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## CYSTIC FIBROSIS STEALS TIME FROM PATIENTS

'IT TAKES UP  
A LOT OF MY TIME'

TAMARA BOTTING  
tbotting@sachem.ca

The cruelty of cystic fibrosis is how much time it steals.

Not only does the disease cut the lives of patients short — the median age of survival for those with a diagnosis in Canada is about 53 years old — but the treatments currently available here can take literally hours to complete each day.

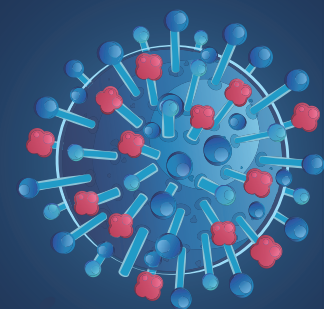
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Torstar file photo

Binbrook sisters Madison, left, and Mikayla Bianchin both have cystic fibrosis, which requires them to spend about three hours daily on inhalation treatments and chest physiotherapy.

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# BINBROOK SISTERS HOPING NEW DRUG WILL BECOME AVAILABLE IN CANADA

Continued from front

Binbrook sisters Mikayla Bianchin, 19, and Madison Bianchin, 17, know it all too well.

"It takes up a lot of my time, my day," Madison said. "I feel like I'm constantly busy during the school year."

Between inhalation treatments and chest physiotherapy, as well as having to take about 50 pills, the sisters each spend about three hours a day "just so they can try to stay as healthy as possible and prevent their lungs from deteriorating over time," said their mom, Tammy Strong.

Last year, Madison went on a school trip to Boston. She had to bring her medical equipment with her and get up that much earlier than her classmates.

Mikayla noted that when you're diagnosed with cystic fibrosis, "(It) has to come with you. CF does not take a day off."

Now in her third year at Sheridan College's illustration program, Mikayla said it can be hard attending post-secondary with cystic fibrosis.

"It's a lot of work, and you're ... trying to stay healthy enough to go (to class)," she said. "Now that I'm older, I feel like I'm around the age where people typically start to notice their health declining if they have cystic fibrosis."

For Strong, it's frustrating to see how much time the disease has taken from her daughters.

"They just want to be teenagers. They want to hang out, have time with their friends," she said, but instead they have to spend over a thousand hours a year just trying to stay

**"Getting Trikafta is my dream. That is all I want; that would be the best possible scenario for my life. We want a new normal."**

— Mikayla Bianchin

healthy to keep the disease's worst symptoms at bay.

"Quality of life is a big issue," Strong said.

There are also the ripple effects. Strong was a stay-at-home mom for 18 years, just to make sure a parent was available if either of the sisters needed help with their treatments, or for when they were hospitalized — over the years, they've collectively had 15 surgeries.

"The cost to society is a big deal," Strong said.

She wanted to help bring in changes, not only for her daughters, but also for other families living with cystic fibrosis. That's why Strong has been a volunteer with Cystic Fibrosis Canada since her daughters were born. She's currently the Hamilton chapter president.

The organization works to combat the disease on multiple fronts, including supporting families, raising funds for research and advocacy.

One of the things they are working on the hardest on that front is trying to get the medicine Trikafta available to cystic fibrosis patients in Canada.

Strong noted the drug

has been approved in several countries, including the United States last year.

"People with cystic fibrosis regularly do lung function tests. Their lung function improves drastically with this drug. People instantly notice a difference in their health," she said.

Besides improving patients' quality of life and reducing how much time they have to spend on daily treatments, it could also lessen their number of hospitalizations and raise the median age of survival for Canadians with cystic fibrosis.

Geoffroy Legault-Thivierge is a media relations officer for Health Canada.

He said that to date, Vertex Pharmaceuticals, the manufacturer of the drug, hasn't submitted an application for Trikafta to Health Canada for review.

"Every drug submission is ... reviewed by scientists to assess the product's safety, efficacy and quality," he said.

"While Health Canada encourages manufacturers to file drug submissions in Canada, it does not have the authority to compel a manufacturer to do so. Therefore, it is ulti-

mately up to a manufacturer to decide whether they choose to seek market authorization for their product in Canada."

Legault-Thivierge also noted that the prices for patented medicines in Canada are among the highest in the world, "and these high prices negatively affect the ability of patients to access new medicines."

According to Cystic Fibrosis Canada's website, the list price for Trikafta in

the United States is US\$311,000 annually.

Legault-Thivierge said that in August 2019, the federal government announced the final amendments to the Patented Medicines Regulations, which help protect Canadians from excessive prices of patented medicines.

"The amendments were scheduled to come into force on July 1, 2020. The COVID-19 pandemic has increased demands on the pharmaceutical industry

related to supply chains and shortages. As such, Health Canada delayed the coming into force of the amendments by six months — until Jan. 1, 2021," he said.

In the meantime, the Bianchin sisters wait and hope while continuing their regular daily treatment regimen.

"Getting Trikafta is my dream. That is all I want; that would be the best possible scenario for my life," Mikayla said. "We want a new normal."

*STORY BEHIND THE STORY: When hearing about the positive impact the drug Trikafta could have on the lives of Canadians with cystic fibrosis, we wanted to know more about why it isn't available here.*

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