

Soleil, Ella (CF Champion) and Allegra



Cystic Fibrosis  
Fibrose kystique  
Canada

2018/2019  
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.

For us, it's a matter of *when* a cure or control for cystic fibrosis will be discovered, not *if*. Cystic Fibrosis Canada is one of the world's leading 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)  
Ron Anderson  
Lee Burry

Louise Desjardins  
Kathryn Deuchars  
Barbara M. Hill  
Stuart Hodge  
François Levert

James Mountain  
Hugh O'Brodvich  
Claude Provencher\*  
Robert Sankey  
Ian Thompson

\*Resigned in May 2018

## MESSAGE FROM OUR PRESIDENT AND CEO

Before I joined Cystic Fibrosis Canada, I was aware of the organization's reputation for impactful and strategic investments, leading to life-altering change. Now, almost a full year into my tenure, it is clear to me that the strides made in the treatment of cystic fibrosis (CF) worldwide are in large part due to the contributions of Cystic Fibrosis Canada.

In this report, you will read about some of our achievements over the last year, including the launch of two new initiatives to empower Canadians living with cystic fibrosis to improve their health: the MyCFLifePortal and the Cystic Fibrosis Canada Accelerating Clinical Trials (CF CanACT) Network. These world-class programs are a reminder of our changing and aging patient population, which is a result of the progress in health outcomes for Canadians with CF.

I am inspired by the fact that today we know more about cystic fibrosis than we ever have before. With over \$5 million invested in research and care in 2018/19, and \$258 million over our 60 year history, advancing knowledge of CF remains a top priority.

We remain committed to our advocacy work as well. In November 2018, we hosted a successful day at the Legislature in Regina which had a wonderful outcome. Following this event, a commitment was made by the governments of Saskatchewan, Alberta and Ontario to collectively agree on prescribing criteria for Orkambi for pediatric patients. While we wish that this criteria was more inclusive, we know that some of our community will be able to access this medication and this is a step in the right direction.

As we draw closer to the conclusion of our current strategic plan, One CFocus 2020, and with significant changes in the CF landscape, we are putting careful thought into our vision for the future and how we can make the greatest impact.

Thank you to our partners, sponsors, donors, volunteers and community members from across Canada. We simply could not do this without you.

Sincerely,



**Kelly Grover**  
President and CEO  
Cystic Fibrosis Canada



## MESSAGE FROM OUR CHAIR

Cystic Fibrosis Canada is approaching the end of our strategic plan, ONE CFocus 2020, our plan to end cystic fibrosis (CF). Reflecting on the accomplishments of 2018, we can all be proud of the impact we have made.

Over the past year we welcomed Kelly Grover as President and CEO of Cystic Fibrosis Canada. Kelly's strategic focus for our organization, as well as her approachability and warmth, are precisely the balance we were seeking in our leader and we are grateful that she has joined us.

As a result of Cystic Fibrosis Canada's advocacy efforts, we have witnessed positive developments in Orkambi access in Alberta, Saskatchewan and Ontario. While we should certainly celebrate this achievement, the continued lack of access in the rest of Canada is unacceptable and we call on all remaining provincial Health ministers to adopt these criteria, at a minimum.

The Board of Directors is engaged in a review of current activities and priorities to ensure that our efforts yield the greatest benefit for people living with cystic fibrosis. This strategic clarity work will form the foundation of a new strategic plan where our sights will remain squarely fixed on our vision of a world without cystic fibrosis. Cystic Fibrosis Canada and the Board of Directors are committed to ensuring the long-term sustainability of our organization so that we can continue the legacy of advancements and finish the work started by our founders almost 60 years ago.

On behalf of the Board of Directors, I wish to thank our community of passionate supporters, researchers, clinicians, partners, donors, volunteers, CF families, dedicated staff and most importantly, individuals living with cystic fibrosis. You continue to inspire us and our vision of a world without cystic fibrosis is within sight because of you.

I thank all of you for your support. Together we will end CF.

With sincere thanks,



**Mitch LePage**

Chair

Cystic Fibrosis Canada



# RESEARCH



In 2018-2019, Cystic Fibrosis Canada invested over \$5 million in leading-edge research, supporting 45 research projects, 27 post-doctoral research fellowship and graduate student training 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.

## **CYSTIC FIBROSIS INDIVIDUALIZED THERAPY PROGRAM (CFIT)**

Progress continued unabated on the CF Individualized Therapy program, Cystic Fibrosis Canada's signature partnership with Toronto's Hospital for Sick Children (SickKids). To date 78, volunteers have participated with researchers having collected 66 nasal cultures and 41 stem-cell samples and researchers are on track to complete recruitment of 100 participants by program's end. Program materials are currently available and have been provided to the international CF research community; pharmaceutical collaborators have used CFIT resources to test emerging combinations; new organoid models were developed; and sequencing of the samples is breaking new ground. As part of the CFIT program, 13 research grants have been awarded to scientists across Canada, and several grants for technical workshops, for example, about how to create lung tissue from stem cells.

## **CYSTIC FIBROSIS CANADA ACCELERATED CLINICAL TRIALS NETWORK (CF CANACT)**

Clinical trials are an integral part of the process that brings new therapeutics and better care to Canadians who are living with cystic fibrosis. In July 2018, CF Canada launched CF CanACT to build our capacity to run trials and increase the participation of Canadians living with cystic fibrosis in clinical trials. The CF CanACT network consists of six sites across Canada, with plans to expand in the future. Canadians living with CF interested in specific trials may be referred to one of the existing sites to participate.

## **NEW PARTNERSHIP TO BUILD CF RESEARCH CAPACITY**

In 2018, Cystic Fibrosis Canada partnered with the Canadian Institutes of Health Research (CIHR) Institute of Circulatory and Respiratory Health (ICRH) to jointly fund the *CIHR- ICRH/Cystic Fibrosis Canada 2018 Early Career Investigator Award in CF Research*. The award is designed to support the early career of a promising scientist and to build Canada's research capacity in the area of CF. The 2018 recipient is clinician-scientist, Dr. Jonathan Rayment, working at BC Children's Hospital. Funding will run from 2019-2022.

# HEALTHCARE PROGRAMS



Cystic Fibrosis Canada continues to support the network of 42 CF clinics in the country, and in 2018/19, awarded Clinic Incentive grants to all clinics. Cystic Fibrosis Canada's grants help to ensure continued professional development for clinic personnel, and assist healthcare providers with travel to outreach centres, enabling them to provide CF-specific care in communities that do not have CF clinics.

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 funds awarded are expended to the best advantage, and according to policy. In 2018, Accreditation Site Visits were conducted at four clinics in Ontario and without exception, all four clinics that hosted a visit are providing the highest level of care to their patients, in many cases with limited institutional resources. Healthcare professionals from other CF clinics in Canada participated on review teams, volunteering their expertise to this program, and in turn, ensuring a consistent network and standard of care across the country.

## **Mental Health Pilot Program**

Cystic Fibrosis Canada received a one-time grant from the British Columbia government to benefit British Columbians with CF. Administered by Cystic Fibrosis Canada, the grant enabled the two Vancouver clinics and the two Victoria clinics to engage and enhance the services of mental health practitioners, in addition to the social worker supports already available. This was a pilot initiative, and Cystic Fibrosis Canada looks forward to learning the results and spreading the successes to other CF clinics in the country.



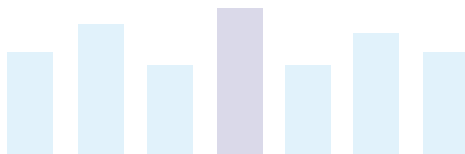
# REGISTRY

In December 2018, Cystic Fibrosis Canada published the 2017 Canadian Cystic Fibrosis Registry Annual Data Report. The Registry is used both by CF clinicians and researchers to improve knowledge of disease patterns and care of patients with CF. The data collected within the Registry can be used to better understand clinic populations, respond to emerging health care issues, develop quality improvement initiatives and track clinical outcomes over time. These efforts can translate to improved outcomes for people with cystic fibrosis.

## Notable insights from the 2017 Annual Data Report include:

- ✓ There are over 4,300 patients in Canada that attend one of 42 CF clinics
- ✓ Nearly 61% of Canadians living with CF are adults
- ✓ More than half of all new CF diagnoses were identified through provincial newborn screening programs
- ✓ Over 50% of those transplanted today can expect to live over 10 more years
- ✓ The estimated median age of survival is 52.3 years
- ✓ Of the Canadians with CF who died in 2017, half were under the age of 33

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.



## MyCFLifePortal

In the fall of 2018, Cystic Fibrosis Canada launched MyCFLifePortal, a secure, online read-only website specifically designed for participating CF patients and their caregivers, enabling them to access their (or their child's) clinical data from the Registry from the comfort of their own home. This website is fully bilingual and includes features such as interactive graphs and summary reports that are also now available to clinic staff. MyCFLifePortal is provided free for any eligible user and participation is completely voluntary.

Prior to the launch of MyCFLifePortal, the Registry data was only accessible to healthcare professionals from the 42 CF clinics who manually enter in data. Patients can now view their data, watch their progress and prepare for clinic visits through better knowledge of their current health status and how it has changed over time. The portal is currently available to a limited number of clinics, with plans to be available at all 42 clinics by the end of 2019.

# GOVERNMENT RELATIONS AND ADVOCACY



## ACCESS TO CF MEDICINES

Access to medicines is one of Cystic Fibrosis Canada's key advocacy priorities. In November 2018, Cystic Fibrosis Canada hosted a Day at the Saskatchewan Legislature. At the MPP reception, Honorable Minister Jim Reiter committed to consult with CF clinicians and his fellow Health ministers in other provinces about creating a prescribing criterion for those who are the most vulnerable, who could potentially benefit from Orkambi. As a result, in **February 2019, Saskatchewan, Alberta and Ontario established prescribing criteria for paediatric patients to determine if patients qualify for public coverage of Orkambi.** Cystic Fibrosis Canada has urged the other provinces to adopt the criteria, at minimum and have called on jurisdictions to also consider access for adults.

**In January 2019, Cystic Fibrosis Canada continued to demonstrate its commitment and leadership on the access to medicines file by hosting a one-day forum, *There's Promise in the Pipeline: Now How Do We Pay for It?*** The forum brought together stakeholders including patients, patient groups, private insurers, researchers, and regulatory and reimbursement bodies to discuss how to improve access and affordability of personalized and precision medicine. Using the Cystic Fibrosis Individualized Therapy Program (CFIT) as an example, we showcased the potential of precision medicine to manage drug budgets while still providing access to needed medications that may help some members of our community live longer and healthier lives.

## ENGAGING THE CF COMMUNITY

Cystic Fibrosis Canada is growing its National Advocacy Program. In 2018, CF Canada had approximately 50 volunteers across the country, today, through active recruitment and the support of our community, the program has grown to over 100 advocacy volunteers. In 2018, the Adult Cystic Fibrosis Advisory Committee (ACFAC) started to develop new resources for three areas of focus: fertility and sexuality, transition of care, and parenting with CF. Additionally, members assisted in the review of the CF transition program (CF STEP) and led the creation of a transition guide template that is intended for use during the transition from paediatric to adult care. In 2018, the committee also developed an eight part webinar series that explores aspects of fertility and family planning, which will be delivered over the course of 2019-2020. The series will provide insights from experts in CF and fertility, as well as people with CF who will share their personal experiences.

## INFORMATION AND REFERRAL PROGRAM

In 2018, CF Canada established a new billingual information request and referral service to help the CF community navigate government and community-based resources. This service assists with inquiries typically related to the following topics: CF diagnosis, CF facts, CF health, clinical, education, employment, finances, government relations and advocacy, global affairs, and research.



# FUNDRAISING, PARTNERS & CHAPTERS



Cystic Fibrosis Canada provides a diverse portfolio of fundraising options to donors; from investing in strategic research projects, planned and monthly giving, community events, corporate partnerships and more. We are extremely grateful to all the donors who have chosen to make a philanthropic gift to our mission.

## ONE TEAM

CF 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.



## COMMUNITY

A tremendous amount of Cystic Fibrosis Canada's success is due in part to the commitment of our community members who volunteer, attend and fundraise for various community events throughout the year. In 2018, **The Walk to Make Cystic Fibrosis History**, Canada's largest CF fundraising event raised over \$3.4 million and saw over 10,000 supporters, including volunteers, donors, partners and participants.

In 2018, regional events significantly contributed to Cystic Fibrosis Canada's overall revenue with signature galas including **Decant, 65 Roses and Fusion** raising a combined total of over \$1 million and **Lawn Summer Nights** raised nearly \$800,000. We are so grateful to the many volunteers who organize and participate in events throughout the year. In addition, the 2018 **Shinerama** campaign raised over \$470,000, with more than 35,000 student volunteers across 39 universities.

## KIN CANADA

For 55 years, Kin Canada has been an undeniable force in the fight against cystic fibrosis. The strength of the Kin support and dedication shines through in the events and fundraisers they host, and in the incredible \$47 million raised for the advancement of CF research, healthcare and advocacy since 1964. In 2018, Kin Canada raised a total of more than \$1.2 million to support our shared mission to end cystic fibrosis.

# 2018/2019 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, 2019, with comparative information for 2018

	2019	2018
<b>Revenue</b>		
Chapter	\$11,886	\$11,725
Bequests	1,373	1,229
Leadership gifts and sponsorship	1,628	2,167
Kin Canada	1,212	1,257
Shinerama	472	670
Royalties	341	552
Other	432	357
	<b>17,344</b>	<b>17,957</b>
Less direct fundraising costs	4,619	4,460
<b>Net fundraising revenue</b>	<b>12,725</b>	<b>13,497</b>
<b>Expenses</b>		
<b>Program:</b>		
Research	6,306	6,140
Healthcare	2,710	2,808
Education/Public awareness	1,892	1,708
Advocacy	684	567
Other	106	110
	<b>11,698</b>	<b>11,333</b>
<b>Other:</b>		
Administration	3,248	2,960
Fundraising	1,503	1,486
	<b>16,449</b>	<b>15,779</b>
Excess of expenses over revenue before the undernoted	<b>(3,724)</b>	<b>(2,282)</b>
<b>Investment Income</b>		
Realized gains on investment	535	863
Change in unrealized gain on investments	(507)	61
	<b>28</b>	<b>924</b>
Deficiency of revenue over expenses	<b>\$(3,696)</b>	<b>\$(1,358)</b>

## STATEMENT OF FINANCIAL POSITION

(in thousands of dollars)

January 31, 2019, with comparative information for 2018

	2019	2018
<b>Assets</b>		
<b>Current Assets:</b>		
Cash and cash equivalents	\$1,901	\$2,115
Short-term investments	1,310	947
Receivables and other assets	788	1,109
	<b>3,999</b>	<b>4,171</b>
Contributions receivable	150	151
Long-term investments	7,412	10,934
Capital assets	68	81
	<b>11,629</b>	<b>15,337</b>
<b>Liabilities and Net Assets</b>		
<b>Current Liabilities:</b>		
Accounts payable and accrued liabilities	952	1,169
Deferred revenue	457	217
	<b>1,409</b>	<b>1,386</b>
Long-term deferred contributions	<b>324</b>	<b>359</b>
<b>Net Assets:</b>		
Endowment	94	94
Internally restricted for research and clinics <sup>1</sup>	5,329	10,543
Unrestricted	4,473	2,955
	<b>9,896</b>	<b>13,592</b>
	<b>\$11,629</b>	<b>\$15,337</b>

<sup>1</sup> The research fund which amounts to \$5,329 as of January 31, 2019 (2018 - \$10,543) represents commitments for research and clinic grants and initiatives, which are scheduled to be paid out in varying amounts during the year ending January 31, 2020.

During the past year, a total of \$7,065 (2018 - \$7,157) was spent directly on research, clinic grants and initiatives.

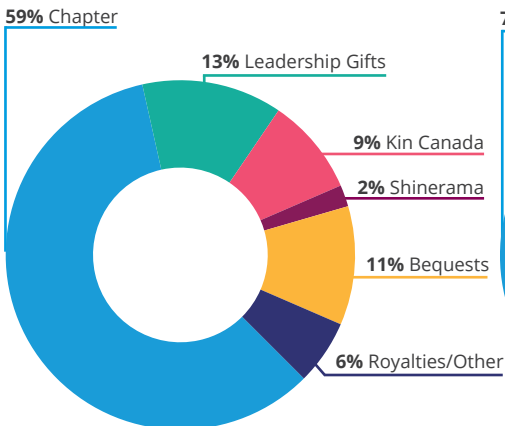
## STATEMENT OF CHANGES IN NET ASSETS

Year ended January 31, 2019, with comparative information for 2018  
(in thousands of dollars)

	Endowment	Internally restricted for research and clinics	Unrestricted	2019 Total	2018 Total
Net assets, beginning of year	\$94	\$10,543	\$2,955	\$13,592	\$14,950
Deficiency of revenue over expenses	-	-	(3,696)	(3,696)	(1,358)
Transfer between funds	-	(5,214)	5,214	-	-
Net assets, end of year	\$94	\$5,329	\$4,473	<b>\$9,896</b>	<b>\$13,592</b>

## STATEMENT OF FUNDRAISING REVENUE

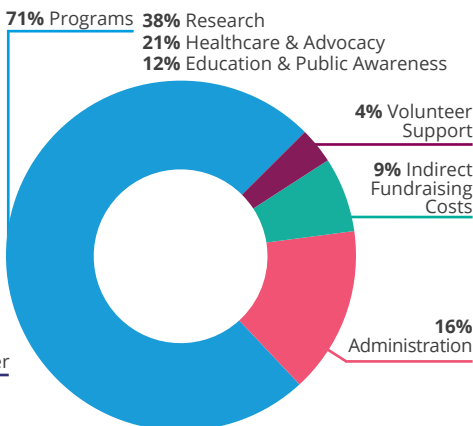
(Net of direct fundraising costs)



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 NATIONAL PARTNERS

The generosity of our partners allows us to continue our work to support and invest leading-edge CF research and world-class 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.



**Kin Canada**  
Kinsmen • Kinettes • Kin

iii HealthPartners  
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Charities At Work  
La philanthropie au travail



**SIEMENS**



**PartyCity**



**LAWN  
SUMMER  
NIGHTS.**

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