

From: s.22
To: [CC Minister MCF:EX; Minister, MCF MCF:EX](#)
Subject: 147435 Incoming part 2 Attention Executive Council: We are at the mercy of your support
Date: January 31, 2020 12:42:13 PM
Attachments: [How is s.22 doing brochure 2018.pdf](#)
[Okanagan 2019 - Melissa Verleg letter to PM Trudeau - Nov 6.docx](#)

Please accept my apology for the duplication however I see you are on the "Executive Council" and with that position of authority you have yet a heavier burden.

From: s.22

Sent: Friday, January 31, 2020 12:35 PM

To: 'adrian.dix.MLA@leg.bc.ca' <adrian.dix.MLA@leg.bc.ca>

Subject: We are at the mercy of your support

Greetings. What a huge responsibility you have in public life. Hats off to you,

Please meet s.22

s.22

Treatment is available, approved by health Canada over 4 years ago, s.22

When Health Canada approved Orkambi, for use in Canada 4 years ago there was so much hope in the CF community. It was a miracle. With the positive results in the clinical trials, and approval by Health Canada, s.22

s.22

This is a huge responsibility you shoulder. It is with heavy heart that I burden you with this responsibility, the life of this wonderful s.22 along with the other children and young adults in the cf community accross Canada. Young lives being cut short, needlessly.

s.22

s.22

But, Orkambi is very costly. We and almost all CF families in Canada cannot pay the costs. For most therefore, the only hope is you. Without your help these children will as surely as I write this, will all die a brutal, torturing death, starving for air.

Despite numerous appeals, support by the medical community and unending testing confirming the effectiveness of Orkambi your government, to date, refuses to cover it under the medical program. Meanwhile, Orkambi has gained acceptance worldwide and at this time at least 14 countries provide coverage for their citizens: U.S.A, Australia, England, Wales, Scotland, Ireland, Sweden, Denmark, France, Germany, Austria, Italy, Netherlands, and Luxemborg.

Canadians with CF and their families are rightfully, distraught seeing Canada lagging far behind the developed countries of the world in terms of citizen support for cystic fibrosis.

I am so hopeful you might assist.

You can assist. Funding for Orkambi without delay would be a huge step. Please consider: Time is critical. The consequences of having cf are cumulative. Each day without effective treatment is

detrimental to the well being of these children

Can you help us, please.

Sincerely

s.22

· living with and dying from Cystic Fibrosis,
untreated due to government, nothing more, right here in Canada

(See attached:s.22

To date we have raised over a quarter million dollars. But it seems to be in vain. \$ and research have provided effective drugs to treat CF, but they not being prescribed because they are totally unaffordable and there is no government assistance. The provincial government of BC refuses. Shockingly, our provincial government even refuses to negotiate price with the manufacturer, who has demonstrated multiple times they are very willing to provide substantially better pricing, even reduce the cost by half.

Can we meet? I would be honored.

On another note: You may also be familiar with Melissa, a young mother of two^{s.22}

s.22 Her letter to the Prime Minister is attached.



Cystic Fibrosis
Canada

"So close!"

Our goal: "Children living with Cystic Fibrosis today, will live to hear: "A cure for your condition has been found".

s.22 is one of the local Kelowna children living with terminal cystic fibrosis. Only with your generous support will s.22 and thousands of kids like her have a chance at life.

Kids with CF frequently fight reoccurring and damaging throat/lung/ear infections. The disease is "progressive". That means, over a short period of time, permanent lung damage, resulting from the infections, will leave these children unable to breathe. (Imagine that for a moment.)



s.22

This past year, our s.22 has again avoided any extended stay in hospital☺

s.22

The Vancouver Children's Hospital visits, as always, were a little crazy: travel, a barrage of tests: X-rays, needles☹, blood work, lung function tests and prodding and poking for several hours by as many as 6-8 different specialists. s.22 says: "The needles don't hurt. I am used to them."

s.22

What comes next? More effective treatment or lung damage. Remember, CF is "progressive". Piece by piece, CF takes away the child's ability to breathe and live.

Last year you provided a generous donation. Thank you. 100% of all donations will again be donated to Cystic Fibrosis Canada. Do these kids deserve the same chance at life that you and I enjoy every day?

We are so close. Not many years back, anyone born with CF was not expected to live long enough to go to kindergarten.

Please make your check payable to: Cystic Fibrosis Canada.

Mail to: Cystic Fibrosis Canada
c/o A&W
2703 – Hw 97N.,
Kelowna, BC. V1X 4J8

An official tax receipt will be issued.

s.22 and the thousands of infants, children and young adults afflicted with Cystic Fibrosis say... (Over)

“Thank you!”

S.22

And....You are invited. Please join us:

Saturday, Dec. 1st, 2018.

- Kelowna, 2703 Hw 97N (corner of Hw 97 & Leathead Rd)

100% of the store's net sales, on this day, will go directly to Cystic Fibrosis Canada.

Last year, with your support, \$46,000.00 was raised! This year's target: \$50,000.00

What about my right to live?

Vernon woman makes emotional plea for government help

Darren Handschuh - Nov 6, 2019 / 7:00 pm

Court Records

Photo: Facebook

Melissa Verleg has Cystic Fibrosis, a degenerative disease for which there is no cure and will eventually be fatal.

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