

A World Without Cystic Fibrosis

2015/2016 ANNUAL REPORT

Marc LePage
Team Leader

Marc, Adult with CF



Cystic Fibrosis
Fibrose kystique
Canada

Cystic fibrosis is the most common fatal genetic disease among 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. 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)
Ron Anderson

Ross Drake
Robert Sankey
Stuart Hodge
Douglas Ingersoll

Carol Ann Kairns
Leona Pinsky
Ian Thompson
Claude Provencher

MESSAGE FROM OUR PRESIDENT AND CEO

ONE CFocus. Last year began with a new cohesive theme across Cystic Fibrosis Canada to unite as one team in our vision for a world without cystic fibrosis (CF) and we never looked back.

We created a cutting-edge five-year strategic plan - *One CFocus 2020 to END CF*. This plan provides a clear path for future advancements in achieving Cystic Fibrosis Canada's goals, objective and priorities. Every action and initiative we undertake finds its inspiration in our strategic directions that put Canadians with CF, their families, donors and volunteers first.

We were awarded with Imagine Canada's Standards Program accreditation and we joined a growing community of 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: board governance; financial accountability and transparency; fundraising; staff management; and volunteer involvement.

Over the next five years we are committed to raising an additional \$15 million. These funds will support clinical care resources with a major focus on our ever-growing CF adult population and the Program for Individualized Cystic Fibrosis Therapy. This program will help researchers accelerate the discovery of new treatments and determine the most effective, personalized therapies for people living with CF.

Thank you for all that you do to END CF. Our successes and progress would be impossible without our coast-to-coast network of volunteers, partners and donors. We continue to turn hope into reality for Canadians living with cystic fibrosis.

Together, let's END CF.



Norma Beauchamp,
President and CEO



MESSAGE FROM OUR CHAIR

Thanks to the dedication and commitment of our researchers, clinicians, partners, donors and volunteers working in every corner of the country as we continue to power our mission forward.

This year Cystic Fibrosis Canada undertook a comprehensive review of our strategic plan, consulting with people from across the organization and from all of our constituent stakeholders in order to set out the direction the organization will take over the next five years.

Our new strategic plan calls for strengthening our core initiatives and sets transformative goals, focusing on research, care, advocacy and fundraising. Our objective is to continually improve our capabilities so that we can continue to enhance the quality of life for all Canadians with cystic fibrosis.

We are also collaborating with other CF organizations around the world to work more closely in our shared cause to change the face of this disease.

As we look forward on our journey to END CF, we know there will continue to be many challenges, but also great opportunities. With the remarkable support from and commitment of our community I am confident that we are moving closer to our ultimate goal, a world without cystic fibrosis.

Jim Mountain,
Chair



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



We invested more than **\$5.3 million** in cystic fibrosis research, including grants to support innovative science across a broad spectrum of areas, to improve the health and quality of life of Canadians living with CF, and bridge the gap between research and clinical care.

PROGRAM FOR INDIVIDUALIZED CYSTIC FIBROSIS THERAPY

In October 2015, Cystic Fibrosis Canada partnered with the SickKids Foundation to create the Program for Individualized Cystic Fibrosis Therapy, which involves a multi-year commitment to raise \$7.5 million.

The program will address the complexity and varying severity of CF that is influenced by factors such as type of genetic mutation, environment and genetic background. A personalized medicine approach will ensure that each individual with CF has access to the therapies that will work best for them.

2015/2016 Research Highlights

More than \$5.3 million awarded to **46** studies, **24** fellows and students, and **8** targeted research programs and partnerships.

Invested over **\$1.6 million** in **18 CF infection studies (the largest area of funded research)** on topics including antibiotic resistance and drug development.

“It’s clear that not all CF patients will respond well to the same treatment so we need to be able to identify those people who will respond well to new therapies as they are developed. We will soon be able to compare multiple treatments in lung cells grown from stem cells to determine whether potential therapy will work for a particular individual with CF.”

Dr. Christine Bear, Senior Scientist, Molecular Structure & Function research program, SickKids

PROGRAM FOR INDIVIDUALIZED CYSTIC FIBROSIS THERAPY



SickKids



CLINICAL CARE



In 2015/2016 we invested more than **\$2.2 million** in funding to **42** cystic fibrosis (CF) clinics and associated outreach centres; transplant programs; the **Quality Improvement Learning and Leadership Collaborative (LLC)**; and the **Canadian Cystic Fibrosis Registry**.

Now in its third year, Cystic Fibrosis Canada's Quality Improvement Learning and Leadership Collaborative (LLC) has had a total of **12** clinics participate – more than a quarter of all Canadian CF clinics

CANADIAN CF REGISTRY HIGHLIGHTS

In April 2015, a newly redesigned and updated Canadian CF Registry was launched that provides clinics with real-time access to data and has many new features including reporting and analytical tools to help clinics monitor and understand the patient population they care for. The updated system also includes enhanced security, improved French language support and additional functionality to better support the Canadian CF community.

Other insights include:

- Over **4,100 Canadians** received care at one of 42 CF clinics across the country
- **34 CF patients** received transplants in 2014
- There were **120 new diagnoses made in 2014**: 52 were through newborn screening and 18 were over 18 years of age



Sophia

Accreditation site visits took place in Ontario, Newfoundland, and Quebec

ACCORDING TO THE LATEST CANADIAN CYSTIC FIBROSIS REGISTRY DATA (2010 - 2014), THE PREDICTED MEDIAN AGE OF SURVIVAL IS

51.8 YEARS

ADVOCACY



Megan, Adult with CF

NEWBORN SCREENING

Every province and territory in Canada has committed to newborn screening for CF, except Quebec. In 2015, Cystic Fibrosis Canada continued to engage the Quebec government regarding the importance of newborn screening. We conducted a study with CF clinicians that demonstrated that those identified with CF at birth have fewer lung infections, reduced hospitalizations and better nutritional status. Another health economics study revealed that it is also more cost effective, from the perspective of the public health system, than not implementing newborn screening.

ORKAMBI™ APPROVAL

On January 26, 2016 Health Canada announced a Notice of Compliance (NOC) for ORKAMBI™, approving the drug for use in Canada. This gives Canadians with CF ages 12 and older who have two copies of the *F508del* mutation a chance to gain access to this breakthrough treatment.

Cystic Fibrosis Canada made a powerful patient submission to the Canadian Agency for Drugs and Technology (CADTH) highlighting the importance of equitable and affordable access to ORKAMBI™. Following its review, CADTH will send a recommendation to participating public drug programs, the next step in the approval process. Access to ORKAMBI™ is one of our key priorities.

ENGAGING POLITICAL DECISION-MAKERS

We continue to raise awareness amongst political decision-makers about CF and the importance of affordable and equitable access to drugs and treatments. This year Cystic Fibrosis Canada met with elected politicians across Canada, including the Minister and Deputy Minister of Health and Wellness in Nova Scotia, and the Deputy Minister of Health and Long Term Care in Ontario. We also held a Legislative Reception in Ontario, and collaborated with other health charities to host an all-candidates' debate focused on health care and rare diseases during the provincial election in Newfoundland and Labrador.



FUNDRAISING, PARTNERS & CHAPTERS

“Kin Canada has been answering the call for over 52 years as partners of Cystic Fibrosis Canada. Our inspiration is derived from the CF community’s fight and determination towards a world without cystic fibrosis. Kin Canada’s network spans across the country and we are committed to ending CF.”

Grant Ferron
Executive Director, Kin Canada



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.

RAISING FUNDS ACROSS CANADA

Our signature events help fund life-sustaining cystic fibrosis research and care. The 2015 CARSTAR's Great Strides™ Walk for Cystic Fibrosis Canada was a huge success. More than 7,000 participants came together at 75 locations across Canada in 66 communities and raised more than \$3.5 million making it our largest and most successful fundraiser.

Shinerama, Canada's largest post-secondary fundraiser in support of Cystic Fibrosis Canada, brings over 35,000 student volunteers from 50 Canadian universities and colleges across the country together to make a difference in the lives of those battling cystic fibrosis. In 2015, Shinerama, raised almost \$900,000 for cystic fibrosis research and care.

Lawn Summer Nights, one of our most successful CF community events, raised almost \$500,000 in seven cities across Canada. Since 2009, the event has grown in popularity and has exciting plans for expansion in 2016.



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.

The commitment and dedication of our partners allow us to continue to make important investments in life-sustaining CF research and care.

Thank you



**Kin Canada raised more than
\$1 million**



**HealthPartners and Federated Health Charities contributed
\$300,000**



**CARSTAR Automotive Canada Inc. contributed almost
\$200,000**



**Advocis® members gave
\$115,000**



**Siemens Canada raised
\$110,000**

2015/2016 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, 2016, with comparative information for 2015

	2016	2015
Revenue		
Chapter	\$11,683	\$12,126
Bequests	2,411	490
Leadership Gifts and Sponsorship	1,279	1,567
Kin Canada	1,069	1,204
Shinerama	862	953
Royalties	522	347
Other	219	155
	18,045	16,842
Less direct fundraising costs	4,026	4,295
Net fundraising revenue	14,019	12,547
Expenses		
Program:		
Research	6,290	5,699
Clinics	2,370	2,285
Quality Improvement Initiative	208	318
Education/Public awareness	1,414	1,064
Advocacy	356	444
Other	100	100
	10,738	9,910
Other:		
Administration	2,716	2,586
Fundraising	1,097	860
	14,551	13,356
Excess of expenses over revenue before the undernoted	(532)	(809)
Investment Income		
Realized gains on investment	1,145	835
Unrealized gains (losses) on investments	(1,201)	526
Unrealized Derivative loss on foreign exchange contracts	(28)	(86)
	(84)	1,275
Excess (deficiency) of revenue over expenses	\$(616)	\$466

STATEMENT OF FINANCIAL POSITION

(in thousands of dollars)

January 31, 2016, with comparative information for 2015

	2016	2015
Assets		
Current Assets:		
Cash	\$709	\$751
Short-term investments	4,782	4,802
Receivables and other assets	1,017	735
	6,508	6,288
Contribution receivable	154	154
Long-term investments	10,846	11,513
Capital assets	109	123
	17,617	18,078
Liabilities and Net Assets		
Current Liabilities:		
Accounts payable and accrued liabilities	579	364
Deferred Revenue	213	238
	792	602
Long-term Deferred Contributions	432	467
Net Assets:		
Endowment	94	94
Internally restricted for research and clinics ¹	11,598	11,753
Unrestricted	4,701	5,162
	16,393	17,009
	\$17,617	\$18,078

¹ The research fund which amounts to \$11,598 as of January 31, 2016 (2015 - \$11,753) 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, 2019.

During the past year, a total of \$7,530 (2015 - \$7,133) was spent directly on research, clinic grants and initiatives.

STATEMENT OF CHANGES IN NET ASSETS

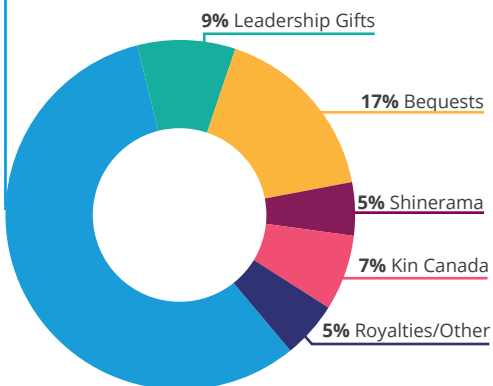
Year ended January 31, 2016, with comparative information for 2015
(in thousands of dollars)

	Endowment	Internally restricted for research and clinics	Unrestricted	2016 Total	2015 Total
Net assets, beginning of year	\$94	\$11,753	\$5,162	\$17,009	\$16,543
Excess (deficiency) of revenue over expenses	-	-	(616)	(616)	466
Transfer between funds	-	(155)	155	-	-
Net assets, end of year	\$94	\$11,598	\$4,701	\$16,393	\$17,009

STATEMENT OF FUNDRAISING REVENUE

(Net of direct fundraising costs)

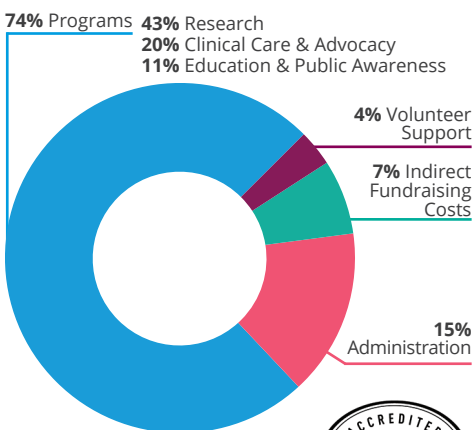
57% Chapter



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.

*Working towards our
vision of a world
without cystic fibrosis*



cysticfibrosis.ca

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