

*Date*

Hon. Dr. Eric Hoskins  
Minister of Health and Long-Term Care  
10<sup>th</sup> Floor, Hepburn Block  
80 Grosvenor Street  
Toronto, ON  
M7A 2C4

Dear Minister,

I am writing as a resident of the province and as someone touched by scleroderma, as well as pulmonary arterial hypertension (PAH), a rare but very complex and serious lung disease, which is progressive and potentially fatal. I would like to bring to your attention the fact that Opsumit (macitentan), the first therapy approved in Canada for the long-term treatment of PAH, is not publicly accessible as a treatment choice for patients in Ontario.

*INSERT A BRIEF PARAGRAPH OUTLINING YOUR PERSONAL STORY AND THE LINK YOU HAVE TO A PERSON WITH PAH.*

It is estimated that more than 5,000 Canadians have been diagnosed with pulmonary hypertension (PH), but as many as 10,000 may be affected by the condition. Patients with PAH, the most severe form of PH, live an average of two to three years if left untreated. While the prognosis has improved somewhat in recent years, as you know it remains poor despite currently available treatments.

Scleroderma and PAH often go hand-in-hand. Virtually all persons with scleroderma have some loss of lung function in the forms of pulmonary fibrosis and/or pulmonary hypertension. Unfortunately, those living with scleroderma have an increased risk of developing PAH because of the significant fibrosis of their lungs, which can in turn reduce the blood oxygen levels and cause a reflex of increased blood pressure in the pulmonary arteries.

In January 2015, the Common Drug Review (CDR) recommended that Opsumit be publicly funded (with criteria and a condition) for the long-term treatment of PAH to reduce morbidity in patients with Functional Class II or III. Since the end of March 2015, Opsumit has been the subject of provincial funding negotiations through the Pan-Canadian Pharmaceutical Alliance (pCPA). Yet the only treatment proven to reduce long-term morbidity remains unfunded in our province.

Without public funding for Opsumit through the Ontario Public Drug Program, PAH physicians are restricted from exercising their individual clinical judgement, which is essential to the proper treatment of PAH, and patients are unable to access optimal treatment for their disease. Treatment decisions for this rare and complex disease should be left in the hands of PAH specialists who are best able to assess their patients' individual needs, which will benefit their long-term health at diagnosis and beyond.

**I am asking that you ensure that all patients living with scleroderma and PAH have publicly-funded access to Opsumit immediately.**

Thank you for your consideration and your ongoing commitment to people living with PAH, their families and loved ones.

Sincerely,

*Your Name*

cc *Your MPP*  
*SSC*