



FEBRUARY 28TH IS
RARE DISEASE DAY

*"I had to
fight to get
oxygen..."*

Rare Access

Pulmonary fibrosis is rare.
Getting the oxygen you need to breathe shouldn't be.

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Rare Diseases Affect One in Twelve or Nearly Three Million Canadians

Each day presents a new challenge for the more than 30,000 Canadians living with pulmonary fibrosis (PF), an incurable and fatal lung disease. And despite these numbers, PF is considered a rare disease in Canada.

What is rare is the courage of those living with the disease and their families, and their determination to work with the Canadian Pulmonary Fibrosis

Foundation (CPFF) to advocate for improved access to care and raise funds to invest in PF research.

The disease kills more than 2,500 Canadians each year but remains a little-known, despite having survival rates lower than many cancers. This chronic and debilitating condition causes irreversible scarring (fibrosis) of the lungs, making it difficult to breathe and reducing

oxygen flow to the body. 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, ON, describes her journey with PF as an incredibly long and difficult one. With her amazing positive demeanour, each day is still a challenge as she plans out each day in meticulous

detail to work the restrictions of 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 when you consider that some PF patients can't get access to oxygen therapy when they need it, to breathe easier each day.

Although it should be an effortless act, breathing, for people with a rare lung disease like pulmonary fibrosis, can be a painful, anxiety-inducing experience. A 2022 CPFF patient and caregiver survey found that 20 per cent of patients did not receive an oxygen therapy prescription when they needed it. In addition, more than one-third have no backup oxygen in the event of a power failure.

Provincial government policies on oxygen therapy access vary widely, and access in remote areas and in the Maritime provinces is particularly dire. Some physicians report that their patients have to experience dangerously low oxygen levels before

they can access publicly-funded oxygen therapy.

"Our survey results highlight the need for change and action," said Sharon Lee, CPFF Executive Director. "The situation is 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."

"Breathing should never be hard work, but for Jeannie, and for all those living with PF, breathing is a precious and highly precarious endeavour," said 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."

Rare Disease Day is February 28. Take a deep breath, then help support the brave, resilient, and rare individuals living with pulmonary fibrosis.

Donate today at
cpff.ca/raredisease.



JEANNIE TOM WALKING UP STAIRS WITH OXYGEN © COURTESY OF CANADIAN PULMONARY FIBROSIS FOUNDATION