

# Focus on a Cure

2014/2015 ANNUAL REPORT



Sierra, CF Champion



Cystic Fibrosis  
Canada

**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.**

## **MISSION**

Cystic Fibrosis Canada's Mission is to help people with cystic fibrosis by:

- Funding research towards the goal of a cure or effective control for cystic fibrosis
- Supporting high quality cystic fibrosis care
- Promoting public awareness of cystic fibrosis
- Raising and allocating funds for these purposes

## **VISION**

A world where cystic fibrosis is no longer a progressive, life-shortening disease.

## **VALUES**

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

- Excellence
- Caring
- Accountability
- Teamwork

## **BOARD OF DIRECTORS**

**James Mountain  
Mitch Lepage  
Stephen McCourt  
Ron Anderson**

**Ross Drake  
Stuart Hodge  
Douglas Ingersoll**

**Carol Ann Cairns  
Leona Pinsky  
Ian Thompson**

## MESSAGE FROM OUR PRESIDENT AND CEO



### **Excellence, Caring, Accountability and Teamwork:**

these are the values at the heart of our mission as we look ahead to the coming year and refocus our commitment to the over 4,000 Canadians with cystic fibrosis (CF). With a renewed sense of purpose and dedication – we must work together to breathe fresh air into the quest for a cure or control and a world where cystic fibrosis is no longer a progressive, life-shortening disease.

This past year over \$16.8 million was raised, as we continue to build and sustain revenue to invest in critical CF research and care. We launched a new Cystic Fibrosis Canada Clinical Research grant program to support clinical projects to improve the quality of life of CF patients and bridge the gap between research and clinical care.

Today nearly 60 percent of all Canadians with cystic fibrosis are adults. The increased length and quality of life for Canadians with cystic fibrosis is a great achievement, but one that comes along with its own challenges in the treatment, care and research focus of the disease. We have partnered with St. Michael's Hospital Foundation to create the first-ever Chair in Adult Cystic Fibrosis Research at the University of Toronto. Through a matched funding program, we just completed the first year of a five-year program in which just over \$1 million will be invested, including \$500,001 from Cystic Fibrosis Canada's donors, with the ultimate goal of improving the lives of adults with CF.

Join us as we revitalize our focus into finding a cure or control for this fatal disease. Together, we can make a difference in the lives of Canadians with cystic fibrosis.

A handwritten signature in grey ink that reads "Norma Beauchamp".

**Norma Beauchamp,**  
President and CEO

## MESSAGE FROM OUR CHAIR

This past year saw many exciting changes at Cystic Fibrosis Canada. I, and our Board of Directors, were thrilled to welcome our new President and CEO Norma Beauchamp in November. Norma joins Cystic Fibrosis Canada as an accomplished business and non-profit leader, with over three decades of senior leadership positions in Canada and Germany. With a nephew living with cystic fibrosis and as a three-time cancer survivor herself, Norma knows first-hand how investments in research can improve the health and wellbeing of Canadians living with cystic fibrosis.



The dedication of our donors, volunteers and partners lies at the foundation of our progress and work across Canada to see our mission through. Our national partners have achieved milestone after milestone, Kin Canada - our longest-standing partner raised over \$1.2 million in 2014.

We are humbled by the tireless dedication of the volunteers and champions for Cystic Fibrosis Canada. There is no greater strength than individuals linking together for a remarkable cause.

Despite this wonderful work, the lives of Canadians with cystic fibrosis are still cut far too short and our work is far from over. Surrounded by our incredible supporters, we are ready to approach the challenges of new milestones, towards the day when a cure or control for cystic fibrosis is found.

A handwritten signature in black ink, appearing to read 'Jim Mountain'. The signature is fluid and cursive, with a long horizontal stroke extending to the right.

**Jim Mountain,**  
Chair

# FOCUS ON RESEARCH



The pursuit of excellence through the rigorous peer review of all applications is the cornerstone of all Cystic Fibrosis Canada's funding decisions. In 2014/2015 we invested more than **\$5 million in research** grants and training awards.

## RESPONDING TO THE NEEDS OF THE ADULT CYSTIC FIBROSIS COMMUNITY

Cystic Fibrosis Canada has partnered with St. Michael's Hospital Foundation to create the first-ever Chair in Adult Cystic Fibrosis Research at the University of Toronto. Through a matched funding program, just over \$1 million will be invested from 2014-2019, including \$500,001 from Cystic Fibrosis Canada's donors.

**More than \$5 million awarded to 43 research projects, 27 fellows and students, and 8 special research initiatives and partnerships**

We celebrated the 25th anniversary of the cystic fibrosis gene discovery, led by Dr. Lap-Chee Tsui, a Cystic Fibrosis Canada-funded researcher.

**"I have spent 24 years caring for adults with CF and am amazed and inspired by the improvements in survival and quality of life that have occurred over this time. This is a result of meticulous patient care and application of treatments developed through research discoveries"**

Dr. Elizabeth Tullis,  
Chair in Adult Cystic Fibrosis Research



## CYSTIC FIBROSIS CANADA CLINICAL RESEARCH GRANT PROGRAM

Clinical research grants demonstrate Cystic Fibrosis Canada's commitment to improving patient care and health outcomes. The goal of this program is to support clinical projects that will improve the health and quality of life for CF patients and/or bridge the gap between research and clinical care. In 2014/2015 we invested **\$173,345** in **five** clinical research projects.

# FOCUS ON CLINICAL CARE



In 2014/2015 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**.

## CANADIAN CF REGISTRY HIGHLIGHTS

Canada continues to be a world leader in CF research and care. Based on the most recent data from the *Canadian Cystic Fibrosis Registry*, there is a promising increase once again in the predicted median age of survival of Canadians with cystic fibrosis. In 2013, it was 50.9 years, over 25 years higher than in the early 1980s.

### Other insights include:

- Over 4,000 Canadians received care at one of 42 CF clinics across the country.
- Forty-four CF patients received transplants.
- In 2013, 118 new CF diagnoses were made – 38 were through the newborn screening program.

While we have made great progress – too many lives are still cut too short – of the patients who lost their battle to CF in 2013, half were under 35 years old.

In collaboration with professional medical and clinical advisors, Cystic Fibrosis Canada has created the *Health Human Resources Guidelines: Minimum Staffing Standards* with the goal to provide the best care possible to Canadians with CF and their families.

ACCORDING TO THE LATEST  
CANADIAN CYSTIC FIBROSIS  
REGISTRY DATA, THE PREDICTED  
MEDIAN AGE OF SURVIVAL IS  
**50.9 YEARS**

Accreditation Site Visits took place in three regions of Canada during 2014.



Tara Bourque performs a lung function test at Toronto General Hospital

Cystic Fibrosis Canada provided funding to over 50 hospitals, universities and research institutes across Canada.

# FOCUS ON ADVOCACY



*Madi and Beth Vanstone have been strong advocates for KALYDECO® - including visits to Queen's Park*

## NEWBORN SCREENING IS ALMOST NATIONWIDE

Our long-time Celebrity Patron Céline Dion lent her voice to our cystic fibrosis newborn screening Public Service Announcement (PSA) campaign "Raise Your Voice," which resulted in newborn screening commitments in four more provinces (totalling nine out of ten): Nova Scotia, Newfoundland, New Brunswick and Prince Edward Island. Quebec is now the last remaining province before we achieve nationwide screening for cystic fibrosis in newborns.

## EXPANDING ACCESS TO KALYDECO®

Cystic Fibrosis Canada continued to build capacity in helping Canadians with cystic fibrosis gain equitable and affordable access to high-quality, specialized CF care and treatments they need to live longer, healthier lives. In 2014, Cystic Fibrosis Canada made significant progress in one of our key priorities - KALYDECO®, a breakthrough drug for CF patients with the G551D gene mutation.

KALYDECO® is now available in seven provinces and one territory: British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, New Brunswick, Nova Scotia, and Yukon.



*Chance was diagnosed with cystic fibrosis through newborn screening in Ontario*

# FOCUS ON MAKING A DIFFERENCE

**“My inspiration to volunteer will always be my son, but I am continually touched by the entire CF community. I can’t stop until CF stands for cure found and we can all breathe a little easier for the future of Canadians with cystic fibrosis.”**

- Helen Meinzinger, Ottawa, Ontario



## RAISING FUNDS ACROSS CANADA

Our national events help fund cystic fibrosis research and care. More than 8,000 participants came together at 70 locations across Canada in 55 communities and raised more than \$3.2 million at the 2014 Great Strides™ walk. Shinerama, Cystic Fibrosis Canada’s largest post-secondary fundraiser, raised almost \$1 million and celebrated its 50th anniversary.

Lawn Summer Nights took place in seven cities across the country this year – Victoria, Vancouver, Calgary, Ottawa, Toronto, London and Halifax, the events raised \$435,000 in 2014. Lawn Summer Nights has now passed the million dollar mark for total funds raised to date for Cystic Fibrosis Canada since the event began in 2009.

|   |               |
|---|---------------|
| Great Strides™ walk raised more than          | \$3.2 million |
| Shinerama raised almost                       | \$1 million   |
| Lawn Summer Nights raised                     | \$435,000     |
| Danny Gallivan Golf Tournament teed up almost | \$90,000      |
| Ride for the Breath of Life raised more than  | \$164,000     |

## STRATEGIC PARTNERSHIPS

Cystic Fibrosis Canada’s dedicated partners continue their history of unwavering support in the fight against cystic fibrosis. This year, we celebrated a milestone 50 years of partnership with Kin Canada. Devoted Kinsmen and Kinettes raised over \$1.2 million through numerous 2014 fundraisers and the Great Strides™ walk.

Our national partners Advocis®, BioGuard Canada®, CARSTAR® Automotive Canada Inc., Mac’s Convenience Stores Inc., Siemens Canada HealthPartners and Federal Health Charities made generous contributions in the past year.



Strong relationships with our partners are essential to achieving our mission to help Canadians living with 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 to our major partners!*



**Kin Canada raised more than \$1.2 million**



**HealthPartners and Federated Health Charities contributed more than \$260,000**



**CARSTAR Automotive Canada Inc. contributed almost \$180,000**



**Advocis® members gave almost \$175,000**



**Mac's Convenience stores Inc. raised \$134,000**



**Siemens Canada raised more than \$90,000**



**BioGuard® Canada Inc. and their dealer network tallied \$58,000**



“We are proud of our franchise partners’ commitment to their communities and to helping Canadians who live with cystic fibrosis. Every time we raise awareness and money for cystic fibrosis we are motivated by our commitment to finding a cure.”

**Lisa Mercanti-Ladd, Executive Vice-President of CARSTAR Automotive Canada Inc.**

# 2014/2015 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, 2015, with comparative information for 2014

|   | 2015          | 2014           |
|---|---------------|----------------|
| <b>Revenue</b>  |               |                |
| Chapter   | 12,126        | 11,781         |
| Major Gifts   | 1,567         | 1,270          |
| Kin Canada  | 1,204         | 1,140          |
| Shinerama   | 953           | 1,117          |
| Bequests  | 490           | 1,132          |
| Royalties   | 347           | 328            |
| Other   | 155           | 151            |
|   | <b>16,842</b> | <b>16,919</b>  |
| Less direct fundraising costs                         | 4,295         | 4,109          |
| <b>Net fundraising revenue</b>                        | <b>12,547</b> | <b>12,810</b>  |
| <b>Expenses</b>                                       |               |                |
| <b>Program:</b>                                       |               |                |
| Research  | 5,679         | 5,845          |
| Clinics   | 2,284         | 2,381          |
| Quality Improvement Initiative                        | 318           | 131            |
| Public awareness                                      | 1,035         | 1,074          |
| Advocacy/Education                                    | 504           | 608            |
| Other   | 100           | 113            |
|   | <b>9,920</b>  | <b>10,152</b>  |
| <b>Other:</b>   |               |                |
| Administration and meetings                           | 2,554         | 2,590          |
| Fundraising   | 882           | 929            |
|   | <b>13,356</b> | <b>13,671</b>  |
| Excess of expenses over revenue before the undernoted | <b>(809)</b>  | <b>(861)</b>   |
| <b>Investment Income</b>                              |               |                |
| Realized gains on investment                          | 835           | 1,231          |
| Unrealized gains on investments                       | 526           | 676            |
| Derivative loss on foreign exchange contracts         | (86)          | (29)           |
|   | <b>1,275</b>  | <b>1,878</b>   |
| Excess of revenue over expenses                       | <b>\$466</b>  | <b>\$1,017</b> |

## STATEMENT OF FINANCIAL POSITION

(in thousands of dollars)

January 31, 2015, with comparative information for 2014

|   | 2015            | 2014            |
|---|-----------------|-----------------|
| <b>Assets</b>   |                 |                 |
| <b>Current Assets:</b>                                      |                 |                 |
| Cash  | 751             | 2,203           |
| Short-term investments                                      | 4,802           | 2,795           |
| Receivables and other assets                                | 735             | 932             |
|   | <b>6,288</b>    | <b>5,930</b>    |
| Contribution receivable                                     | 154             | 159             |
| Long-term investments                                       | 11,513          | 11,589          |
| Capital assets  | 123             | 136             |
|   | <b>18,078</b>   | <b>17,814</b>   |
| <b>Liabilities and Net Assets</b>                           |                 |                 |
| <b>Current Liabilities:</b>                                 |                 |                 |
| Accounts payable and accrued liabilities                    | 364             | 447             |
| Deferred revenue  | 238             | 367             |
|   | <b>602</b>      | <b>814</b>      |
| Long-term deferred contributions                            | <b>467</b>      | <b>457</b>      |
| <b>Net Assets:</b>  |                 |                 |
| Endowment   | 94              | 94              |
| Internally restricted for research and clinics <sup>1</sup> | 11,753          | 11,594          |
| Unrestricted  | 5,162           | 4,855           |
|   | <b>17,009</b>   | <b>16,543</b>   |
|   | <b>\$18,078</b> | <b>\$17,814</b> |

<sup>1</sup> The research fund which amounts to 11,753 as of January 31, 2015 (2014 - \$11,594) represents commitments for research, clinic grants and initiatives, which are scheduled to be paid out in varying amounts during the next four years, ending January 31, 2019.

During the past year, a total of \$7,133 (2014 - \$6,986) was spent directly on research, clinic grants and initiatives.

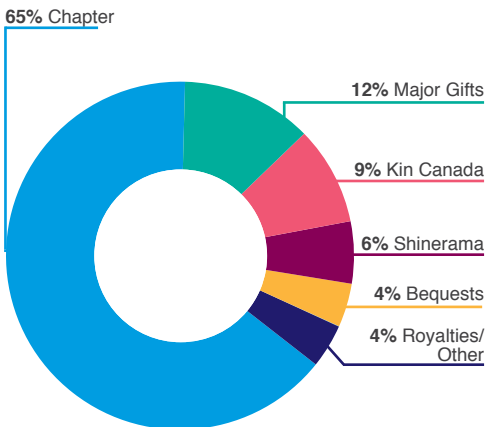
## STATEMENT OF CHANGES IN NET ASSETS

Year ended January 31, 2015, with comparative information for 2014  
(in thousands of dollars)

|                                 | Endowment | Internally restricted for research and clinics | Unrestricted | 2015 Total | 2014 Total |
|---------------------------------|-----------|--|--------------|------------|------------|
| Net assets, beginning of year   | 94        | 11,594   | 4,855        | 16,543     | 15,526     |
| Excess of revenue over expenses | -         | -  | 466          | 466        | 1,017      |
| Transfer between funds          | -         | 159  | (159)        | -          | -          |
| Net assets, end of year         | 94        | 11,753   | 5,162        | \$17,009   | \$16,543   |

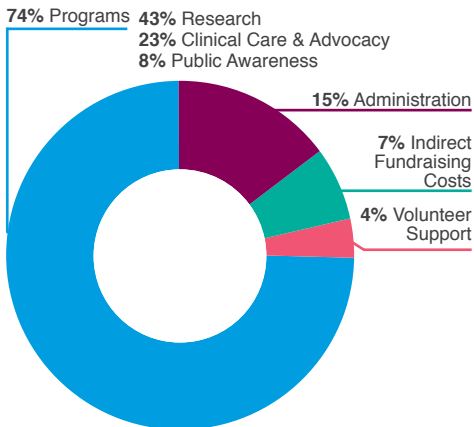
## STATEMENT OF FUNDRAISING REVENUE

(Net of direct fundraising costs)



## USES OF FUNDS

(Excludes direct fundraising costs)



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

Complete audited financial statements can be obtained from the Cystic Fibrosis Canada website at [www.cysticfibrosis.ca](http://www.cysticfibrosis.ca).



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

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