



*Office of the Minister
MLA, Red Deer - North*

AR211426

JUL 26 2023

Sharon Lee
Executive Director
Canadian Pulmonary Fibrosis Foundation
47 Squires Bakers Lane
Markham, ON L3P 3G8

Sent via email: admin@cpff.ca

Dear Sharon Lee:

Thank you for your congratulatory letter on behalf of the Canadian Pulmonary Fibrosis Foundation (CPFF) regarding my re-election as MLA for Red Deer-North and my appointment as Minister of Health.

I am honoured and humbled to have the privilege of overseeing Alberta's health care system. I look forward to working with our health professionals and stakeholders to continue our efforts to improve access to health care for Albertans and to ensure quality in the overall continuum of care across our province.

I appreciate that you shared the CPFF's recommendations regarding access to oxygen for those living with pulmonary fibrosis (PF). The Alberta Aids to Daily Living program is reviewing its policies for exertional oxygen with the Alberta Health Services Clinical Advisory Committee, which is made up of respirologists from across the province, to ensure that the funding criteria remain fair and appropriate for clients. This review will also consider access to oxygen for clients in rural and remote communities. As well, we are working with our provincial and territorial partners to discuss the federal government's strategy on rare diseases, and I value your input.

Thank you again for taking the time to share your kind words and for the invitation to meet. Please know that the Government of Alberta has tremendous respect for the important role that the CPFF plays in supporting Albertan's living with PF.

Sincerely,

Adriana LaGrange
Minister of Health



Canadian Pulmonary Fibrosis Foundation
47 Squires Bakers Lane
Markham, Ontario
L3P 3G8
www.cpff.ca
Charitable number: 850554858 RR0001

June 19, 2023

Dear Minister LaGrange:

I am writing to congratulate you on your re-election and on your new role as minister of health. I am also writing to introduce you to the work of the [Canadian Pulmonary Fibrosis Foundation \(CPFF\)](http://www.cpff.ca) and our work with people living with and caring for people living with pulmonary fibrosis (PF).

The CPFF is Canada's only national organization supporting people affected by pulmonary fibrosis. The CPFF was created 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.

People living with PF and other diseases that make breathing difficult experience shortness of breath as the disease progresses. Many describe the feeling like trying to breathe through a drinking straw, while others mention being 'tethered' to their supplemental oxygen source. On top of this, getting enough oxygen in a timely manner is not assured. In fact, our 2022 survey of Canadians living with PF found that oxygen is unacceptably scarce:

- 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's recommendations concerning access to oxygen:

1. Programs such as Alberta's Aids to Daily Living (AADL) Respiratory Benefits program are reviewed with a focus on developing and implementing strategies to improve access to oxygen by people in rural, remote and Indigenous communities; and
2. The federal government's recent announcement of a strategy on drugs for rare diseases offers provincial governments the opportunity to negotiate a set of new and emerging drugs for which coverage would be cost shared and consistent across the country. CPFF recommends the Government of Alberta government use these negotiations to address issues of access to oxygen as well as drugs for medical therapy for pulmonary fibrosis, which is a rare disease.

I would be pleased to meet with your staff to provide an overview of the CPFF's work in Alberta and to answer any questions. To arrange a meeting, please do not hesitate to have your staff contact me at sharon@cpff.ca or 416-903-6925.

Sincerely,

Sharon Lee
Executive Director