

New treatment offers hope for an incurable disease

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For too many years Hamilton respirologist Dr. Martin Kolb sat across from patients dying of a rare lung disease and told them there was nothing he could do.

Recruited to McMaster University from Germany 12 years ago to work with a research group trying to find a way to help those with idiopathic pulmonary fibrosis, Kolb can finally offer relief to patients whose lungs have so much scar tissue they've become stiff, making breathing a chore.

OFEV, also known as nintedanib, is not a cure. But Kolb's research proved the drug slows the illness by 50 per cent. It was approved by Health Canada in June and is being evaluated for coverage by OHIP.

"It has taken 10 years of hard research globally to come up with a drug," said Kolb, director of respirology at McMaster and research director at the Firestone Institute for Respiratory Health at St. Joseph's Hospital. "It's hard to tell a patient your disease is serious and will get worse and you will die and there is nothing we can do to stop it. It's much better to say we have a drug that slows it down."

OFEV, manufactured by Boehringer Ingelheim, is actually the second drug approved by Health Canada. Esbriet, also known as pirfenidone, by Roche was approved in 2012 and OHIP started to cover its cost in 2014.

A second drug on the market raises hope that combination therapy could one day cure the disease that affects 5,000 to 15,000 Canadians, most between the ages of 60 and 75.

"Having an alternative is crucial," said Kolb who does consulting for both Roche and Boehringer Ingelheim. "We hope to stop the disease, not slow it down. There's a lot of work still to be done."

Both drugs have difficult side effects, such as nausea, and they don't work on everyone so it's important to have two choices.

"To have one treatment was an absolute relief," said Robert Davidson, president of the Canadian Pulmonary Fibrosis Foundation. "It is a huge advance for IPF patients to have a choice of treatments."

Davidson, who had to have a lung transplant because it was the only option when he was diagnosed in 2007, founded the foundation that has so far raised \$600,000 for research and \$150,000 for patient support.

"You're working at trying to breathe," the 68-year-old Markham man says of the disease. "It's extremely tiring and at times desperate. Normal day to day activities like showering or walking are quite difficult. You're struggling to breathe and have a dry cough that won't stop. It's an awful feeling."

About half of IPF patients die within three years.

"It kills more people than melanoma or colon cancer," says Kolb.

He headed up a study of OFEV paid for by Boehringer Ingelheim in more than 30 countries with more than 1,000 patients. It was published in the New England Journal of Medicine in 2014.

"It's exciting," says Kolb. "There are many other drugs in development. Down the road, in 10 to 15 years, we'll likely have combination therapies."

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