

# Cystic Fibrosis in Canada



Canadian Cystic  
Fibrosis Foundation

*Breathing life into the future™*

“When Mikayla was diagnosed with cystic fibrosis, a few weeks after her birth, we had never even heard of CF.

For us, raising a child with a fatal disease means dealing with the uncertainty of her future on a daily basis. With hours of inhalation treatments, chest physiotherapy and handfuls of pills, we try to make each day as normal and fulfilling as possible.

Every day, we appreciate how precious our beautiful girl is, and just being with her renews our hope for a future with her.”

*Mikayla's parents Tammy and Darrin*



### Mikayla's Daily Schedule

- 6:30 a.m. Mikayla wakes up for two separate inhalation treatments, puffers, PEP (positive expiratory pressure) treatment and nasal sprays
- 8:00 a.m. She eats breakfast, takes 6-7 enzymes, vitamins and a high-calorie supplemental drink
- 8:40 a.m. She boards the school bus for grade 2
- 9:00 a.m. School. Mikayla's lunchbox is packed full
- 3:15 p.m. of high-calorie food. A teaching assistant ensures that she takes enzymes before each snack and lunch
- 5:30 p.m. She takes another 6-7 enzymes at dinner with vitamins and a high-calorie supplemental drink
- 8:00 p.m. Bedtime inhalation treatments, nasal sprays and chest physiotherapy

*The Canadian Cystic Fibrosis Foundation (CCFF) was established in 1960 by a group of concerned parents who refused to accept that their children, who had been diagnosed with cystic fibrosis (CF), would not live long enough to attend kindergarten. Today, volunteers from more than 50 CCFF chapters across Canada raise awareness and funds to help find a cure, or an effective control, for this disease.*

*The Foundation's mandate is to help individuals with cystic fibrosis principally by funding CF research, and by supporting high quality clinical and transplant care. The Foundation's goal is to ensure that every dollar raised works for all persons with CF in Canada.*

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## What is cystic fibrosis?

Cystic fibrosis is the most common fatal genetic disease affecting Canadian children and young adults. There is no cure for CF.

Cystic fibrosis causes a build-up of thick mucus in the lungs leading to severe respiratory problems. Meanwhile, mucus and protein build-up in the digestive tract results in extreme difficulty in digesting and absorbing adequate nutrients from food.

The effects of cystic fibrosis are most devastating in the lungs. Ultimately, most CF deaths are due to lung disease.

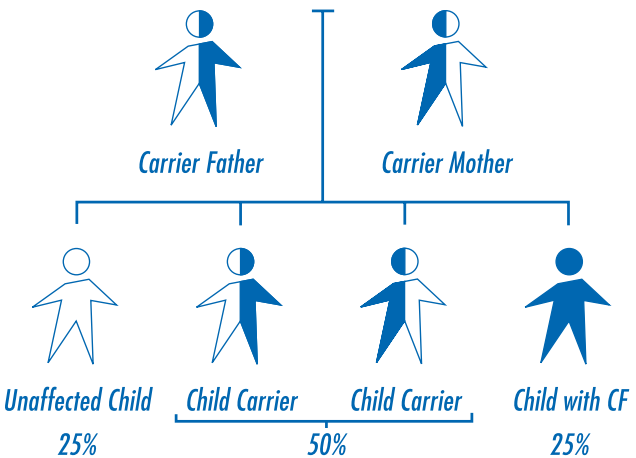
It is estimated that one in every 3,600 children born in Canada has cystic fibrosis. Approximately 3,500 Canadian children, adolescents, and adults with cystic fibrosis attend specialized CF clinics.

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## What causes cystic fibrosis?

Cystic fibrosis is a genetic disease. Cystic fibrosis is not contagious. People are born with cystic fibrosis. About one in 25 Canadians carries a defective version of the gene responsible for CF. Carriers do not have cystic fibrosis, nor do they exhibit any of the symptoms of the disease. Cystic fibrosis occurs when a child inherits two defective copies of the gene responsible for CF, one from each parent.

Each time two parents who are carriers have a child, there is a 25 percent chance that the child will be born with cystic fibrosis; there is also a 50 percent chance that the child will be a carrier; and a 25 percent chance that the child will neither be a carrier nor have cystic fibrosis.



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## What are the signs and symptoms of CF?

Because cystic fibrosis is a disorder that affects several bodily systems, it is associated with a variety of symptoms, including: difficulty breathing; constant cough that expels thick mucus; excessive appetite combined with weight loss; bowel disturbances; skin that tastes unusually salty; repeated or prolonged bouts of pneumonia.

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## How is cystic fibrosis diagnosed?

If a doctor suspects CF, he or she will carry out special tests. A “sweat test”, which analyzes the salt content of the sweat, or a test for presence of enzymes in the intestine may be performed. Genetic testing, prenatal and newborn screening are other methods of determining the presence of cystic fibrosis. These are relatively simple, non-invasive tests.

In some provinces, newborns are screened for cystic fibrosis.

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## How does cystic fibrosis affect everyday life?

Cystic fibrosis affects each individual differently, with varying degrees of severity. Each person with the disease follows an individualized treatment program, which may include a demanding daily routine of physical and, sometimes, inhalation therapy to keep the lungs free of congestion and infection. Children and adults with CF must also consume a large number of pancreatic enzymes (on average 20 pills a day) with every meal and snack, to help absorb adequate nutrition from food. Regular visits to a CF clinic are also an essential part of CF care and treatment.

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## What kind of CF care is available in Canada?

Expert care for adults and children with cystic fibrosis is provided at 40 accredited CF clinics, located in major centres across Canada. The clinics offer specialized multidisciplinary medical care for children and adults. In addition, CF outreach clinics provide medical care to individuals in remote areas.

In addition, lung transplantation provides individuals who have end-stage lung disease with the possibility of regaining their health. However, due to the limited availability of donor organs, obtaining a transplant may be difficult. The Foundation supports organ donor awareness and encourages Canadians to discuss organ donation with their loved ones.



## Research yields progress

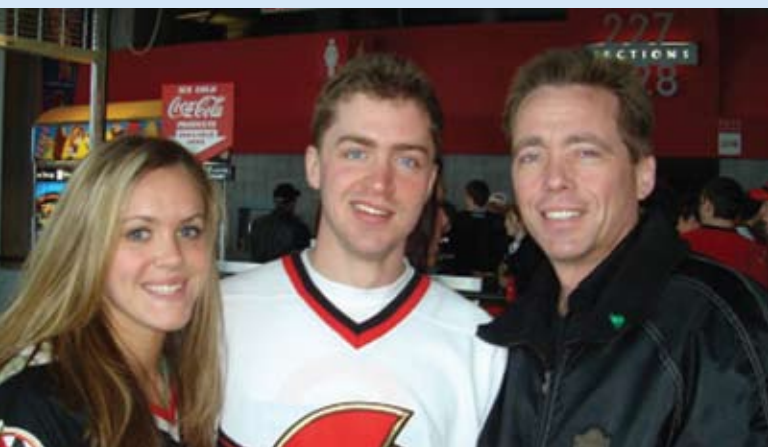
“When I was diagnosed with cystic fibrosis, Canadians with the disease weren’t expected to live beyond four years of age. Most didn’t get the chance to learn to read, attend school, or dream of a future.

Now, I am approaching my 50th birthday. Thanks to significant improvements in treatment and scientific understanding, I have lived long enough to complete university, have a challenging career, get married and raise a family.

My son graduated from university and my daughter is studying nursing.

Growing older is an unexpected, priceless treasure. ”

*Wally Speckert*



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## How does the Foundation help?

The Canadian Cystic Fibrosis Foundation is one of the world's largest non-governmental granting agencies in the field of cystic fibrosis research.

The Foundation's primary objective is to fund CF research and care: the Foundation annually funds approximately 50 research projects, in addition to scholars, post-doctoral fellows, and students undertaking CF investigations. Each year, the CCFF awards more than \$6 million in grants to CF researchers, and approximately \$2 million in grants to the 40 CF clinics, and five transplant centres across the country.

With the aid of funding from the CCFF, researchers working at institutions across Canada have achieved many milestones on the road to a cure for cystic fibrosis. In 1960, most children with cystic fibrosis did not live long enough to attend kindergarten; today half of all Canadians with CF are expected to live into their 40s, and beyond.

Canadian researchers are viewed as leaders in the global effort to find a cure or control for the disease. In 1989, Canadian researchers, funded by the Foundation, discovered the gene responsible for cystic fibrosis, and they continue to play a leading role in the worldwide race to develop new treatments, and a cure for this disease.

The CCFF also undertakes advocacy initiatives with, and on behalf of, Canadians with CF, to enhance their quality of life. Daily, caring and committed CCFF chapter volunteers support families and friends who are living with cystic fibrosis.

In addition, the Foundation creates educational and promotional materials to raise awareness and understanding about cystic fibrosis.



CCFF-funded researchers are focused on finding a cure or control for cystic fibrosis.

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People with cystic fibrosis follow individualized treatment programs.



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## Partners, Sponsors and Special Friends

Funds and awareness are raised through the efforts of CCFE chapter volunteers; Kin Canada; Hbc Foundation; CARSTAR Canada; Advocis; university and college students who participate in the annual Shinerama fundraiser; Mac's Convenience Stores Inc.; BioGuard; tens of thousands of individuals and corporations; Honorary Director, Mrs. Mila Mulroney; and Celebrity Patron, Céline Dion.

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## How can you help?

### Volunteer

The CCFE has more than 50 chapters comprised of dedicated volunteers who help in the fight against cystic fibrosis every day. By lending your time, you too can help fight cystic fibrosis. New volunteers are always welcome. To find out more, visit [www.cysticfibrosis.ca](http://www.cysticfibrosis.ca) or call 1-800-378-2233.

### Donate

Every dollar donated moves us one step closer to a cure or effective control for cystic fibrosis. Across Canada, people affected by CF are hoping that a cure for cystic fibrosis will be found in time to save their child, their mother, their uncle, or their friend. Please help. Every dollar you give brings the dream a little closer, and makes the hope a little stronger. Donate online at [www.cysticfibrosis.ca](http://www.cysticfibrosis.ca) or call 1-800-378-2233.



Volunteers, partners and donors help raise awareness of cystic fibrosis and funds to support CCFF-funded research and treatment programs.



For more information about cystic fibrosis,  
please contact a chapter or:



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416-485-9149 | 1-800-378-2233  
info@cysticfibrosis.ca

[www.cysticfibrosis.ca](http://www.cysticfibrosis.ca)

In Quebec, you may contact the CCFF's  
provincial association:



**Quebec Cystic  
Fibrosis Association**

425 Viger Avenue West, Suite 510  
Montreal, Quebec H2Z 1X2

514-877-6161 | 1-800-363-7711  
Quebec City office: 1-877-653-2086  
info@aqfk.qc.ca

[www.aqfk.qc.ca](http://www.aqfk.qc.ca)

The QCFA is a provincial association of the Canadian Cystic Fibrosis Foundation.



Canadian Cystic  
Fibrosis Foundation

*Charitable registration:*  
10684 5100 RR0001

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2010-03 | *Cette publication est aussi disponible en français.*