



Cystic Fibrosis Canada

## Cystic Fibrosis in Canada

### What is cystic fibrosis?

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

Cystic fibrosis causes a build-up of thick mucus in the lungs leading to severe respiratory problems. Similarly, 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.

Almost 4,000 Canadian children, adolescents and adults with cystic fibrosis receive specialized care at one of the 42 CF clinics across the country.



Breathing life into the future®



"Because of medical advances, overall life expectancy has greatly increased for CF patients and today nearly 60 percent of all Canadians with cystic fibrosis are adults. Even 20 years ago life expectancy wasn't that great when diagnosed with CF. As a photographer and an adult living with CF, it is my goal to put a new face on cystic fibrosis and raise awareness that it is not just a childhood disease."

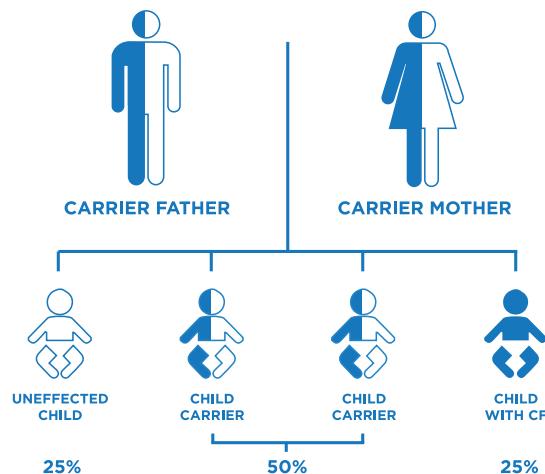
**Ian Pettigrew**, Hamilton, Ontario

## What causes cystic fibrosis?

Cystic fibrosis occurs when a child inherits two abnormal copies of the gene responsible for cystic fibrosis — one from each parent. Approximately one in 25 Canadians is a cystic fibrosis carrier, with one abnormal version of the gene responsible for this life-altering disease. Many people are unaware that they are carriers.

Over 1,900 different mutations in the Cystic Fibrosis Transmembrane Regulator (CFTR) gene have been identified. However, 87.5 percent of individuals with cystic fibrosis in Canada carry at least one copy of the most common CF-causing mutation, deltaF508.

When two individuals 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. It is estimated that one in every 3,600 children born in Canada has cystic fibrosis.



## What are the signs and symptoms of cystic fibrosis?

Because cystic fibrosis is a multi-system disorder, it is associated with a variety of symptoms, including:

- ◆ Persistent cough with productive thick mucus
- ◆ Wheezing and shortness of breath
- ◆ Frequent chest infections, which may include pneumonia
- ◆ Excessive appetite combined with weight loss
- ◆ Bowel disturbances
- ◆ Skin that tastes unusually salty
- ◆ Infertility (men) and decreased fertility (women)

## How is cystic fibrosis diagnosed?

If a physician suspects cystic fibrosis, he or she will carry out a “sweat test” that analyzes the salt content of the sweat.

**FACT:** 58.9 percent of people with cystic fibrosis are diagnosed in the first year of life, and 88.7 percent by 10 years of age. *CF Registry 2012 Annual Report*

Genetic tests are also being used to diagnose cystic fibrosis, especially in adults, or when results of sweat tests are inconclusive. DNA from a cheek swab or blood sample is analyzed to look for mutations in the gene responsible for cystic fibrosis. Genetic tests are also used to diagnose cystic fibrosis prenatally.

Many provinces include cystic fibrosis as part of their newborn screening programs (NBS).

## How does cystic fibrosis affect everyday life?

Cystic fibrosis affects each person differently, with varying degrees of severity. Each person with the disease follows an individualized treatment

**“Cystic fibrosis affects each person differently, with varying degrees of severity.”**

program, which may include a demanding daily routine of physical and inhalation therapy to keep the lungs free of congestion and infection. People with cystic fibrosis must also consume a large

number of pancreatic enzymes (on average 20 pills a day) to help absorb nutrients from food.

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



Expert care for anyone with cystic fibrosis is provided at 42 accredited adult and pediatric CF clinics located across Canada. CF outreach services also provide medical care to those located in some remote areas where there are no local clinics.

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.

## **How does Cystic Fibrosis Canada help?**

Cystic Fibrosis Canada is one of the world's top three charitable organizations committed to finding a cure for cystic fibrosis. We invest more funding in life-saving cystic fibrosis research and care than any other non-governmental agency in Canada.

Since 1960, Cystic Fibrosis Canada has invested more than \$150 million in leading research and care, resulting in Canada having one of the world's highest median age of survival for people with cystic fibrosis.

Cystic Fibrosis Canada provides funding to 42 CF clinics and five transplant centers across Canada through Clinic and Transplant Centre Incentive Grants. Our funding supports clinic staff salaries, professional education, and assists with travel costs for cystic fibrosis outreach clinics.

Cystic Fibrosis Canada advocates for Canadians living with cystic fibrosis. We work to influence public policy for better treatment and care, for the inclusion of newborn screening in every province, and for equitable and affordable access to medicines and treatments. We are committed to advocating for policies and programs that help people with cystic fibrosis, their families, caregivers and healthcare professionals. Together, we're working to raise the voice of Canadians with cystic fibrosis.

## **Who are our donors, partners and volunteers?**

We are thankful for the generosity of many individual donors, corporate partners, governments, organizations and volunteers who enable Cystic Fibrosis Canada to continue our work to improve the lives of Canadians with cystic fibrosis.

Cystic Fibrosis Canada's dedicated partners continue their history of unwavering support in the fight against cystic fibrosis. Our national partners Kin Canada, CARSTAR Automotive Canada Inc., Advocis, Mac's Convenience Stores Inc., and Bioguard® Canada continue to make generous contributions. Kin Canada continues to lead the way in their commitment to Canadians with cystic fibrosis and have raised more than \$40 million for CF research and care over the past 50 years.

Cystic Fibrosis Canada could not do our important work without the dedication and support of our volunteers. Our Celebrity Patron, Céline Dion, long-standing partners like Kin Canada, and enthusiastic participants in fundraising events like our Great Strides™ walk and Shinerama, all share one vision — a world where cystic fibrosis is no longer a progressive life-shortening disease.

## **How can you make a difference?**

### **Volunteer**

Cystic Fibrosis Canada has more than 50 chapters of dedicated volunteers who raise funds and awareness to 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 finding a cure or effective control for cystic fibrosis. When you make a gift to Cystic Fibrosis Canada you are helping Canadians with this disease live a longer and healthier life. There are many ways to give to Cystic Fibrosis Canada, donate online at [www.cysticfibrosis.ca](http://www.cysticfibrosis.ca) or call 1-800-378-2233.

### **Advocate**

Cystic Fibrosis Canada advocates for public policies, better treatment and care, as well as equitable and affordable access to medicines and therapies that aim to enhance the quality of life for people with cystic fibrosis. We work with members of the CF community to identify issues, develop strategies, and effect change. Together we are raising the voice of Canadians with Cystic Fibrosis.

## **How can I connect with other Canadians with cystic fibrosis?**

Join the My Cystic Fibrosis (CF) Canada Network, Canada's first-ever social network designed by CF patients specifically for CF patients to connect and share important information about living with this severe and potentially fatal genetic disease. Canadians with cystic fibrosis can discuss the treatments, programs and services available in their province/region, via video chat and instant message, share stories and personal issues, and receive support for advocacy and fundraising initiatives from a much broader community.

Cystic Fibrosis Canada acknowledges Novartis Pharmaceuticals Canada Inc. for the collaboration that has made the My CF Canada Network possible.

**Sign-up today at [www.mycfnetwork.com](http://www.mycfnetwork.com)**

**For more information, visit [www.cysticfibrosis.ca](http://www.cysticfibrosis.ca)**

### **Acknowledgment:**

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

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