

Lung disease treatment approved on drug plan

KELSEY PYE
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SAINT JOHN • Doug Greene was diagnosed with idiopathic pulmonary fibrosis in 2012 at age 69. He spent two years suffering, not being able to perform basic functions without having to catch his breath.

IPF causes scarring of the lungs, making everyday activities incredibly difficult.

"You can't do anything. You've got to have an oxygen bottle with you at all times," said Greene, who is from Grand Bay.

There is no cure for the disease aside from a lung transplant. Greene started to lose hope. Transplants are rare for older people and Greene knew he wouldn't get one.

"I'm a little too old to be cut open like that. It's not a simple operation by any means," he said.

Instead he started searching for a treatment.

He found one. Esbriet is a pill that slows the scarring of the lungs. It doesn't cure the disease but it makes life easier for those who have it. And thanks to Green and Robert Davidson, who had IPF when he was in his sixties, Esbriet is now available on the New Brunswick Prescription Drug Plan. But it wasn't an easy journey.

Davidson established the Canadian Pulmonary Fibrosis Foundation in 2009 after he was diagnosed in 2007 at age 60. He wanted to start a support circle for those suffering from the rare disease. He himself got a lung transplant, but his interest turned to helping others battling IPF because he knew how difficult living with the disease was.

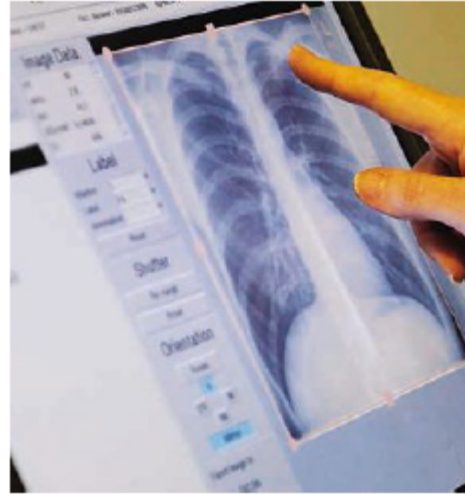
Davidson said he used to get breathless talking on the phone and taking showers. He would keep chairs around the house for when he got winded.

Through the foundation, Davidson and Greene connected. Esbriet was unveiled in 2012, and the duo made it their mission to get the drug, which costs approximately \$40,000 a year, approved on Canadian health plans.

Davidson, who is originally from England, said the system for getting drugs approved in Canada is strange. Once the drug is approved by Health Canada, it has to be assessed by a drug review committee that then recommends to either fund the drug, fund the drug with conditions, or reject the drug. Originally, the committee recommended not to fund the drug.

"They said it didn't improve life expectancy and it didn't improve quality of life," Davidson said. "We knew from people who had been on clinical trials, and I had spoken to lots of them. Their quality of life had drastically improved.

"Obviously it's a rare disease drug so it's expensive, so I think the (committee)



A radiographer reads an X-ray of lungs. Esbriet is a pill that slows the scarring of the lungs. It doesn't cure the disease but it makes life easier for those who have it.

PHOTO: LEFTERIS PITARAKIS/ASSOCIATED PRESS

just seemed to ignore the evidence."

They then had to convince each province Esbriet was a good treatment for IPF. Davidson said he has been to all the provinces except Manitoba and Saskatchewan to meet with health ministers and provincial and federal representatives.

On Oct. 9, New Brunswick approved Esbriet under its drug plan. Davidson said it's a big relief for him and those suffering from IPF.

"It's tremendous. If you've got a fatal disease and there's nothing to treat you with, then there's a treatment but you can't get it, and finally you can, imagine the huge relief the patients are getting."

Greene, who is now 72, said getting the drug approved has been incredibly helpful. He still takes an oxygen tank

with him everywhere, sometimes needing only one per day, sometimes needing four. He lives in a basement apartment and says the three stairs he needs to climb are "killer".

He also takes pills for other conditions and takes approximately 14 pills a day; the nine Esbriet pills he needs to take in addition to pills for cholesterol, sleeping pills, and Gravol. The last two are for side effects of Esbriet.

"It's a \$110 a day habit," he said.

Esbriet is currently the only treatment drug available for those with IPF, so Davidson said getting it approved is incredibly helpful.

"It's an orphan drug for a rare disease. There are no other drugs you can compare it against."

He said IPF is an unpredictable disease, so the sooner people have access to it, the better. In some provinces people have to apply to receive the drug, a process that takes on average six weeks to complete. And the disease can escalate to severe quickly, at which point Esbriet is useless.

"While you're waiting for the drug to get approved, it could be too late."