About Cystic Fibrosis
Cystic fibrosis (CF) is the most common fatal genetic disease affecting children and young adults in Canada.

There is no cure. Cystic fibrosis causes various effects on the body, but mainly affects the digestive system and lungs. The degree of cystic fibrosis severity differs from person to person; however, the persistence and ongoing infection in the lungs, with progressive loss of lung function will eventually lead to death in the majority of people with cystic fibrosis. Other consequences of having cystic fibrosis include malnutrition and very low BMI, pulmonary exacerbations requiring weeks of hospitalization and I.V. antibiotics, and CF-related comorbidities like CF-related diabetes and CF-related liver disease.

Cystic fibrosis is a complex disease caused by mutations in the gene for the Cystic Fibrosis Transmembrane Conductance Regulator (CFTR). There are over 2,000 known mutations. Cystic fibrosis has a huge impact on the people who live with it, their loved ones, and on society. Every week in Canada, two people are diagnosed with cystic fibrosis with one of them diagnosed through newborn screening. And every week in Canada, one person with CF will die.

Approximately one in every 3,600 children born in Canada has cystic fibrosis. More than 4,300 children, adolescents and adults with cystic fibrosis attend one of 42 specialized multidisciplinary cystic fibrosis clinics in Canada. Cystic fibrosis is still often considered a paediatric disease because children who were diagnosed with CF survival in the 1960s died at a young age. However, progress in combating cystic fibrosis has been exceptional. Now, because of our ability to manage care through specialized multidisciplinary clinics and due to the availability of therapies to treat the symptoms associated with CF, the estimated median age of survival of a child born in 2018 is 52.1 years. This means that a child born today has a 50 percent chance of living past that age.

More than sixty percent of people living with cystic fibrosis are now adults. They are finishing school and university, launching careers in areas such as law, science, and business and starting families. Yet, their ambitions are still far too often cut short. Half of the people with cystic fibrosis who died in 2018 were under the age of 33. While people are living longer, they are still dying far too young.

Cystic fibrosis remains a relentlessly progressive disease. Comorbidities accumulate with age, and quality of life declines. In 2018, Canadian cystic fibrosis patients attended over 18,900 CF-specific outpatient clinic visits. People with CF experience episodes of infection and acute inflammation called pulmonary exacerbations that frequently require in-patient IV antibiotics. These exacerbations typically increase in frequency with age and often come with declining respiratory function.

Here in Canada in 2018, 1,209 individuals with cystic fibrosis spent almost 26,500 days in the hospital (cumulatively). To put that into perspective, this adds up to more than 70 years of time spent in the hospital.

About Cystic Fibrosis Canada

Cystic Fibrosis Canada is a national charitable not-for-profit corporation established in 1960, and is one of the world's top three charitable organizations committed to finding a cure for cystic fibrosis (CF). Cystic Fibrosis Canada funds targeted world-class research, supports and advocates for high-quality individualized CF care and provides information and support to people living with cystic fibrosis. Since establishment, Cystic Fibrosis Canada has invested more than $261 million in leading research, innovation and care. As a result, Canadians with cystic fibrosis have one of the highest estimated median age of survival rates in the world.

Investing in the best research has led to outstanding progress in the fight against cystic fibrosis. Our researchers have:

- Discovered the gene responsible for cystic fibrosis, opening the door to targeting the cause of the disease rather than its symptoms.

- Developed revolutionary diets that reduce malnutrition in cystic fibrosis and were adopted globally.

- Purified the CFTR protein, improving our understanding of its structure and function and leading to the development of the disease-modifying drugs that treat the basic defect of CF.

- Developed the world's first device to test and repair donor lungs, improving transplant outcomes.

- Identified a novel approach to treating bacterial infections that was adopted as a best practice in clinical care.

We rely on the generous support of our volunteers, donors, and partners in our shared mission to improve the lives of Canadians living with cystic fibrosis, and ultimately to find a cure for this devastating disease.