

For Immediate Release

Oxygen unacceptably scarce for some Canadians

20% of pulmonary fibrosis patients experience delays in accessing oxygen when they need it, survey finds

September 6, 2022 (Markham, ON). For the more than 30,000 Canadians living with pulmonary fibrosis (PF), an incurable and fatal lung disease, each day presents a new challenge. Today, the [Canadian Pulmonary Fibrosis Foundation \(CPFF\)](#) released a snapshot of its [2022 Patient and Caregiver Survey](#) results. The survey highlights the many challenges that pulmonary fibrosis (PF) patients continue to face, but most notably, that oxygen is unacceptably scarce for PF patients – 20% of patients did not get an oxygen therapy prescription when they needed it.

Since the last survey was released in 2020, conditions for those affected with PF have gotten worse. Patients are still facing many significant barriers to receiving effective treatment, specifically in the areas of diagnosis and access to treatments - one in three patients with PF wait up to three years for their diagnosis.

“Our 2022 Patient and Caregiver Survey results highlight the need for change and action,” says Sharon Lee, Executive Director of the Canadian Pulmonary Fibrosis Foundation. “These results are disheartening, but we need to keep fighting for change, and with increased awareness and continued investment, we believe we can help lessen the countless burdens this terrible disease has on people across this country.”

Survival rates lower than some cancers

PF looms large over the lives of patients – physically, mentally, in every respect possible. The disease kills more than 2,500 Canadians each year, but remains a little-known disease, despite having survival rates lower than many cancers. This chronic and debilitating condition causes irreversible scarring (fibrosis) of the lungs and reduces oxygen flow to the body. As the disease progresses, the scarring typically worsens, making it more challenging to breathe. For some patients, medication and physiotherapy can slow the progress of the disease, but the only long-term treatment is a lung transplant.

Jeannie Tom of North York, Ontario describes her journey with PF as an incredibly long and difficult one. Diagnosed in 2011, despite her amazing positive demeanour, each day is as challenging as it is unorthodox for Jeannie. She plans each of her days out in great and meticulous detail to work around this terrible disease. When Jeannie is home, she is tethered to a 50-foot tube that is connected to a stationary oxygen concentrator. Stories like Jeannie’s become all the more heartbreaking especially when you consider that some PF patients can’t even access enough oxygen to breathe each day.

“Breathing should never be hard work, but for Jeannie, and for all those living with PF, breathing is a precious and highly precarious endeavour,” says Kirk Morrison, CPFF

Board Chair. “The sheer act of breathing for people with pulmonary fibrosis, something we all take for granted, is incredibly hard work.”

For other notable highlights from the 2022 CPFF Patient and Caregiver Survey, please [click here](#) to view the infographic.

Global Pulmonary Fibrosis Month

September is Global Pulmonary Fibrosis Month. CPFF will be holding a number of in-person/ online events to help mark this incredibly important month. Some of the events include:

- [Community Walks](#) - All across the country, people are gathering to walk, roll, and run to raise awareness, hope and funds for people living with pulmonary fibrosis. The ultimate goal is to collectively walk across Canada by the end of September 2022. That's 6,818 kilometers!
- [Pucker Up Challenge](#) - CPFF is launching the Pucker Up Challenge to raise awareness about pulmonary fibrosis and the effect it has on breathing - something most of us take for granted.
- [Light Up Canada in Red & Blue](#) - Cities across the country, will also be lighting local landmarks in red and blue to mark Pulmonary Fibrosis Month.

About Canadian Pulmonary Fibrosis Foundation

The [Canadian Pulmonary Fibrosis Foundation](#) is a registered Canadian Charitable Foundation established in 2009 to provide hope and support for people affected by pulmonary fibrosis. The organization educates Canadians about the disease, supports patients, families and caregivers and funds research to find treatments and a cure.

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