



# ALPHA-1 CANADA

**Alpha-1 Antitrypsin Deficiency Canada Inc.**

IMPROVING THE LIVES OF ALPHAS

## *News Release*

**For Immediate Release  
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### **Ontario Government Plays Favourites with People's Lives**

WINDSOR, ON – If you have a rare life-threatening disease called alpha-1 antitrypsin deficiency, don't work for the Ontario Government and you don't have private insurance the government is content to see you waste away struggling for every breath until you join other Ontarians on the lung transplant list. If, on the other hand you work for the Government of Ontario your expensive lifesaving treatment is paid for by the taxpayers.

The Ontario Liberal Government's platform states that, "Providing high-quality health care on the basis of need, rather than the ability to pay, is a defining characteristic of Canada and a core principle of the Ontario Liberal Party. It is the most important thing a government can do to provide people with security."

Ask Doug Cooper of Beamsville if the Ontario government is delivering on this promise. Doug was a high school teacher and as such received his lifesaving treatment, known as alpha-1 antitrypsin augmentation therapy, through the Halton school board. Doug retired recently and was told his treatment would no longer be covered. "I do not want to die gasping for every breath when there is treatment available but beyond the reach of ordinary citizens," Doug says.

After covering the treatment for 18 years, in a cost cutting measure, the Ontario Drug Benefit Program ceased approving funding of alpha-1 antitrypsin augmentation therapy for newly prescribed patients over five years ago. This therapy is the only treatment available for lung-involved patients with a rare genetic disease called alpha-1 antitrypsin deficiency. But they continued providing it to for people who work in the broader public sector. For example, MPPs.

Fewer than 40 Ontarians are currently receiving this therapy (some funded through private insurance). As many as 10 newly diagnosed Ontarians have been denied funding by the Ontario Drug Benefits Program. There are no doubt more today but doctors have stopped applying on behalf of their patients because they have learned the answer will be no.

“Alpha-1 antitrypsin deficiency is a rare condition that is often misdiagnosed as asthma or COPD. We did a survey and found that in Canada, it takes on average 9.9 years from the time symptoms appear until an accurate diagnosis is obtained. Waiting this long to find out what is wrong and then being denied treatment because you can’t afford it is a situation the Canadian healthcare system was designed to prevent, not cause,” says Jim Mundy, Executive Director of Alpha-1 Antitrypsin Deficiency Canada Inc. (Alpha-1 Canada) an Ontario-based national patient support organization.

Dr. Ken Chapman of the University of Toronto is a world renowned researcher on this and other airway diseases. In a submission to the Ontario government, Dr. Chapman said, “Decisions outside of Ontario reflect the growing body of medical evidence that augmentation therapy not only reduces the rate of lung function decline (by conventional lung function monitoring) but preserves lung tissue (as measured by the latest in x-ray technology) and reduces mortality. When more and more private and public payers are adding augmentation therapy to their lists of treatments covered it is disturbing that Ontario would ignore its own policy on the treatment of rare diseases.”

But the Ontario government, always careful to look after its own, chose to only stop funding this lifesaving treatment for the rest of us, not for themselves.

### **About Alpha-1 Canada and Alpha-1 Antitrypsin Deficiency**

We provide information and education to Canadians affected by alpha-1 antitrypsin deficiency (Alpha-1) and to the medical community. We make available support to patients and generate broad awareness. Alpha-1 Antitrypsin Deficiency, also known as ‘hereditary COPD’ is a rare genetic disorder that can affect the lungs, liver and skin in infants, children and adults.

For more information and to arrange an interview with Mr. Doug Cooper or Dr. Chapman, please contact:

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