Canadian
Pulmonary Fibrosis
Foundation

Appearance before the Standing Committee on Finance and Economic Affairs

Remarks by Sharon Lee, Executive Director, Canadian Pulmonary Fibrosis Foundation

Thursday, December 11, 2023

2:00 pm – 3:00 pm

Mississauga, Ontario

Good afternoon,

- Thank you to all the members of the Standing Committee on Finance and Economic Affairs for inviting me to tell you more about the Canadian Pulmonary Fibrosis Foundation and our recommendations for the 2024 Ontario budget

- My name is Sharon Lee and I am the Executive Director of the Canadian Pulmonary Fibrosis Foundation (CPFF)

- 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 disease in which the lungs become scarred, making breathing progressively more difficult. There is no cure, and the prognosis is worse than many types of cancer. Approximately 12,000 Ontarians live with PF

- CPFF's founder, Robert Davison believed that "breathing should never be hard work" ©. Yet for Ontarians living with PF, shortness of breath is a daily challenge. In fact, many describe the feeling like trying to breathe through a drinking straw, while others mention being 'tethered' to their supplemental oxygen source.

- But don't take my word for it. Feel free to use the straws being handed out when you're back at your desk.

- All you need to do is try breathing normally through the straw.

- But now, take this up a notch and block your nose with the other hand, and just breathe through the straw. This is harder than you think! Breathe slowly and deeply. Imagine what it's like to be conscious of every breath.

- As you can see, breathing can be extremely difficult for people with PF. As there is no cure for the disease, for many, the use of supplemental oxygen is often a life saver, allowing for less breathlessness and fatigue and for a more active lifestyle and in some cases, continuing working.

- And oxygen therapy also helps maintain proper blood oxygen levels which is extremely important for muscles, organs, and the brain to function properly.

- CPFF's recommendations to you today are on behalf of the 12,000 Ontarians (diagnosed by a Respirologists) who require supplemental oxygen to breathe and to live a high quality of life. This number will increase due to research showing how Canadian with Scleroderma, Rheumatoid Arthritis, Lupus, and other connective tissue diseases, along with individuals who had COVID will also develop PF. The National Institute of Health (NIH) predicts that due to COVID and our understanding of how connective tissue disease, will increase the number of patients in developing PF and will no longer remain a rare disease.

- Our recommendations are focused on two key aspects of Ontario's program for oxygen support through the Assistive Devices Program: the criteria to qualify for oxygen therapy, and the criteria for reimbursement for oxygen therapy

- First, qualifying for oxygen therapy is much more complicated than it needs to be

    - Medical criteria to qualify for oxygen therapy are rigid or unsuitable, and rely on testing protocols based on the needs of those with chronic obstructive pulmonary disease, or COPD, a different disease altogether

    - The reality is that PF patients tend to require more oxygen upon exertion than COPD patients. In particular, they have trouble qualifying for exertional oxygen, which is simply an additional supply for walking, and other daily activities.

    - In fact, in CPFF's 2023 survey about the impact of pulmonary fibrosis, 75 per cent of oxygen providers said PF patients need significantly more oxygen than COPD patients

  - Finally, a healthy oxygen level is 95 per cent or higher. Oxygen therapy can be helpful when oxygen levels drop below 88 per cent. But, in some provinces, including right here in Ontario, that level must drop below 80 per cent for patients to be eligible for supplemental oxygen.

  - So, our first set of recommendations is a common-sense solution to these avoidable barriers:
    - Establish standardized medical criteria based on the unique needs of pulmonary fibrosis patients;
    - The current practice of using the “six-minute walk test” is resource-intensive, and not available in all regions. It is also unnecessary to ask pulmonary fibrosis patients to requalify for oxygen, as once you have this disease, there is no cure, so it’s a waste of funding.
    - Lower the bar for supplemental oxygen

- Second, reimbursement criteria for home oxygen equipment are simply inadequate

  - Oxygen is classified as a drug in Canada, however in many aspects it is managed and funded as a medical device. As a result, access to a provincially funded drug plan does not guarantee access to funding for home oxygen equipment

  - Lightweight, portable equipment is not funded, essentially leaving people housebound

  - CPFF’s second recommendation then is that all costs, *including equipment*, should be reimbursed for people receiving home oxygen therapy

- These sensible and practical recommendations were developed in consultation with Ontarians living with PF, their caregivers, their healthcare providers and oxygen suppliers.

- The findings of these consultations can be found in CPFF’s 2022 and 2023 Access to Oxygen Therapy in Canada reports, and I encourage all members of this committee to review them. The flyers being passed out, has a QR Code which will take to straight to the reports.

- In closing, I would like to impress upon all members of this committee that these recommendations are simple, practical and affordable measures that can and should be taken if patient-centred care is the objective

- Thank you again for this invitation to appear before the committee. I would be pleased to answer any questions.