

# Courage to **Transform**

2011 Annual Report



**Cystic Fibrosis  
Canada**

*Breathing life into the future®*

# A Message From the **Chair and CEO**

**Our 2011/12 year was distinguished by courage as we embraced transformation. Cystic Fibrosis Canada is now positioned better than ever before to build on our well-earned reputation for excellence in Canada — and internationally. As we begin a new chapter in our Canadian success story, we are now able to seize outstanding opportunities to strengthen our prospects for the future. Supported by our outstanding donors and volunteers, we will set our sights squarely on finding a cure.**

Cystic Fibrosis Canada took our first step on this journey with the launch of our new name and logo. Throughout the year, we demonstrated the courage to change in a way that will set us apart from similar charities, and courage to paint a future for all Canadians who share our dream of finding a cure or control for cystic fibrosis.

We embarked on a governance renewal process that is among the first of its kind, and our members are poised to make the most significant governance decision in 50 years at our 2012 Annual Meeting, supported by our donors and stakeholders.

Our internal structure has been reorganized to align with this modernized strategic decision-making framework. We have redefined our core businesses proactively, focusing on research, advocacy, and fundraising. We saw growth in all three areas, with added investment in research and care, new emphasis on advocacy and public awareness, and a 17 percent increase in fundraising revenue.

We responded to new infection control challenges by revising our Infection Control Policy, investing in additional research, and taking steps to keep the CF community informed and engaged.

Our 2011 strategic investments in advocacy, technology, and our volunteers improved efficiencies within our organization and boosted future revenue potential. As a result, we now have a stronger platform that will allow us to enhance quality of life for Canadians with cystic fibrosis.

Researchers, clinicians, partners and volunteers are working in every corner of Canada to see our mission through. We are humbled by their commitment and passion.

We remain privileged to serve as your Chair and CEO, respectively.

Thank you for your courage.



**Debra Berlet,**  
*Chair*



**Maureen Adamson,**  
*Chief Executive Officer*



**Debra Berlet, Chair**



**Maureen Adamson, CEO**

# Courage to Lead

**Cystic Fibrosis Canada is a world leader in cystic fibrosis research, innovation, and clinical care. In 2011, we invested \$6.3 million in research and \$2.1 million in clinical care programs across Canada.**

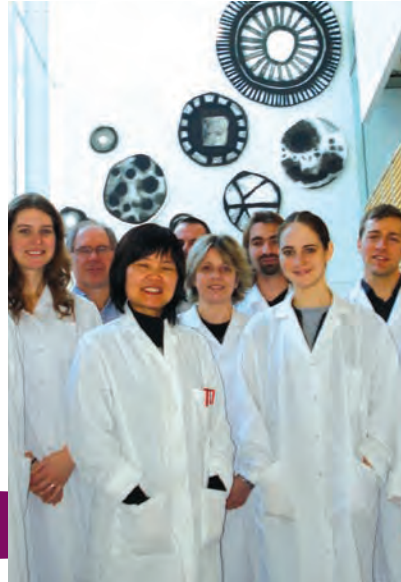
## Leading the Field

The launch of the Cystic Fibrosis Technology Initiative (CFTI), an innovative partnership with the University of British Columbia and the Centre for Drug Research and Development (CDRD), is our first attempt at bridging the gap between academia and business with the aim of improving the lives of people with cystic fibrosis through advancing drug commercialization.

Our 14<sup>th</sup> Broken Arrow Conference held in Quebec City brought together nearly 100 scientists and healthcare professionals to exchange ideas and developments in cystic fibrosis research and care.

Canadian researchers funded by Cystic Fibrosis Canada made a number of innovative discoveries this year, including Dr. Gergely Lukacs' findings on restoring CFTR folding and function, and Dr. Daniela Rotin's work on mice with CF-like lung disease. Our researchers are also shaping the next generation of leaders, mentoring talented young researchers like 16-year-old Marshall Zhang, who made an interesting finding while studying CFTR correctors under the mentorship of Dr. Christine Bear.

The research team at  
McGill University in Montreal.



## Responding to the Needs of Our Community

People with cystic fibrosis are now living longer and are facing new health challenges as a result. Our Canadian CF Patient Data Registry (CPDR), has been enhanced to include information about medications, CF complications, and transplantation. This database is a valuable asset to researchers and clinicians as they work to find new therapies for treating cystic fibrosis.

With the guidance of our Medical/Scientific Advisory Committee (M/SAC) and leading-edge infection control specialists, Cystic Fibrosis Canada responded to new information about a dangerous bacterium by revising our Infection Control Policy. This policy is being considered as a new standard for policies worldwide. To keep our community informed and engaged we provided educational resources and hosted webinars with medical experts. In 2011, we also invested \$170,000 in new research to examine the frequency of transmissible *Pseudomonas* and its effects on cystic fibrosis sufferers.

## Realizing a Return on Our Investment

Our Clinic Accreditation Site Visit program ensures CF care is of the highest quality, and helps identify opportunities for improvement in care. In 2011, seven site visits were conducted, including one in Saint John, New Brunswick that resulted in this clinic receiving more resources to improve patient care.

Cystic Fibrosis Canada's long-term investment in the **Breathe** research program at Montreal's McGill University helped establish a network of clinical and research collaborators focusing on therapies that target the basic defect in cystic fibrosis and foster partnerships. As a result, the Cystic Fibrosis Translational Research Centre (CFTRc) was launched in 2011.

**Cystic Fibrosis Canada funds some of the world's leading CF researchers and clinicians, including Dr. Elizabeth Tullis.**



**Dr. Elizabeth Tullis**  
*M/SAC Clinic Subcommittee Chair*

“Cystic Fibrosis Canada's leadership is making a difference on the research and clinical front. Sustained investment has built enormous capacity to help individuals with cystic fibrosis.”

# Courage to Advocate

**Cystic Fibrosis Canada is enhancing our focus on advocacy and raising public awareness, with the addition of a Vice President to provide strategic leadership and counsel for government affairs and public relations.**

## Advocating on Key Issues

To help improve access to life-sustaining therapies, Cystic Fibrosis Canada provided seven patient and caregiver submissions to provincial and federal drug reviews. Our submission to the Common Drug Review was referenced as a key factor to a drug's positive recommendation and other patient advocacy groups are using this submission as a model of excellence.

Manitoba launched a program to screen newborns for cystic fibrosis on an interim basis, with funding from the Manitoba Children's Hospital Foundation. We continue to advocate for the inclusion of cystic fibrosis in this province's newborn screening program on a permanent basis, and in other provinces across Canada.



Advocates at our reception in the Ontario Legislative Assembly during May.

## Raising Public Awareness

In May 2011, we met with elected officials as part of Cystic Fibrosis Awareness Month, and were successful in having Member's Statements read in nine provincial legislatures. A reception at the Ontario Legislative Assembly was held, and we shared our story with elected officials and key staff from all parties. Our proactive public awareness campaign and media relations outreach activities resulted in over 400 print and online articles, including: a front page article in the *National Post*, a feature article in *The Globe and Mail*, television coverage on Global and CTV, a partnership with TVO in Ontario (which aired a documentary about cystic fibrosis), and interviews on *The Agenda* with Steve Paikin.

Cystic Fibrosis Canada also elevated awareness of the important issues affecting the CF community among politicians during the provincial elections in Saskatchewan, Manitoba, Ontario, Newfoundland and Labrador, and Prince Edward Island, by sending detailed questionnaires to each political party for their response.

## Building Strategic Relationships

Cystic Fibrosis Canada continues to collaborate with like-minded organizations on common issues. In 2011, we worked with Health Charities Coalition of Canada (HCCC), Canadian Organization for Rare Disorders (CORD), Canadian Coalition for Genetic Fairness (CCGF), and Research Canada, by advocating for major issues, participating in committees and providing input for position papers.

We empower people, like **Christine Black**, to lead change in their region through advocacy initiatives.



**Christine Black**  
B.C. Association Chair

“Cystic Fibrosis Canada is bringing advocates together – including people with cystic fibrosis, caregivers, families, and members of the clinical team – to improve care. This enables us to become more vocal advocates and to speak with one voice to bring about positive change.”

# Courage to Make a Difference

Cystic Fibrosis Canada's work relies on the generosity of many individual donors, corporate partners, organizations and volunteers allowing us to improve the lives of Canadians affected by cystic fibrosis. In 2011, we saw a 17 percent increase in our fundraising revenue. Thank you for your ongoing commitment and support, which allows us to advance the fight and race to a cure.

## Working in the Community

Every year, Cystic Fibrosis Canada is inspired by the enthusiasm, creativity and dedication of our volunteers and supporters. This year, our chapters across Canada brought communities together for a variety of outstanding events, raising \$4.2 million. A new Chapter Engagement Strategy and investments in technology will help support our volunteers and continue growth in fundraising.

## Raising Funds Across Canada

Once again, our national events exceeded our expectations. More than 10,000 participants laced-up their shoes in 65 locations to make the Great Strides™ walk a tremendous success, raising nearly \$3 million. Shinerama, Canada's largest student fundraiser, had yet another record-breaking year, raising more than \$1.1 million.

## Strategic Partnerships

Cystic Fibrosis Canada's dedicated partners continue their history of unwavering support in the fight against cystic fibrosis. Our national partners Advocis, Mac's, CARSTAR, Siemens, and Bioguard made generous contributions in 2011. Special thanks to Kinsmen and Kinettes, who continue to lead the way in commitment to our cause. Our 14<sup>th</sup> Broken Arrow conference was supported by funding from pharmaceutical partners. We are grateful for the generosity of our dedicated partners, who gave a total of \$1.8 million this year.

## Thanks to our major partners!



SIEMENS



The generosity of supporters like Mark Giroux and Metro are essential to achieving our mission to help people with cystic fibrosis.



**Marc Giroux**

*Vice-President, Marketing,  
Metro Inc.*

“My family has been touched by cystic fibrosis, so this cause is very close to my heart. Metro is proud to support Cystic Fibrosis Canada because so many of our clients, colleagues and loved ones have been impacted by this devastating disease.”

Cystic Fibrosis Canada remains in a favourable financial position, thanks to the gracious support of our donors, partners, and volunteers. We continue to invest our resources carefully and strategically with a view to the future, to ensure donations achieve the greatest impact. An overview of our financial statements is provided below. Full audited statements are available on our website.

Cystic Fibrosis Canada is a member of Imagine Canada.

## Statement of Operations

Year ended January 31, 2012, with comparative figures for 2011  
(in thousands of dollars)

	2012	2011
<b>Revenue<sup>1</sup></b>		
Chapter - Operating	13,789	12,213
Chapter - Bequests	564	171
Kin Canada	938	937
Shinerama	1,117	1,004
Corporations	770	196
Foundations	144	141
Royalties	220	366
	<b>17,542</b>	<b>15,028</b>
Less direct fundraising costs	4,836	4,240
<b>Net fundraising revenue</b>	<b>12,706</b>	<b>10,788</b>
<b>Investment Income</b>		
Realized gains on investments	389	414
Unrealized gains on investments	(357)	749
Derivative gain in foreign exchange contracts	32	0
	<b>12,770</b>	<b>11,951</b>
<b>Expenses</b>		
<b>Program:</b>		
Research grants and awards	5,814	5,404
Special research initiative	445	300
Breathe Research Initiative	0	175
Clinics	2,110	2,175
Advocacy / Education	458	478
Public awareness	1,355	1,315
	<b>10,182</b>	<b>9,847</b>
<b>Other:</b>		
Administration	2,013	1,836
Meetings	625	601
Fundraising	869	849
	<b>13,689</b>	<b>13,133</b>
Excess of revenue over expenses (expenses over revenue)	<b>\$ (919)</b>	<b>\$ (1,182)</b>

## Statement of Financial Position

Year ended January 31, 2012, with comparative figures for 2011  
(in thousands of dollars)

	2012	2011
<b>Assets</b>		
<b>Current assets:</b>		
Cash	1,633	1,706
Short-term investments	3,687	4,051
Receivables and other assets	870	844
	<b>6,190</b>	<b>6,601</b>
Long-term investments	9,868	10,352
	<b>\$16,058</b>	<b>\$16,953</b>
<b>Liabilities and Net Assets</b>		
<b>Current liabilities:</b>		
Accounts payable and accrued liabilities	520	502
Deferred contributions	280	274
	<b>800</b>	<b>776</b>
<b>Net Assets:</b>		
Endowment	94	94
Internally restricted for research and clinics <sup>2</sup>	12,123	12,868
Unrestricted	3,041	3,215
	<b>15,258</b>	<b>16,177</b>
	<b>\$16,058</b>	<b>\$16,953</b>

<sup>1</sup> Donations receipts for income tax purposes amounted to \$7,834 (2011 - \$7,708).

<sup>2</sup> The research fund, which amounts to \$12,123 as at January 31, 2012 (2011 - \$12,838) represents commitments for research and clinic grants, which are scheduled to be paid out in varying amounts during the next three years, ending January 31, 2016.

During the past year, a total of \$7,591 (2011 - \$7,432) was spent directly on research and clinic grants. In addition, the Board of Directors approved grants in the amount of \$8,094 (2011 - \$7,815) for future years.

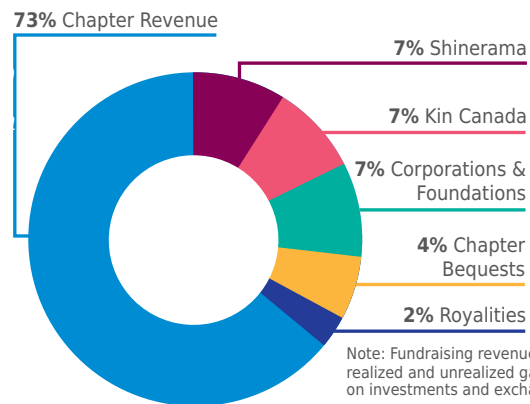
## Statement of Changes in Net Assets

Year ended January 31, 2012, with comparative figures for 2011  
(in thousands of dollars)

	Endowment	Internally Restricted for Research and Clinics	Unrestricted	2012 Total	2011 Total
Net assets, beginning of year	94	12,868	3,215	16,177	17,359
Excess of revenue over expenses (expenses over revenue)	-	-	(919)	(919)	(1,182)
Transfer between funds	-	(745)	745	-	-
Net assets, end of year	94	12,868	3,215	<b>\$16,177</b>	<b>\$17,359</b>

## Statement of Fundraising Revenue

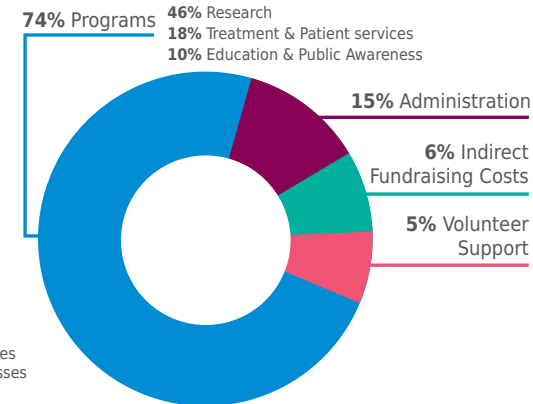
(Net of direct fundraising costs)



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

## Uses of Funds

(Net of direct fundraising costs)





Katie, age 5

## Our 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



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

Charitable registration: 10684 5100 RR0001