

2017-2018 IMPACT REPORT

# IMPACT

FOR CYSTIC FIBROSIS CANADA SUPPORTERS IN QUEBEC



**YOUR  
DONATIONS  
AT WORK**

**UNITED**  
for Better  
Access to  
Medication

**A PROMISING  
DISCOVERY  
BY A QUEBEC  
RESEARCH TEAM**



Dear supporter of Cystic Fibrosis Canada,

Year after year, your commitment to our organization gives us the strength and support that we need to keep our promise to the 1,200 people in Quebec with cystic fibrosis (CF). Our commitment to them is that we will not give up until there are no more lives claimed by this disease.

That's why it is so important to share this Impact Report with you. We want you to see what we were able to accomplish with your support. It is because of you that we are able to have an impact on cystic fibrosis. And, for that, thank you.

**Yannick Brouillette**  
Executive Director, Quebec  
Cystic Fibrosis Canada



**52.3 YEARS**  
THE ESTIMATED MEDIAN SURVIVAL AGE FOR  
CANADIANS WITH CYSTIC FIBROSIS, IS AMONG  
THE HIGHEST IN THE WORLD

**MORE THAN 1/4**  
OF CANADIANS WITH CF  
LIVE IN QUEBEC

ABOUT CYSTIC FIBROSIS

Cystic fibrosis is the most common fatal genetic disease affecting Canadian children and young adults. More than 4,300 Canadians, including 1,200 people in Quebec, currently live with this disease that interferes with digestion, destroys the lungs due to infection and inflammation, and leads to other serious health problems, including malnutrition and CF-related diabetes. Although research is making great strides against CF, there is currently no cure.

THE IMPACT OF YOUR DONATION IN NUMBERS

<div>\$50</div> <div></div> <div>You've helped one adult with CF receive a hospital consultation to help find ways to cover the costs of therapy equipment and drugs.</div>	<div>\$150</div> <div></div> <div>You've helped a laboratory technician complete one day of CF research.</div>	<div>\$300</div> <div></div> <div>A graduate can conduct four days of lab work.</div>
<div>\$500</div> <div></div> <div>You're helping a physician to deliver specialized care to individuals with CF who live in remote areas.</div>	<div>\$1,000</div> <div></div> <div>16 adults with CF can have access to one year of specialized "whole person" care.</div>	<div>\$2,500</div> <div></div> <div>A hospital social worker can have 50 sessions to help families to cope with the emotional and practical issues related to living with CF.</div>

Cover photo: Emile, a two-year-old with cystic fibrosis, and his mother. Emile likes to play and simply loves animals. His best friend is Blue, the family dog, a tall Great Dane. His parents, both healthcare workers, hope for Émile to have a long and healthy life. Your generosity enables him to receive the best care possible, and, help him look towards the future and follow his dreams. Thank you. Photo credit : Ariane Bousquet

# RESEARCH

## A SNAPSHOT OF CURRENT RESEARCH PROJECTS



### A DISCOVERY MADE IN QUEBEC FUNDED BY CYSTIC FIBROSIS CANADA

Researchers at the McGill University Health Centre in Montréal, funded in part by Cystic Fibrosis Canada, have made an important discovery that has the potential to improve the lives of hundreds of cystic fibrosis patients here and around the world. These scientists have found a new cellular target that is likely to weaken *Pseudomonas*, a dangerous bacteria that can cause infections in people with CF. This bacterium, which can become highly resistant to antibiotics, is responsible for a chronic pulmonary infection that is the leading cause of death among people with CF. At the moment, there is no antibiotic that can stop this dangerous infection, but the discovery of this bacterium's weak spot will make it possible to improve existing antibiotics in order to make them more effective. This discovery stands as concrete evidence of the efficacy of research in CF and the importance of funding it.

SINCE 1960, CYSTIC FIBROSIS CANADA **\$253 MILLION**  
**HAS INVESTED** IN LEADING RESEARCH AND CARE

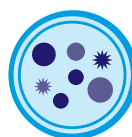


“Much progress has been made recently in the development of first-generation drugs to correct the basic defect in CF. However, more basic research is needed to understand how they work so they can be improved, and to find the best drug combinations for individual patients. Fundamental research on inflammation and infection in CF will also help identify new drug targets to make life better for people with CF. We need to continue supporting research - it provides hope for the future.”

Dr. John Hanrahan, Professor, Department of Physiology and McGill University Health Centre Research Institute  
Director, Cystic Fibrosis Translational Research centre

### CYSTIC FIBROSIS INDIVIDUALIZED THERAPY PROGRAM (CFIT)

Every person with cystic fibrosis is different, and the severity of the disease can vary greatly among the carriers of a given mutation. That's why Cystic Fibrosis Canada is working in collaboration with researchers at the Hospital for Sick Children (SickKids) in Toronto to test drugs that are currently available or under development, as well as drug combinations, to determine their effectiveness in each patient, thereby personalizing treatment. We are working hard to ensure that one day all people with CF will have access to the drugs or drug combinations that are ideal for them, therefore improving their quality of life and life expectancy.

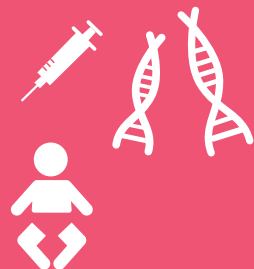






## NEWBORN SCREENING: A VICTORY IN 2017

On June 8, 2017, after 10 years of fierce advocacy by the CF community, Quebec Minister of Health and Social Services, Gaétan Barrette, announced that CF would finally be added to Quebec’s Neonatal Blood and Urine Screening Program. A diagnosis of CF at birth ensures early management of the disease, which ultimately enables people with CF to live longer, healthier lives. Thank you to the entire community, which mobilized to help score this important victory!



## UNITED FOR BETTER ACCESS TO MEDICATION

In 2018, Cystic Fibrosis Canada’s Quebec region advocated for improved access to medication with the "UNITED for better access to medication" campaign. More than 10,200 people signed the petition calling for the reimbursement of the CF drug Orkambi by the Régie de l'assurance maladie du Québec (RAMQ). Without private insurance or coverage under the exceptional patient measure, people with cystic fibrosis (CF) who could benefit from this drug struggle to gain access to it due to its high cost. Your support helps our advocacy work and will help us to ensure there is a rare disease strategy for Quebec - an important step in ensuring rare disease drugs are available to those who need them.



## A WELL-MANAGED ORGANIZATION

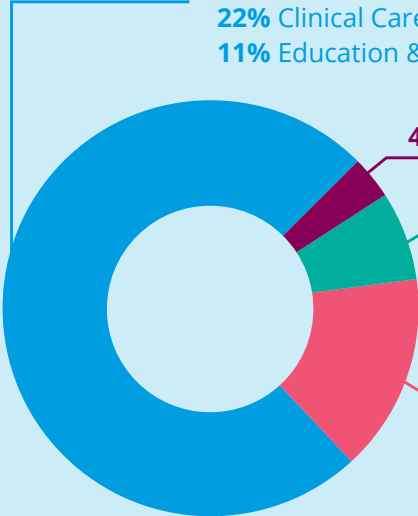
**USE OF FUNDS**  
*excludes direct fundraising costs*

**72% Programs**      **39% Research**  
**22% Clinical Care & Advocacy**  
**11% Education & Public Awareness**

**4% Volunteer Support**

**9% Indirect Fundraising Costs**

**15% Administration**



# CLINICAL CARE

The CF clinics provide high-quality, personalized multidisciplinary care to the 1,200 patients living with the disease in the province. Part of the donations received by our organization helps to increase the resources of specialized CF clinics and offer continuing education to clinicians about the newest research and available treatments. Your support is essential to improving the quality of care and consequently, the quality of life and median survival age of children and adults with CF.



2017-2018 CF CANADA CONTRIBUTION TO 11 QUEBEC CLINICS			
Hôpital de Chicoutimi \$45,038	Centre hospitalier de l'Université de Montréal \$94,754	CHUL et Centre mère-enfant Soleil \$44,663	Institut universitaire de cardiologie et de pneumologie de Québec \$63,573
Montreal Chest Institute \$42,938	Montreal Children's Hospital \$30,338	Hôpital de Gatineau \$6,653	Hôpital régional de Rimouski \$18,766
Hôpital de Rouyn-Noranda \$19,039	Centre hospitalier universitaire de Sherbrooke \$42,938	Centre hospitalier universitaire Sainte-Justine \$59,648	TOTAL \$468,348

## MyCFLifePortal

Launched in the fall of 2018, MyCFLifePortal enable Canadians living with cystic fibrosis to access their CF health data online – anytime they want. The portal is a secure, online read-only website specifically designed for participating CF patients and their caregivers, and will enable them to access their (or their child's) Canadian Cystic Fibrosis Registry data from the comfort of their own home. This website is fully bilingual and includes features such as interactive graphs and summary reports. MyCFLifePortal is provided free for any eligible user and participation is completely voluntary.



## IN YOUR COMMUNITY



### EVENTS

Find events in your community that benefit Cystic Fibrosis Canada.  
Visit [evenements.fkq.ca](https://evenements.fkq.ca).



### GET INVOLVED

If you would like to volunteer and do more to help us create a world without CF,  
write to us at [info@fkq.ca](mailto:info@fkq.ca).



### ARE YOU AFFECTED BY CYSTIC FIBROSIS?

Cystic Fibrosis Canada's information and reference services can help you find the answers to your questions or locate resources near you. In addition, we are always searching for people affected by cystic fibrosis who would like to share their stories.  
Write to us at [info@fkq.ca](mailto:info@fkq.ca).

## SPOTLIGHT ON A PARTNER

**Thank you for helping us to make cystic fibrosis history!**

WFG helps Canadian families improve their financial situation.

*"Your brighter future can start today"*

[worldfinancialgroup.com](https://worldfinancialgroup.com) 1-819-420-1880



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