2027 action plan for rare diseases. The Canadian Pulmonary Fibrosis Foundation ([CPFF](http://www.cpff.ca)) has long called for all governments to have a rare disease action plan and we look forward to working with you and your government on this important issue.

I am also writing to introduce you to the work of the CPFF and our work with people living with and caring for people living with pulmonary fibrosis (PF), which is a rare disease characterized by scarring of the lungs and difficulty with breathing. The CPFF is Canada's only national organization supporting people affected by pulmonary fibrosis. It was established to raise money to research causes and treatments for PF, provide education and support for people affected by PF and their caregivers, raise awareness about PF, and represent Canadians affected by PF to governments, healthcare professionals, the media, and the public.

As a rare disease, people living with PF face several barriers accessing the treatment they need. In fact, the CPFF's 2022 Patient Survey tells us:

- 18% of patients did not get an oxygen therapy prescription when needed
- 75% of patients did not get needed oxygen the day it was prescribed and 50% waited a week or more
- Over 1/3 have no backup oxygen in the event of a power failure

The CPFF is encouraged by the scope of Quebec's plan, and its focus on raising awareness and promoting the transfer of knowledge, improving and developing screening for and diagnosis of rare diseases, and establishing a provincial registry of patients with rare diseases.

We are also excited about the designation of "interdisciplinary reference centers" and "regional centers of competence in rare diseases" that will make it possible to bring together rare disease expertise.

The CPFF would be pleased to work with your government as it relates to PF as a rare disease. We would be happy to work with you in the following areas:

- Providing educational materials and resources for people living with PF, their families, caregivers, and health professionals

- Recommending subject matter experts including members of the CPFF Medical Advisory Board (MAB), which is comprised of some of Canada’s most highly respected respirologists and pulmonary fibrosis specialists. Its primary goal is to support the CPFF’s mission to fund research, provide patient support, and raise awareness of pulmonary fibrosis.
- Promoting Quebec’s rare disease plan to members of the PF community, including people living with the disease, their caregivers and health professionals

The CPFF would be pleased to meet virtually to provide a more detailed briefing on our work to support people living with PF, and how we may work with the Government of Quebec on its four-year, rare disease plan. To arrange a meeting, please do not hesitate to have your staff contact me directly at [sharon@cpff.ca](mailto:sharon@cpff.ca) or at 416-903-6925.

Sincerely,

A handwritten signature in black ink, appearing to be 'SLL' or similar initials, written in a cursive style.

Sharon Lee  
Executive Director