

Resident, CPFF lobby to make life-extending drug accessible

By Mark Pavilons

Most of us enjoy a certain quality of life. And when we need it, we hope the care and medical services are available.

For a King City woman, every breath she takes is a reminder of a flawed system. A life-extending drug is not covered in Ontario for her condition, and she's using every breath to make a point and lobby for change



Barbara Barr, 63, suffers from a rare condition known as idiopathic pulmonary fibrosis (IPF) ? a progressive and ultimately fatal lung disease. She relies on oxygen and her mobility is limited.

There is a light at the end of this dark tunnel in the form of Esbriet, a treatment available for patients affected by mild to moderate forms of the disease. Esbriet, the first and only treatment available in Canada, is proven to slow disease progression ? but currently remains out of reach for many patients, like Barr who are unable to pay out-of-pocket to access the drug. It's estimated to cost upwards of \$4,000 per month.

Barr, her own medical advocate, and Canadian Pulmonary Fibrosis Foundation (CPFF) founder Robert Davidson, paid a visit to Oak Ridges-Markham MPP?Dr. Helena Jaczek Friday to make their case and lobby the government.

Jaczek said she will pass on a letter, signed by several IPF?specialists, who attest to Esbriet's efficacy, on to Health Minister and Deputy Premier Deb Matthews.

She will make sure Matthews is aware of the issue. As a doctor herself, Jaczek relies on the recommendations of physicians to prescribe the correct drug to their patients.

If Matthews and her staff are convinced of the drug's effectiveness, it will be funded, Jaczek said.

?I will push ahead. We'll do what we can,??she said.

Barr was diagnosed in 2012, adding she was likely symptomatic as far back as 2005.

?It's terminal but so is life,? she said. Her optimism and knowledge about the disease keeps her fired up and ready to put pressure on elected officials and the health care system. She's not letting the disease slow her down, despite being on oxygen 24/7 and carrying around her portable breathing apparatus.

She still has a lot of limitations and that's where Esbriet can help. Barr admits that it's not a cure, but it does treat the symptoms. The seemingly unfair approach to drug accessibility gets her goat at times.

?Where do you draw the line and what do you have to do to deserve attention??she asked. ?Esbriet will give us time,? she said.

The system, she feels, is broken and the process used by the committee was flawed.

She and Davidson are putting a face to IPF.

They're also helping to increase awareness. Barr noted average respirologists may be able to understand and treat conditions like asthma and COPD, but they're really challenged and ill equipped to handle something like IPF.

For her and others, knowledge really is power.

Despite the severity of the disease, advice from Ontario's leading IPF experts, and the absence of other treatment options, the Ontario government has chosen to deny funding for Esbriet keeping it out of reach for many who are in urgent need, especially seniors who rely exclusively on the provincial drug program.

According to Davidson, who founded the Canadian Pulmonary Fibrosis Foundation (CPFF) in October of 2009, the condition affects roughly one in 2,000 people, or upwards of 10,000 Canadians. Research into this condition began in earnest in 1980.

The drug will not only extend Barr's life, but will allow her to run and play with her grandchildren.

Studies have shown a marked improvement in both exercise tolerance, walking.

The drug was approved by Health?Canada in the fall of 2012 but it's not covered by provincial health care in Ontario. Those who

have drug plans through their work can get the drug covered.

In Barr's case, her only access to the drug right now is to pay for it herself ? estimated at \$40,000 annually.

The committee's decision ?took away hope??Davidson said, adding he's been lobbying for the drug's admission for a year now. He's upset the committee never consulted leading experts or clinical evidence on the drug before releasing their recommendations.

He has submitted patient evidence which documents ?significant improvement.?

?They're just not listening,? he said.

The disease is unpredictable, he noted, adding it can go from mild to moderate to severe without warning. That's what makes it vitally important, before it's too late for many patients.

Davidson, an IPF sufferer himself, received a lung transplant in 2010.

As part of his efforts, CPFF is encouraging people to sign petitions which they plan to introduce in the legislature.

MPP Bill Walker stood up for patients March when he called on the provincial government to deliver affordable access to life-saving drugs to people suffering from IPF.

During his statement to the legislature, Walker ? who previously served as a deputy health critic at Queen's Park ? also commemorated two local constituents who died following a gruesome bout with IPF. The men died in the midst of their fight with the Ministry of Health and Long-Term Care for affordable access to the life-saving drug Esbriet.

?Clearly, this government and this ministry failed them,? said Walker. ?What Ontarians expect is for this government to take action and to advocate for them by negotiating affordable access to life-saving drugs like Esbriet. The government has the power to make this happen.?

For more on the issue, visit CPFF's website at www.canadianpulmonaryfibrosis.ca.