

Blake, CF Champion

A World Without Cystic Fibrosis



Cystic Fibrosis
Fibrose kystique
Canada

2017/2018 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

Mitch LePage (Chair)

Leona Pinsky (Vice Chair)

Stephen McCourt (Chair of Finance)

James Mountain

Ron Anderson

Barbara M. Hill

Robert Sankey

Stuart Hodge

Lee Burry

Ian Thompson

Françoys Levert

Claude Provencher

MESSAGE FROM OUR INTERIM CO-CEOs



Cystic Fibrosis Canada was established in 1960 by a group of parents of children with CF, who were told that there was nothing that could be done for their children, who were expected to not live to be old enough to attend school. From that moment on, the cystic fibrosis (CF) community in Canada has united in an effort to support one another and committed to finding a cure or control for cystic fibrosis. This commitment has strengthened each year, and has materialized in our organization being an internationally recognized leader in the fight against CF.

Three years into the ONE CFocus 2020 Strategic Plan, Cystic Fibrosis Canada continues to be an internationally recognized leader in our mission to end CF. Guided by the strategic direction established by our colleagues and peers, and through strong partnerships, we are well-positioned to continue our momentum and achieve our goals.

The 2016 Canadian Cystic Fibrosis Registry shows that our median age of survival is steadily increasing and is among the highest in the world at 53.3 years. As this figure climbs, we also recognize that there are still far too many young people losing their lives to this disease, and we will continue our work to improve the quality of life and health outcomes for all living with CF.

Our investments in advocacy, research and care demonstrate our accomplishments, commitment and progress. These life-saving investments make high quality care and individualized treatment accessible to our community, and are enhanced by our collaborations with international colleagues, corporate partners, and the Canadian medical community. We know that investing in research is paramount in improving the health and quality of life of Canadians living with CF, and in 2017 we invested over \$5 million in leading-edge, innovative research including grants, fellows and studies.

Thank you to our partners, sponsors, donors, volunteers and community members from across the country. Without you, we would not be able to achieve our goal of a world without CF.

Handwritten signatures of Jennifer Nebesky and Jeffrey D. Beach in black ink. Jennifer's signature is on the left and Jeffrey's is on the right.

Jennifer Nebesky and Jeffrey D. Beach
Interim Co-CEOs
Cystic Fibrosis Canada

MESSAGE FROM OUR CHAIR



Three years ago, Cystic Fibrosis Canada launched ONE CFocus 2020, our strategic plan to end cystic fibrosis (CF) and we can be proud of our progress in 2017. As we enter the midway point of the plan, I'm confident that our organization will continue to realize great achievements toward a cure or control for cystic fibrosis.

2017 was an exciting time for our community; in May, our Cystic Fibrosis Awareness Month campaign focused on engaging a new audience online, generating 11,000 new contact opportunities; in June, newborn screening was announced in Quebec. With the release of the latest Canadian Cystic Fibrosis Registry report, we celebrated the news that the **median age of survival is now 53.3 years**. Despite these successes, we still face challenges in accessing lifesaving medications for individuals living with cystic fibrosis. In response, our advocates are urging governments and other decision-makers to make these medications accessible.

We are also very excited about our ambitious fundraising campaign focused on the development of individualized therapies and the expansion of CF healthcare resources to support all people living with cystic fibrosis.

In 2017, we wished farewell to our President and CEO, Norma Beauchamp. I would like to sincerely thank Norma for her dedication to our cause. As we complete the process of selecting a new leader, our hard-working staff continues to focus on the achievement of our strategic objectives.

On behalf of the Board of Directors, I would like to thank our community of supporters, researchers, clinicians, partners, donors, volunteers, CF families, dedicated staff and most importantly, our friends and family living with cystic fibrosis. You continue to motivate us to achieve our vision of ***a world without cystic fibrosis***.

With appreciation,

A handwritten signature in black ink that reads "Mitch LePage". The signature is written in a cursive, flowing style.

Mitch LePage
Chair
Cystic Fibrosis Canada

RESEARCH



In 2017-2018, Cystic Fibrosis Canada invested over \$5 million in leading-edge research, supporting 50 research projects, 23 post-doctoral fellowship and studentship awards, two national core facilities, and targeted research programs and partnerships aimed at advancing CF knowledge and achieving excellence in the quality of care for CF patients. The single largest area of funded research was infections, a major contributor to lung disease, the leading cause of illness and death in people with CF. Cystic Fibrosis Canada invested almost \$1.3 million in 17 CF infection studies.

NEW TARGETED RESEARCH PROGRAM TO ADDRESS CF PRIORITY AREAS

Cystic Fibrosis Canada launched a new research program in 2017-2018 with the aim of funding research focused specifically on two priority areas: cystic fibrosis-related diabetes and gastrointestinal symptomatology. Projects funded through this program must have a high relevance to people with CF and the potential to impact patient care or health by the end of the two-year funding period. Based on the recommendations of the Scientific Review Panel, one project focusing on gastrointestinal inflammation in CF was selected for funding beginning in 2018-2019.

CATHLEEN MORRISON RESEARCH IMPACT AWARD

Cathleen Morrison was Cystic Fibrosis Canada's longest-serving Chief Executive Officer from 1981-2011. To recognize her significant contributions to the cause, Cystic

Fibrosis Canada has introduced the Cathleen Morrison Research Impact Award. The award recipient is selected by the CF community members who participate on Cystic Fibrosis Canada's Scientific Review Panel. The panel reviews all research grant applications, and the applicant who earns the highest score, with the greatest potential to impact those living with CF, receives this award. Cystic Fibrosis Canada was pleased to present the 2018-2019 Cathleen Morrison Research Impact Award to Dr. David Thomas and Dr. John Hanrahan at McGill University. Their work aims to identify new CFTR therapeutics and therapeutic combinations.

RESEARCH FELLOWSHIP AWARD RECOGNIZES CONTRIBUTIONS TO CF BY DR. JENNIFER STURGESS

Cystic Fibrosis Canada has introduced a second research award, the Jennifer and Robert Sturgess Fellowship. In the 1970s, Dr. Sturgess was a researcher at The Hospital for Sick Children, where she focused on lung diseases, particularly CF. Her work was supported, in part, by Cystic Fibrosis Canada. She was a highly regarded thought leader in CF, served as a consultant to the World Health Organization and the National Institutes of Health, among others. To honour Dr. Sturgess' legacy in CF research, her family has made a generous donation to Cystic Fibrosis Canada which will be recognized by designating a CF research fellow each year for seven years. This year's Jennifer and Robert Sturgess Fellow is Dr. Ana Blanchard, at The Hospital for Sick Children.

HEALTHCARE PROGRAMS



Cystic Fibrosis Canada continues to support the network of 42 CF clinics in the country, and in 2017, awarded Clinic Incentive grants to all clinics, to ensure availability of CF-specific knowledge and expertise.

The **Accreditation Site Visit program** ensures accountability for the funding that Cystic Fibrosis Canada provides, by reviewing clinics' programs on a rotational basis, ensuring that the money that is awarded is being expended to its best advantage, and according to policy. In 2017, Accreditation Site Visits were conducted at clinics in Quebec, British Columbia and Ontario, and five healthcare professionals participated for the first time on review teams, expanding the pool of viable accreditors and reinforcing the network of knowledge across the country.

Initially launched as a three-year program, Cystic Fibrosis Canada's **Quality Improvement Learning and Leadership Collaborative (LLC)** was very successful, and by popular demand was extended with the addition of a fourth year. Activity in this ground-breaking initiative has now formally been completed, but many clinics have sustained – and perpetuated – their quality improvement work. In total, there were 16 clinics that participated – over a third of all clinics in Canada.

New in 2017, Cystic Fibrosis Canada launched two one-time granting opportunities to enhance CF clinical care in Canada, **the Cystic Fibrosis Canada CFRD Training Support Award**, to encourage knowledge and enhance treatment of Cystic Fibrosis-Related Diabetes; and the **Air Canada Foundation – Cystic Fibrosis Canada Clinic Support Grant**, to support and improve patient care in the hospital setting. Both awards have been well-received, and several of each opportunity have been awarded.



REGISTRY

In 2017, Cystic Fibrosis Canada published two Registry Annual Data Reports which was unusual but expected due to the major system upgrades completed in 2015. The Registry Annual Data Report describes the demographics, trends and other statistics of the Canadian CF population and highlights the progress made in CF research and care.

The 2015 and 2016 Canadian CF Registry Annual Reports were published in both English and French, and made publically available online on social media and on Cystic Fibrosis Canada's website.

Highlights from the 2016 Annual Data Report include:

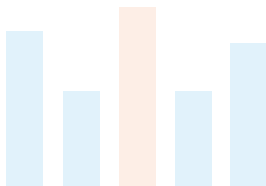
- ✓ There are over 4,200 patients in Canada that attend one of 42 CF clinics
- ✓ 60% of Canadians living with CF are adults
- ✓ More than half of all new CF diagnoses were identified through provincial newborn screening programs
- ✓ The estimated median age of survival is 53.3 years



The incredible work and support from CF clinic team members as well as the continued participation of CF patients contribute enormously to the growing success of the Canadian CF Registry. Thank you to all involved!

INTERNATIONAL COLLABORATION WITH UK'S CF TRUST

Cystic Fibrosis Canada and the Cystic Fibrosis Trust are thrilled to announce an international collaboration on the paediatric feasibility study for the Cystic Fibrosis Trust's SmartCareCF program. The study, referred to as CLIMB-CF, will examine the use of remote home monitoring for children with CF, and is being led by researchers from Imperial College London, UK. This international partnership between two of the largest cystic fibrosis (CF) charities in the world will be the charities' first collaboration together and will combine resources and expertise from both organizations.



ADVOCACY



Government relations and advocacy is a top priority for Cystic Fibrosis Canada to ensure excellent clinical care, as well as equitable and affordable access to medicines and treatments.

ACCESS TO CF MEDICINES

Never has there been such promise in the pipeline. With over 143 drugs in development – 45 of which are CFTR modulating therapies – there is real hope that there may be a control for CF in our lifetimes. Cystic Fibrosis Canada is working with advocates, patients, caregivers and clinicians across the country to ensure that the life-changing medication Orkambi, is available to those who need it. Throughout 2017, we undertook numerous government relations and advocacy activities to advance access to Orkambi across the country:

- ✓ Ran a highly successful Cystic Fibrosis Awareness Month campaign in which 12,601 Canadians signed a petition calling for public coverage of Orkambi.
- ✓ Corresponded and met with Canadian Health Ministers, met with the Human Services Caucus Policy Committee in Saskatchewan, and held a well-attended rally at the British Columbia Legislature.
- ✓ Called on the pan-Canadian body, the Canadian Agency for Drugs and Technologies in Health (CADTH), to accept evidence other than that from randomized clinical trials, such as real world data collected after people have been on the drug for some time. In the fall of 2017, CADTH changed its policy to allow for other forms of data, and as a result, Vertex, the manufacturer of Orkambi, has once again submitted data to CADTH for review as of January 2018.

Our efforts now aim to ensure that CADTH fast-tracks its review process of Orkambi, as well keeping pressure on provincial governments to expedite their review and reimbursement processes.

ACCESS TO CF CARE AND SUPPORTS

Since 2006, CF Canada has been calling on the Quebec government to adopt newborn screening. In 2017, Quebec was the last province to commit to newborn screening for CF. On June 8, 2017 Quebec announced that they would be adding CF to their newborn screening panel. The program is expected to launch in spring 2018.

We received funding from the Government of British Columbia and a matching donor to embark upon a mental health project in the province. As well, we are developing *National Standards in Canada to Successfully Transition Transplant Patients with Cystic Fibrosis*. Part of this initiative is to understand the current challenges and gaps in care, as well as provide educational webinars for patients and caregivers.

ENGAGING THE CF COMMUNITY

Cystic Fibrosis Canada is growing its national advocacy program. In 2017, we had approximately 15 volunteer advocates across the country; through active recruitment efforts we grew the program 50 volunteers across nine provinces. The national advocacy program continues to recruit more advocates and expand advocacy training offerings across the country.

Also in 2017, the Adult Cystic Fibrosis Advisory Committee turned its focus to reviewing and renewing the organization's resources for fertility, children with a parent with CF, and for those transitioning from pediatric to adult care. This work will continue throughout 2018-2019.

FUNDRAISING, PARTNERS & CHAPTERS



KIN CANADA

Within the first few months of 2017, Kin Canada surpassed the \$45 million fundraised milestone which has contributed to the advancement of CF research, healthcare and advocacy. Kin members came out in full force at the 2017 Walk to Make Cystic Fibrosis History, raising more than \$560,000 by donating, fundraising, supporting and organizing various walks across the country. **Kinsmen and Kinettes raised an overall total of more than \$1.2 million** this past year.

LAWN SUMMER NIGHTS

Lawn Summer Nights (LSN) had a record-breaking year in 2017 **raising over \$700,000** – their best fundraising year yet! In 2017, they expanded to three new cities, and also added an additional event in Stratford, bringing their total event count to 16 lawn bowling tournaments across the country. Since their first event in Vancouver in 2009, LSN has raised over \$2.7 million for Cystic Fibrosis Canada, and they have big plans for their #tenthLAWNnual season in 2018.

THE WALK TO MAKE CYSTIC FIBROSIS HISTORY

The Walk to Make Cystic Fibrosis History is Canada's largest cystic fibrosis fundraising event, taking place in over 70 communities and virtual locations across the country. In 2017, the Walk to Make Cystic Fibrosis History **raised over \$3.6 million for CF research, care and advocacy.** This year on May 27, 2018 we celebrate its 14th year, and funds raised will support world-class CF research, advocacy for high-quality individualized CF care, and access to medication. For more information about the walk, please visit cysticfibrosis.ca/walk

SHINERAMA

This 54 year program is Canada's largest post-secondary fundraising event for cystic fibrosis. Shinerama engages over 30,000 students and volunteers across the country in over 40 universities and colleges, and has raised over \$27 million since its inception in 1964. **The 2017 Shinerama campaign raised over \$600,000 for CF Canada.** Cystic Fibrosis Canada works directly with over 70 student leaders to help facilitate and manage local Shinerama events. Funds raised by the students and faculty help support local chapters, clinics and care. For more information about the Shinerama program or how to get involved, please visit shinerama.ca

2017/2018 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, 2018, with comparative information for 2017

	2018	2017
Revenue		
Chapter	\$11,725	\$12,037
Bequests	1,229	956
Leadership gifts and sponsorship	2,167	1,205
Kin Canada	1,257	1,186
Shinerama	670	666
Royalties	552	722
Other	357	161
	17,957	16,933
Less direct fundraising costs	4,460	4,667
Net fundraising revenue	13,497	12,266
Expenses		
Program:		
Research	6,140	5,928
Healthcare	2,808	2,659
Education/Public awareness	1,708	1,476
Advocacy	567	403
Other	110	110
	11,333	10,576
Other:		
Administration	2,960	2,785
Fundraising	1,486	1,324
	15,779	14,685
Excess of expenses over revenue before the undernoted	(2,282)	(2,419)
Investment Income		
Realized gains on investment	863	899
Unrealized gains on investments	61	73
Unrealized derivative gain on foreign exchange contract	0	4
	924	976
Deficiency of revenue over expenses	\$(1,358)	\$(1,443)

STATEMENT OF FINANCIAL POSITION

(in thousands of dollars)

January 31, 2018, with comparative information for 2017

	2018	2017
Assets		
Current Assets:		
Cash and cash equivalents	\$2,115	\$410
Short-term investments	947	3,510
Receivables and other assets	1,109	841
	4,171	4,761
Contributions receivable	151	151
Long-term investments	10,934	11,156
Capital assets	81	95
	15,337	16,163
Liabilities and Net Assets		
Current Liabilities:		
Accounts payable and accrued liabilities	1,169	637
Deferred revenue	217	182
	1,386	819
Long-term deferred contributions	359	394
Net Assets:		
Endowment	94	94
Internally restricted for research and clinics ¹	10,543	11,220
Unrestricted	2,955	3,636
	13,592	14,950
	\$15,337	\$16,163

¹ The research fund which amounts to 10,543 as of January 31, 2018 (2017 - \$11,220) 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, 2021.

During the past year, a total of \$7,157 (2017 - \$6,983) was spent directly on research, clinic grants and initiatives.

STATEMENT OF CHANGES IN NET ASSETS

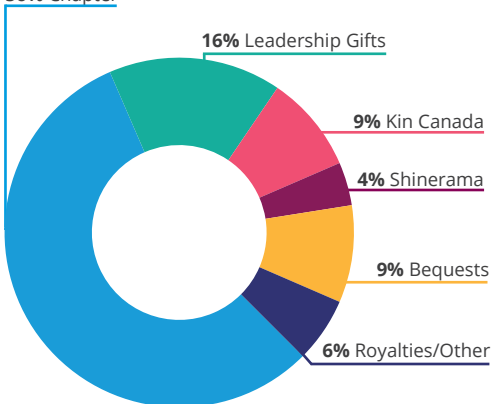
Year ended January 31, 2018, with comparative information for 2017
(in thousands of dollars)

	Endowment	Internally restricted for research and clinics	Unrestricted	2018 Total	2017 Total
Net assets, beginning of year	\$94	\$11,220	\$3,636	\$14,950	\$16,393
Deficiency of revenue over expenses	-	-	(1,358)	(1,358)	(1,443)
Transfer between funds	-	(677)	677	-	-
Net assets, end of year	\$94	\$10,543	\$2,955	\$13,592	\$14,950

STATEMENT OF FUNDRAISING REVENUE

(Net of direct fundraising costs)

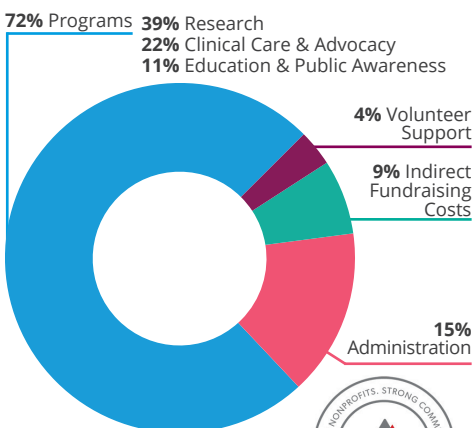
56% Chapter



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.

Thank you to our national partners

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 national partners that are working with us towards our vision of a world without cystic fibrosis.



Kin Canada
Kinsmen • Kinettes • Kin

iii HealthPartners
PartenaireSanté

Charities At Work
La philanthropie au travail



federatedHEALTH
CHARITIES
THE HEART OF THE COMMUNITY



SIEMENS

Advocis®

PartyCity



Paysafe



 cysticfibrosis.ca

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