

# *A World Without Cystic Fibrosis*



Faith, CF Champion



Cystic Fibrosis  
Fibrose kystique  
Canada

**2016/2017 ANNUAL REPORT**

Cystic fibrosis is the most common fatal genetic disease affecting Canadian children and young adults. It is a multi-system disease that affects mainly the lungs and digestive system. There is no cure.

Cystic Fibrosis Canada is one of the world's top three charitable organizations committed to finding a cure or control for cystic fibrosis (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.

## VISION

A world without cystic fibrosis.

## VALUES

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

## 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.

EXCELLENCE

ACCOUNTABILITY

TEAMWORK

CARING

## BOARD OF DIRECTORS

James Mountain (Chair)  
Mitch LePage (Vice Chair)  
Stephen McCourt (Chair of Finance)  
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Stuart Hodge  
Julie Saucier

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## MESSAGE FROM OUR PRESIDENT AND CEO



It was two years ago that we introduced ONE CFocus, a cohesive theme across Cystic Fibrosis Canada, uniting us as one team in our vision for a world without cystic fibrosis (CF). Along with our theme, we introduced the ONE CFocus 2020 strategic plan with the intention of providing us a clear path to achieve our goals – including collaborating with partners and increasing the median age of survival.

I am proud to say that the strategic plan is well underway. Highlights from the recently published 2014 registry show, the median age of survival of Canadians with CF is increasing and is among the highest in the world at 52.1 years. Over the last year, we have strengthened our existing partnerships and formed exciting new ones; collaboration is at the centre of every program, initiative and step that we take.

We continue to invest in life saving CF research, advocacy and care. These funds provide fair and affordable access to care and individualized high quality treatment to enhance health, prolong life and to end CF.

As we head towards 2020, I am inspired by our progress. We are well positioned to continue to meet and exceed the goals in our strategic plan.

Thank you to our partners, sponsors, donors, volunteers and community members from across Canada. Your support and generosity is the heart and soul of our organization; as we could not advance improvements without you.

Together we will achieve our vision of a world without Cystic Fibrosis.

A handwritten signature in black ink that reads "Norma Beauchamp". The signature is fluid and cursive, written in a professional style.

**Norma Beauchamp,**  
President and CEO  
Cystic Fibrosis Canada

## MESSAGE FROM OUR CHAIR

It was two years ago that Cystic Fibrosis Canada consulted with our stakeholders from across the country to create a comprehensive strategic direction for the organization. The objective was to create a plan that would strengthen our core initiatives and set revolutionary goals for research, care, advocacy and fundraising – and would see us meet these goals over the course of the next five years.

Looking back on the accomplishments of the 2016/2017 year, I'm pleased with the progress of our 2020 strategic plan. Collaboration was a key element that dictated much of our growth and decision making and as a result we have forged meaningful relationships with our partners, both internally and externally.

This is an exciting time; with the median age of survival increasing annually, and promising research being conducted. I look forward to what the next year will bring us as well as continuing to watch as we meet and surpass the goals in our plan.

I would like to extend my sincere gratitude to our community of passionate and enthusiastic supporters across Canada. The dedication of our researchers, clinicians, partners, donors, volunteers and CF families continue to inspire us to fight for a world without CF.

Together, we will ENDCF.



**Jim Mountain,**  
Chair  
Cystic Fibrosis Canada



**E**

**Excel in the Advancement of Cystic Fibrosis Care and Advocacy for Patients and Families**

**N**

**Network and Grow Revenue Opportunities**

**D**

**Drive Community and Volunteer Engagement**

**C**

**Communicate Effectively and Demonstrate Impact**

**F**

**Focus on Accelerating Breakthroughs in Cystic Fibrosis Research and Development**



# RESEARCH



In 2016-2017, we invested **\$5 million** in cystic fibrosis (CF) research, including grants to support innovative science across a broad spectrum of areas relevant to CF, improve the health and quality of life of CF patients, and bridge the gap between research and clinical care. The largest area of funded research was **CF infections**, which are chronic in people with CF and a major contributor to lung disease, the leading cause of illness and death in people with CF. Cystic Fibrosis Canada invested over **\$1.4 million in 19 CF infection studies** on topics including antibiotic resistance and how to predict lung infection flare-ups.

\$5 million was awarded to 52 studies, 18 fellows and students, and 8 targeted research programs and partnerships.



## RESEARCH PROGRAMS ENVIRONMENTAL SCAN – PUBLICATION

In 2016, Cystic Fibrosis Canada published an article in the *Journal of CF* highlighting an environmental scan of CF research around the world. The scan enabled a better understanding of the research funding practices of CF charitable organizations, including identification of best practices and research gaps. Canada ranked highly in CF research funding, coming in as the third highest funder of research, despite having the sixth highest CF population globally.

## FIRST-EVER VENTURE PHILANTHROPY INVESTMENT – LAURENT PHARMACEUTICALS

In March of 2016, Cystic Fibrosis Canada announced its first investment in a biopharmaceutical company, Laurent Pharmaceuticals. The company is developing a novel CF therapy that resulted from 10 years of CF Canada research funding at McGill University. In late July, Laurent Pharma received a further investment of up to US\$3 million from US-based Cystic Fibrosis Foundation Therapeutics, Inc., validating Cystic Fibrosis Canada's earlier investment.

# HEALTHCARE PROGRAMS



Cystic Fibrosis Canada supports the network of clinics, and in 2016, awarded **Clinic Incentive grants** to all clinics, ensuring availability of CF knowledge and expertise. These grants ensure that funding benefits all those with CF in Canada by supporting and enhancing high quality care.

**Accreditation Site Visits** provide accountability, ensuring that grants are being expended appropriately; and they help to ensure a consistent standard of care, encouraging the sharing of best practices amongst healthcare providers, administrators, patients and families. In 2016, Accreditation Site Visits were conducted at clinics in Quebec, Alberta, Saskatchewan and Manitoba, and six healthcare professionals participated for the first time on review teams, expanding the pool of viable accreditors and reinforcing the network of knowledge.

For added influence and authority, the **Health Human Resources Guidelines** are now referenced during every Accreditation Site Visit. Published in the Canadian Respiratory Journal, a peer-reviewed, academic journal, the *Health Human Resources Guidelines* provide recommended standards for multidisciplinary roles in clinic teams. With such benchmarks, hospital administrators can determine whether staffing roles are adequate.

Initially a three-year program, the **Quality Improvement Learning and Leadership Collaborative** (LLC) has been very successful, and by popular demand, has been extended with the addition of a fourth year; over a third of all clinics in Canada have now participated. The experience launching this national initiative was the subject of a poster presentation and an oral workshop presentation at the annual North American CF Conference, the first time that Cystic Fibrosis Canada was represented in this way at this conference.



A photograph of a man and a woman walking a large dog in a grassy field. The woman is on the left, wearing a striped shirt and dark pants, holding an orange. The man is on the right, wearing a black shirt and jeans, wearing sunglasses. The dog is a large breed, possibly a Weimaraner, and is standing on the right. The background is a lush green field with trees in the distance.

# REGISTRY

In July 2016, the Registry was designated as a stand-alone program at Cystic Fibrosis Canada demonstrating our long-standing commitment to the Canadian Cystic Fibrosis Registry (CCFR). As the only source of national CF clinical information used in support of research and clinical care, we are incredibly grateful for the continued participation of CF patients who consent to having their data submitted, and the exceptional effort and contribution from CF clinic team members who collect and enter the data.

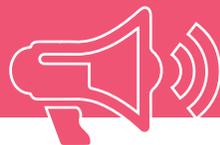
The 2014 Canadian CF Registry Annual Report was published in July 2016 in both English and French and made publicly available online on social media and on Cystic Fibrosis Canada's website. **Highlights from the 2014 report include:**

- ✓ **There are over 4,100 patients in Canada that attend one of 42 CF clinics**
- ✓ **Almost 60% of Canadians living with CF are adults**
- ✓ **The oldest CF patient is nearly 80 years old**
- ✓ **Over 40% of all new CF diagnoses were made through newborn screening programs**
- ✓ **The estimated median age of survival is 51.8 years\***

In August 2016, the Registry team (Dr. Anne Stephenson, Medical Director of the Registry, and Dr. Denise Mak, Data & Analytics Director of the Registry), hosted a live interactive webinar to discuss updates to the CCFR and a brief highlight on upcoming projects.

*\*As of 2015, the estimated median age of survival is 52.1 years.*

# ADVOCACY



Advocacy remains a top priority and an essential component of Cystic Fibrosis Canada's work. We strive to influence decision-makers and ensure the insight, experience and expertise of patients with cystic fibrosis are considered.

Cystic Fibrosis Canada made powerful patient submissions to the Canadian Agency for Drugs and Technologies in Health (CADTH) and to British Columbia's PharmaCare for **Quinsair™**, and to INESSS in Quebec for an **Orkambi™** review. **CADTH recommended Quinsair™ in November 2016.** Cystic Fibrosis Canada has also made pre-budget submissions to Nova Scotia, Alberta, PEI and Quebec with a focus on mental health and care transitions.

Cystic Fibrosis Canada coordinated the creation, by Canadian CF clinicians, of managed care criteria for Orkambi™ to help decision-makers feel confident that its use would be in the best interest of both our patient population and our public drug programs. Unfortunately, CADTH's recommendation for Orkambi™ was negative. Cystic Fibrosis Canada expressed disappointment, noting that the decision was flawed and met to discuss solutions with representatives of the pan-Canadian Pharmaceutical Alliance (pCPA) and CADTH in early 2017.

Subsequent to a meeting with Ontario's Ministry of Health and Long-Term Care (MOHLTC) TOBI podhaler was approved in Ontario.

## NEWBORN SCREENING

A Cystic Fibrosis Canada co-authored study reinforced the benefits of newborn screening and garnered media attention in Quebec. A meeting on the topic took place with the QC Ministry of Health in February 2017.



## THE ADULT CYSTIC FIBROSIS ADVISORY COMMITTEE

The Adult Cystic Fibrosis Advisory Committee has five new prospective members and two new areas represented (Manitoba and PEI) for a total of 16 members. During 2016/2017, the committee met several times and provided feedback and support for Cystic Fibrosis Canada's activities on patient care and treatment.

# FUNDRAISING, PARTNERS & CHAPTERS

## KIN CANADA

In 2016, Kin Canada raised more than **\$1.1 million**, once again demonstrating their passion to find a cure for CF and reinforcing the strength of our incredible partnership that began in 1964. From coast to coast Kin members continued to fundraise and enthusiastically participated in the CARSTAR® Walk to Make Cystic Fibrosis History, helping raise funds and awareness for the CF cause. We continue to be thankful and proud to be aligned with such an incredible national partner and look forward to surpassing the cumulative \$45 million fundraising milestone in 2017.

## LAWN SUMMER NIGHTS

In 2016, Lawn Summer Nights (LSN), one of our most successful CF community events, hosted five new locations for a total of 12 lawn bowling events across the country. The unique lawn bowling fundraiser raised more than **\$550,000** with an exciting plan for expansion in 2017. Since the inaugural event in 2009, LSN has officially raised more than **\$2 million** for CF Canada!

## RAISING FUNDS ACROSS CANADA

Each year Cystic Fibrosis Canada's walk event makes history! In 2016 the CARSTAR® WALK TO MAKE CYSTIC FIBROSIS HISTORY raised an outstanding **\$3.5 million** for Canadians living with CF. Thank you to all who participated! In 2017, we hope to make history once again! Visit [www.cysticfibrosis.ca/walk](http://www.cysticfibrosis.ca/walk) to register, donate or fundraise on May 28, 2017.

## SHINERAMA

Since 1964 student leaders have committed to helping Canadians with CF by spreading the word about how to support our cause and hosting unique events and fundraisers both on and off campus. In 2016, students from 45 university and college campuses across Canada raised an incredible **\$666,000+** for CF Canada! We are so excited to work with such outstanding students year after year.

## ONE TEAM

Cystic Fibrosis Canada has more than 50 Chapters of dedicated volunteers who help raise awareness and funds in support of cystic fibrosis research, advocacy and clinical care through a variety of outstanding community events.



## 2016/2017 FINANCIALS

Cystic Fibrosis Canada is fully committed to transparency and accountability of financial information. We are in a strong financial position as we continue to strategically invest generous donor dollars into vital CF research and care.

### STATEMENT OF OPERATIONS

(in thousands of dollars)

Year Ended January 31, 2017, with comparative information for 2016

	2017	2016
<b>Revenue</b>		
Chapter	\$12,037	\$11,683
Bequests	956	2,411
Leadership Gifts and Sponsorship	1,205	1,279
Kin Canada	1,186	1,069
Shinerama	666	862
Royalties	722	522
Other	161	219
	<b>16,933</b>	<b>18,045</b>
Less direct fundraising costs	4,667	4,026
<b>Net fundraising revenue</b>	<b>12,266</b>	<b>14,019</b>
<b>Expenses</b>		
<b>Program:</b>		
Research	5,928	6,290
Clinics	2,453	2,370
Quality Improvement Initiative	206	208
Education/Public awareness	1,476	1,414
Advocacy	403	356
Other	110	100
	<b>10,576</b>	<b>10,738</b>
<b>Other:</b>		
Administration	2,785	2,716
Fundraising	1,324	1,097
	<b>14,685</b>	<b>14,551</b>
Excess of expenses over revenue before the undernoted	<b>(2,419)</b>	<b>(532)</b>
<b>Investment Income</b>		
Realized gains on investment	899	1,145
Unrealized gains (losses) on investments	73	(1,201)
Unrealized Derivative Gain (loss) on foreign exchange contracts	4	(28)
	<b>976</b>	<b>(84)</b>
Deficiency of revenue over expenses	<b>\$(1,443)</b>	<b>\$(616)</b>

### STATEMENT OF FINANCIAL POSITION

(in thousands of dollars)

January 31, 2017, with comparative information for 2016

	2017	2016
<b>Assets</b>		
<b>Current Assets:</b>		
Cash and cash equivalents	\$410	\$1,216
Short-term investments	3,510	4,275
Receivables and other assets	841	1,017
	<b>4,761</b>	<b>6,508</b>
Contributions receivable	151	154
Long-term investments	11,156	10,846
Capital assets	95	109
	<b>16,163</b>	<b>17,617</b>
<b>Liabilities and Net Assets</b>		
<b>Current Liabilities:</b>		
Accounts payable and accrued liabilities	637	579
Deferred Revenue	182	213
	<b>819</b>	<b>792</b>
Long-term Deferred Contributions	<b>394</b>	<b>432</b>
<b>Net Assets:</b>		
Endowment	94	94
Internally restricted for research and clinics'	11,220	11,598
Unrestricted	3,636	4,701
	<b>14,950</b>	<b>16,393</b>
	<b>\$16,163</b>	<b>\$17,617</b>

<sup>1</sup> The research fund which amounts to 11,220 as of January 31, 2017 (2016 - \$11,598) represents commitments for research and clinic grants and initiatives, which are scheduled to be paid out in varying amounts during the next three years, ending January 31, 2020.

During the past year, a total of \$7,189 (2016 - \$7,530) was spent directly on research, clinic grants and initiatives.

## STATEMENT OF CHANGES IN NET ASSETS

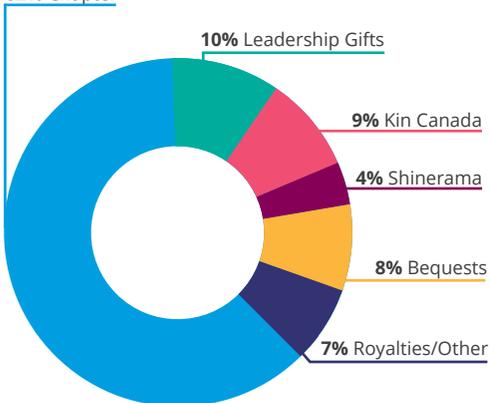
Year ended January 31, 2017, with comparative information for 2016  
(in thousands of dollars)

	Endowment	Internally restricted for research and clinics	Unrestricted	2017 Total	2016 Total
Net assets, beginning of year	\$94	\$11,598	\$4,701	\$16,393	\$17,009
Excess (deficiency) of revenue over expenses	-	-	(1,443)	(1,443)	616
Transfer between funds	-	(378)	378	-	-
Net assets, end of year	\$94	\$11,220	\$3,636	\$14,950	\$16,393

## STATEMENT OF FUNDRAISING REVENUE

(Net of direct fundraising costs)

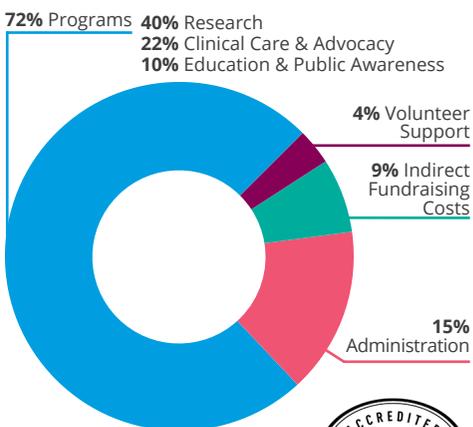
62% Chapter



Note: Fundraising revenue excludes realized and unrealized gains / losses on investments

## USES OF FUNDS

(Excludes direct fundraising costs)



Complete audited financial statements are available on our website at [cysticfibrosis.ca](http://cysticfibrosis.ca).

*Thank you  
to our major  
partners*



**Kin Canada**  
Kinsmen • Kinettes • Kin

**\$1.1 million +**



**healthpartners**  
partenaires santé

Charités at work • la philanthropie au travail



**federatedHEALTH**  
CHARITIES

**HealthPartners and  
Federated Health  
Charities contributed**

**\$295,000**



**CARSTAR**  
Collision & Glass Service

**CARSTAR Automotive  
Canada Inc.  
contributed almost**

**\$284,000**

**SIEMENS**

**Siemens Canada  
raised**

**\$143,000**

**Advocis®**

The Financial Advisors Association of Canada

**Advocis® members  
gave**

**\$92,000**

**PartyCity**

**National Partner**

**\$56,000**

The generosity of our partners allows us to continue to support and invest in life saving CF research and care. We are profoundly grateful for the support from our major partners that are working with us towards our vision of a world without cystic fibrosis.



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



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[@CFCanada](https://twitter.com/CFCanada)



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[instagram.com/cfcanada](https://instagram.com/cfcanada)



**Cystic Fibrosis**  
**Fibrose kystique**  
**Canada**

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