

# VOLUNTEERING WITH CYSTIC FIBROSIS CANADA





Cystic Fibrosis  
Fibrose kystique  
Canada

## *Welcome*

We appreciate your interest in donating your time and talents to Cystic Fibrosis Canada. As a non-profit organization we rely on an enthusiastic, creative and energetic group of volunteers to create a positive impact in our society and help us to achieve our vision of a world without cystic fibrosis.

Volunteers are extremely important to Cystic Fibrosis Canada and we want to make sure that you have all the facts that you need to make the informed decision of joining our incredible team of volunteers. The purpose of this handbook is to provide you with a brief introduction to the organization, share the volunteer opportunities that we have available, and give you some basic information about cystic fibrosis and the impact that it has on Canadians living with this devastating disease.

On behalf of Cystic Fibrosis Canada, we want to thank you for taking the time to learn more about our organization. We sincerely hope that after reading this handbook, you will decide to join our team of amazing volunteers and the fight against cystic fibrosis.

## WHAT IS CYSTIC FIBROSIS?

Cystic fibrosis is the most common fatal genetic disease affecting Canadian children and young adults. [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 involvement differs from person to person. However, the persistence and ongoing infection in the lungs, with destruction of lungs and loss of lung function, eventually causes death in the majority of people who have cystic fibrosis.

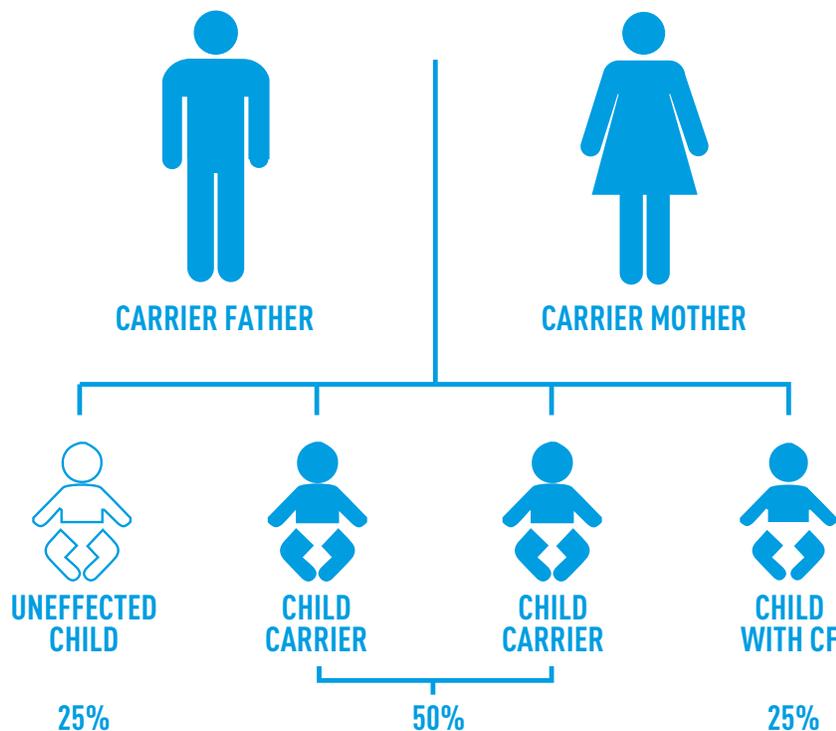
Typical complications caused by cystic fibrosis are difficulty in digesting fats and proteins; vitamin deficiencies due to loss of pancreatic enzymes; and progressive loss of lung function.

It is estimated that one in every 3,600 children born in Canada has cystic fibrosis. Almost 4,000 Canadian children, adolescents, and adults with cystic fibrosis attend specialized CF clinics.

## WHAT CAUSES CYSTIC FIBROSIS?

Cystic fibrosis is a genetic disease that occurs when a child inherits two abnormal genes, 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.

When 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.



## WHAT ARE THE SYMPTOMS OF CYSTIC FIBROSIS?

Cystic fibrosis is a multi-system disorder that produces a variety of symptoms including:

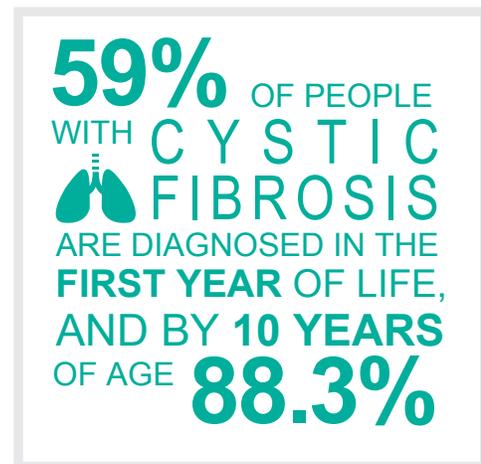
- Persistent cough with productive thick mucus.
- Wheezing and shortness of breath.
- Frequent chest infections, which may include pneumonia.
- Bowel disturbances, such as intestinal obstruction or frequent, oily stools.
- Weight loss or failure to gain weight despite possible increased appetite.
- Skin that tastes unusually salty.
- Infertility (men) and decreased fertility (women).

## DIAGNOSING CYSTIC FIBROSIS

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

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).



CF Registry 2013. Annual Report.

## HOW DOES CYSTIC FIBROSIS AFFECT EVERYDAY LIFE?

Cystic fibrosis affects each person differently, and with varying degrees of severity. Each person with the disease follows an individual treatment 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 large number of pancreatic enzymes (on average 20 pills a day) to help absorb nutrients from food.

## ABOUT CYSTIC FIBROSIS CANADA

### HISTORY

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 CF. As an internationally recognized leader in funding innovation and clinical care, we invest more in life-saving CF research and care than any other non-governmental agency in Canada.

Since establishment, Cystic Fibrosis Canada has invested more than \$226 million in research and healthcare.

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.

### OUR MISSION

To end cystic fibrosis (CF). We will help all people living with CF by funding targeted world class research, supporting and advocating for high quality individualized CF care and raising and allocating funds for these purposes.

### OUR VISION

A WORLD *without*  
CYSTIC FIBROSIS

## IMAGINE CANADA ACCREDITATION

Cystic Fibrosis Canada is committed to the highest quality standards of volunteer involvement and it has been awarded with Imagine Canada's Standards Program accreditation.



With this achievement, Cystic Fibrosis Canada joined a select group of 150 organizations dedicated to operational excellence. The Standards Program is a Canada-wide set of shared standards for charities and non-profits designed to strengthen practices in five fundamental areas including volunteer involvement.

## CYSTIC FIBROSIS CANADA'S VALUES

Cystic Fibrosis Canada is committed to, and encourages the fostering of the following four values:

### EXCELLENCE

Excellence starts with the belief that striving for the ultimate solution or goal is the only path worth following. By challenging the status quo, we are dedicated to achieving or surpassing all of our goals in support of creating a better future for Canadians with cystic fibrosis.

### TEAMWORK

Through teamwork, we are an integrated and united front that speaks as one voice with common goals. We value and are committed to building strong relationships with all our partners, including: volunteers, corporate partners, employees, donors, researchers and clinicians. We strive to help Canadians with cystic fibrosis gain the quality of life they deserve through information, education and the development and delivery of resources.

### ACCOUNTABILITY

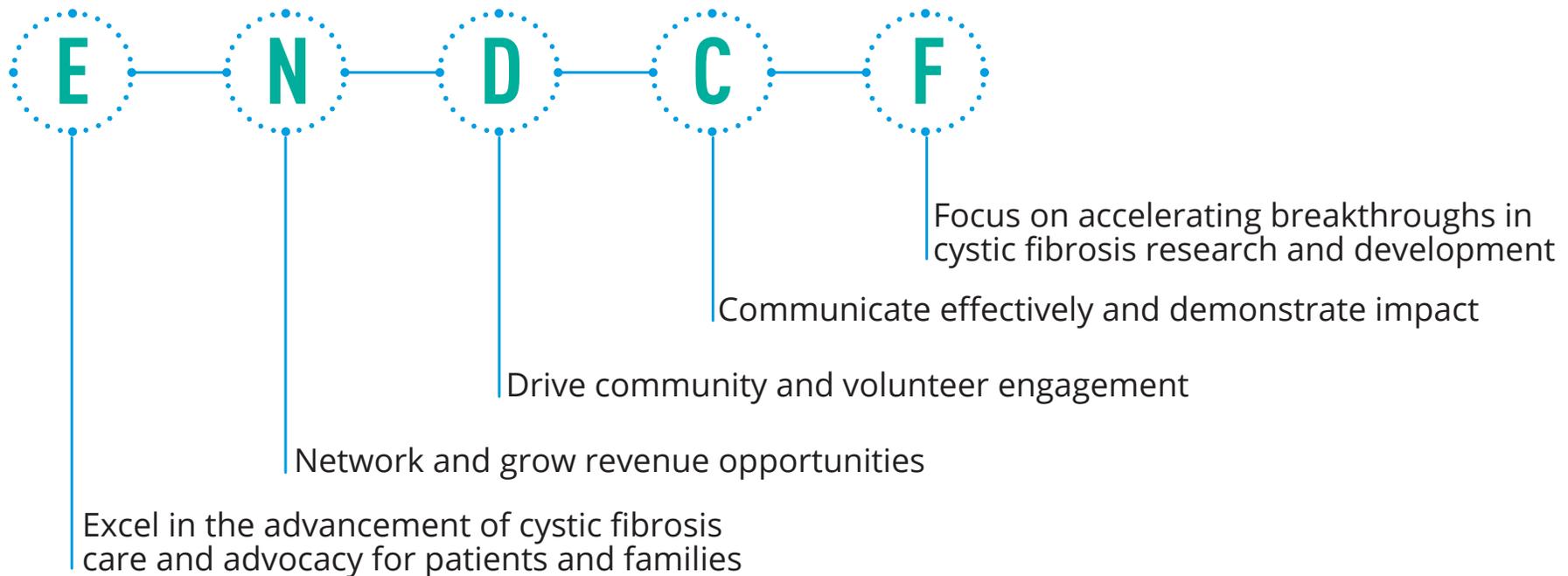
Accountability means that we are committed to financial stewardship with, and for, all stakeholders of Cystic Fibrosis Canada by providing proper governance in relation to our policies and charters. Our organization is well-managed, a great place to work, volunteer, or invest in and we always deliver results to the Canadians with cystic fibrosis we are trying to help.

### CARING

Caring for Canadians with cystic fibrosis by providing an encouraging and supportive environment that will inspire the best care, treatment and research possible



# CFOCUS 2020 STRATEGIC DIRECTIONS



# REGIONS & CHAPTERS

## WESTERN CANADA

- Calgary & Southern Alberta
- Campbell River
- Central Alberta
- Edmonton & Northern Alberta
- Nanaimo
- Victoria
- Kamloops
- Okanagan Valley
- Prince George
- Vancouver/Lower Mainland
- Yukon

## PRAIRIES

- North Saskatchewan
- South Saskatchewan
- Winnipeg

## CENTRAL & SOUTHWESTERN ONTARIO

- Essex-Kent
- Huron-Oxford-Perth
- Kitchener-Waterloo District
- London
- Sarnia/Lambton
- Durham
- Hamilton
- Niagara District
- Peel & District
- Toronto & District

## ONTARIO NORTH & EAST

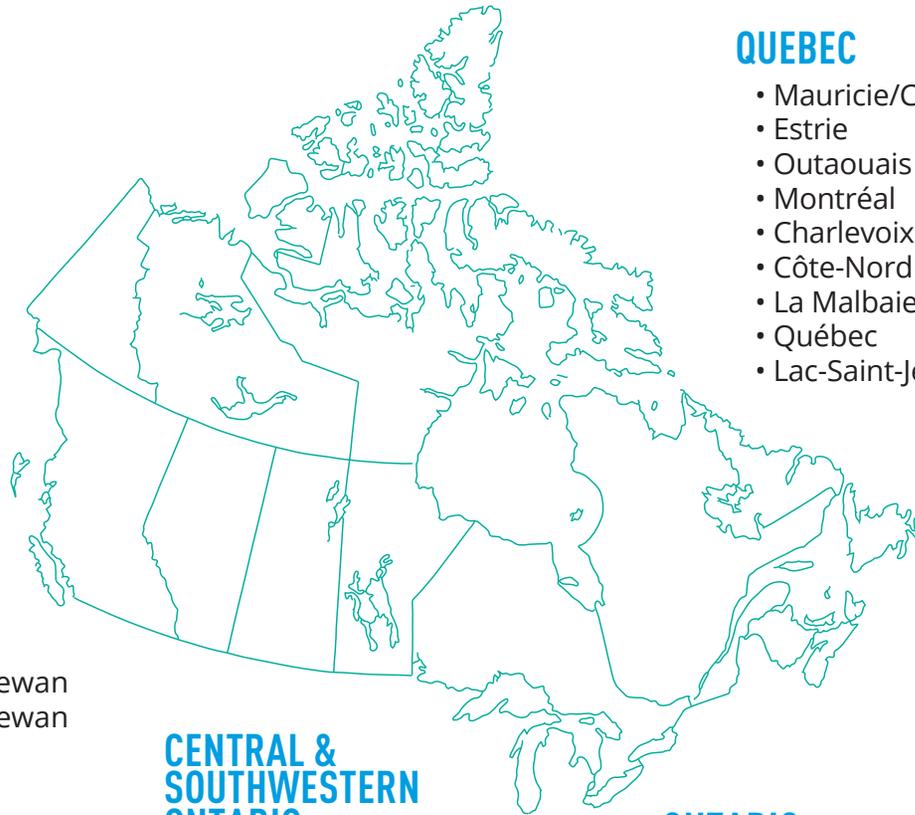
- North Bay
- Sault Ste. Marie
- Sudbury
- Thunder Bay
- Cornwall
- Kingston-Quinte-1,000 Islands
- Ottawa
- Peterborough

## QUEBEC

- Mauricie/Centre-du-Québec
- Estrie
- Outaouais
- Montréal
- Charlevoix-Ouest
- Côte-Nord
- La Malbaie
- Québec
- Lac-Saint-Jean/Saguenay

## ATLANTIC CANADA

- Fredericton & North West Valley (NB)
- Moncton (NB)
- Saint John (NB)
- Prince Edward Island
- Scotia (NS)
- South Western Nova & Valley (NS)
- Cape Breton Island (NS)
- Newfoundland & Labrador



# RESEARCH

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Cystic Fibrosis Canada is proud to fund scientists who are searching for a cure and better understanding of the disease. These researchers are committed to discovering new therapies and interventions to improve the health and well-being of patients.

# ADVOCACY

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Cystic Fibrosis Canada is raising the voice of and enhancing the quality of life for Canadians with cystic fibrosis by supporting advocacy initiatives for universal newborn screening and access to life-changing medication.

# USE OF FUNDS

## CLINICAL CARE

Cystic Fibrosis Canada supports high quality care for people with cystic fibrosis at 42 clinics across the country. Specialized care includes testing lung function and capacity, monitoring weight and diets, and prescribing medication.

# CLINICAL CARE



TM/MC

## THE IMPACT OF CYSTIC FIBROSIS CANADA'S VOLUNTEERS

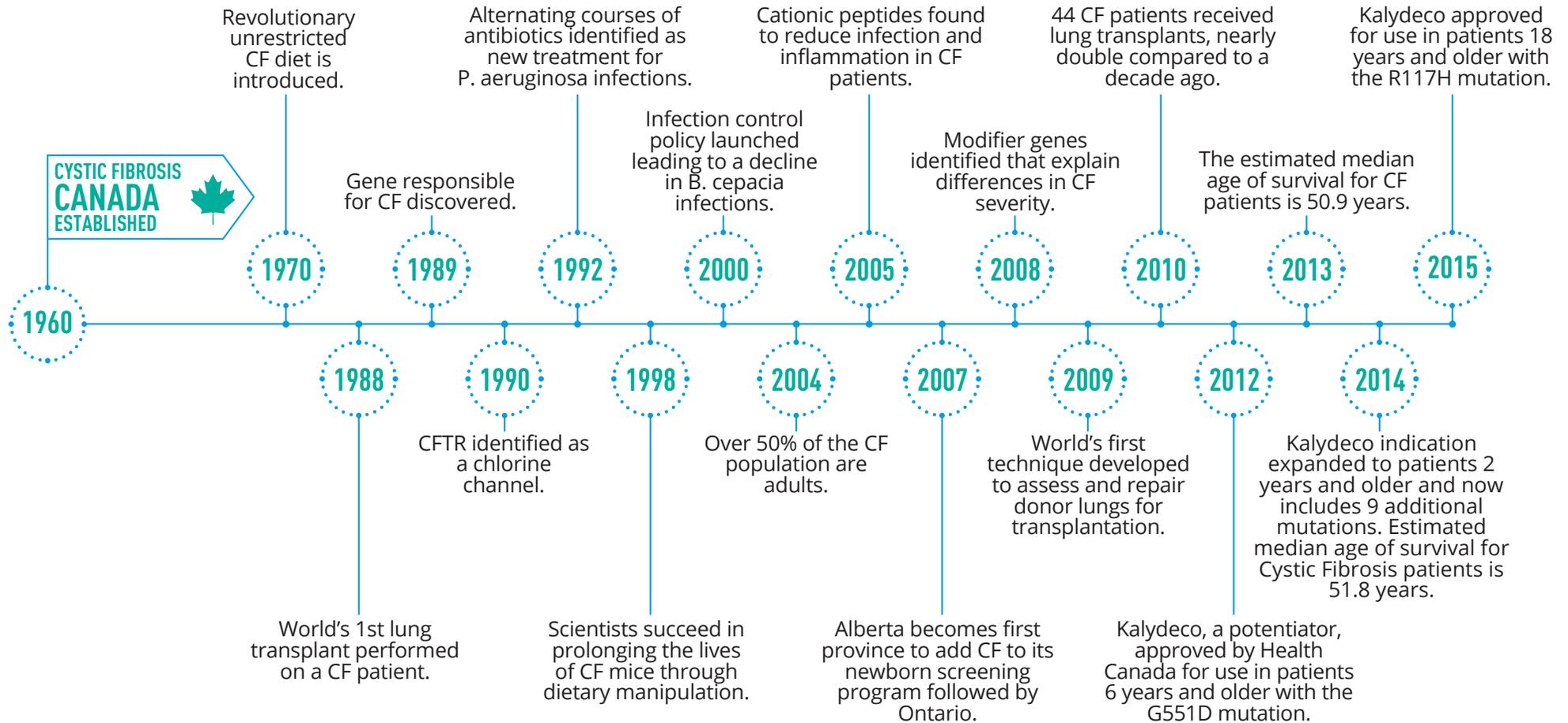
Through the generosity of our many donors, volunteers and partners, we are improving the lives of people with cystic fibrosis. A child diagnosed with cystic fibrosis in the 1960s was not expected to live long enough to attend kindergarten. Since 2014, the median age of survival of Canadians with cystic fibrosis is among the highest in the world, at 51.8 years of age.

Because of our donors and volunteers, we continue to advance the battle against this devastating disease by investing in innovative research in the pursuit of the next medical breakthrough and the highest standard of Cystic Fibrosis care, as well as supporting advocacy initiatives for universal Cystic Fibrosis newborn screening and access to life-changing medication. We are also carving new paths from research lab discoveries to the development of new treatments, and investing in a national quality improvement initiative for Cystic Fibrosis care.

**FACT** TODAY, THE MEDIAN  
AGE OF SURVIVAL OF  
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 **CYSTIC**  
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**IS AMONG THE HIGHEST**  
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**AT, 51.8 YEARS OF AGE**

Canadian Clinics meeting held at the 2015 North American Cystic Fibrosis Conference in Phoenix, AZ

# MILESTONES



# VOLUNTEERING WITH CYSTIC FIBROSIS CANADA

Volunteers are the backbone of Cystic Fibrosis Canada. Hundreds of volunteers from across the country work together every day in the fight against cystic fibrosis.

## VOLUNTEER ROLES

### CHAPTER LEADERSHIP ROLES (LONG-TERM)

Cystic Fibrosis Canada is always looking for people interested in providing insight and leadership within a local Chapter. Leadership volunteers offer strategic and tactical guidance as they contribute with their professional and past volunteer experience to the development and growth of the local Chapter. Responsibilities may include recruiting other volunteers, assisting with the communications of the Chapter, fundraising and securing sponsorships. Some examples of positions include: Chapter President, Chapter Treasurer, Chapter Kin Canada Liaison and others. Please contact your local Chapter or Regional office for more information.

### EVENT ROLES

From helping at the registration table to chairing some great Chapter events, Cystic Fibrosis Canada Event volunteers play a key role in guaranteeing the success of the Chapter's fundraising activities. The volunteer roles in this area are divided into two categories:

- Day of the Event Support (short-term): This is a short-term commitment where volunteers help by providing logistical support on the day of the event (registration, silent auctions, selling raffle tickets, etc.)
- Event Planning Committees (mid/long-term): The members of an event planning committee provide the logistical decisions about particular fundraising events. Some examples include: taking on the role of the Chair of the Walk, or being in charge of securing sponsorship for an event.

### OFFICE SUPPORT ROLE (IF APPLICABLE)

Office support volunteers play a very important role in the day-to-day operations of the Regional Office or the local Chapter. Office volunteers can work on a regular basis or casually (depending on the needs of each location) and they assist staff with tasks such as data-entry, answering the phone, greeting the public and other activities as need.

## WHY VOLUNTEER WITH CYSTIC FIBROSIS CANADA?

We believe that any volunteer experience with Cystic Fibrosis Canada is a two-way street where both, volunteer and organization, benefit from such interaction. Cystic Fibrosis Canada's successes are the direct result of having a strong and enthusiastic team of volunteers that is always looking for new and creative ways to raise funds for cystic fibrosis research.

Cystic Fibrosis Canada is committed to making sure that everyone has a rewarding, meaningful and fun volunteer experience. This includes making sure that volunteers receive clear information on the role that they will play within the organization and that their volunteer placement is a stimulating task that matches their interests and skills (and helps them to develop new ones). Furthermore, as an organization, we will make sure that they have all the tools and staff support required to excel in their role a volunteer.

As an organization that is accountable to all stakeholders, particularly volunteers, your respectful feedback is always welcome to help us excel in the fight against cystic fibrosis. Cystic Fibrosis Canada is committed to respecting the privacy of volunteers, donors and people living with cystic fibrosis by following the most up to date privacy policy. As a Cystic Fibrosis Canada volunteer, you will be a valuable contributor to the advancement of our organization and our goal of finding a cure for cystic fibrosis.

We sincerely hope that after reading this handbook, you decide to join our team of amazing volunteers. You will find a Volunteer Application Form on the next page or alternatively, you can apply [online](#).

ARE YOU READY  
TO JOIN THE  
FIGHT AGAINST  
 C Y S T I C  
F I B R O S I S ?