



CYSTIC FIBROSIS CANADA . 2012 ANNUAL REPORT

# BOLD NEW PATHS



Cystic Fibrosis  
Canada

*Breathing life into the future®*

Jessica Carver, a member of the Adult Cystic Fibrosis Advisory Committee, had a successful double lung transplant at Toronto General Hospital on December 13, 2012.



## 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

## CONTENTS

A MESSAGE FROM OUR LEADERSHIP

03

04

ADVOCACY

EXCELLING IN CLINICAL CARE

06

08

RESEARCH AND INVESTMENTS

FUNDRAISING, PARTNERS, AND CHAPTERS

10

14

FINANCIALS

BOARD OF DIRECTORS

16

## LAST YEAR BEGAN WITH THE BOLD, CONFIDENT STRIDES OF OUR MODERNIZED GOVERNANCE STRUCTURE AND WE NEVER LOOKED BACK.

We adopted a new set of Strategic Directions for our organization, providing a clear path for future success by renewing our focus on research and CF care, effective advocacy, sustainable fundraising, commercialization efforts, and bolstering our volunteer base across the country.

We have already carved new trails. In the fall, we hosted our first ever commercialization symposium. Our relentless advocacy is showing tangible results across the country. Manitoba became the latest province to screen newborns for cystic fibrosis, and Nova Scotia made its own commitment to CF newborn screening this spring. New CF therapies such as TOBI, TOBI Podhaler and Cayston become more accessible for British Columbians. We launched a sustainable major gift program, and are putting patients and donors first in every conversation.

The dedication of our volunteers in every corner of the country, national partners, donors, and advocates lies at the foundation of so much progress. Our national partners achieved milestone after milestone, led by \$40 million raised by Kin Canada over the course of a productive partnership that now spans nearly half a century.

Our donors and volunteers are unmatched in their generosity, each of them personally invested in our collective battle against this terrible disease.

Thank you on behalf of almost 4,000 Canadians who struggle to breathe. Together, we have set our sights squarely on finding a cure.

## IT HAS BEEN A TREMENDOUSLY EXCITING YEAR FOR CYSTIC FIBROSIS CANADA FILLED WITH MANY INSPIRING MOMENTS AND MILESTONES.

Our successes and progress would be impossible without our coast-to-coast network of volunteers and donors, whose steadfast support inspires hope and provides the critical funding needed to continue our important work.

With every step we take our donors, partners, advocates and volunteers are by our side.

It has been a privilege to serve as your chair. Thank you for your ongoing commitment to our cause and the hope you bring me and my family.



**Maureen Adamson,**  
*President and CEO*

A handwritten signature in black ink, appearing to read 'Maureen Adamson'.



**Debra Berlet,**  
*Chair*

A handwritten signature in black ink, appearing to read 'Debra Berlet'.



Amelia was diagnosed with CF through newborn screening.



Sophia, diagnosed with cystic fibrosis, receiving daily therapy.

# RAISING OUR VOICE ADVOCACY

## MANITOBA ADOPTS NEWBORN SCREENING

On May 8, 2012, the government of Manitoba announced the expansion of its newborn screening program to include cystic fibrosis, a major win for CF families and advocates across Canada.

Efforts led by Cystic Fibrosis Canada urging Manitoba to implement CF newborn screening on a permanent basis were answered with the announcement from Health Minister Theresa Oswald.

“We want to provide peace of mind to new families and ensure disorders are found early so infants can receive the care and treatment they need immediately,” said Oswald, who went on to acknowledge cystic fibrosis as one of the key diseases that will be screened under the new program.

## FIGHT FOR CF SCREENING GATHERS STEAM IN THE MARITIMES

On April 4, 2013, the Nova Scotia government delivered their annual budget address with a commitment to expand their newborn screening program to include cystic fibrosis. This was the result of the groundwork laid by Cystic Fibrosis Canada over the previous year, which included the following actions:

- A June 1<sup>st</sup> letter sent to the four Atlantic Canada Health Ministers prompted responses from three, each of them expressing support for our mission and a promise to examine the matter further.
- News coverage included stories in the *Chronicle-Herald*, CBC radio in both Cape Breton and Newfoundland & Labrador, and CBC.ca.
- The issue was raised in the Nova Scotia legislature by members of the Opposition Liberal and Progressive Conservative party, and was also championed by a member of NDP opposition in Newfoundland & Labrador.
- A petition launched in January 2013 urging the Nova Scotia government to adopt CF newborn screening quickly garnered nearly 2,000 signatures of support.

As the IWK Health Centre is the only Atlantic Canada facility capable of screening for the disease, Nova Scotia’s participation in the program is of crucial importance to the success of CF newborn screening throughout the Maritimes.

Cystic Fibrosis Canada is now hard at work in the effort to bring the remaining Atlantic provinces (New Brunswick, Prince Edward Island, and Newfoundland & Labrador) on board, as well as Quebec.

## KALYDECO™ APPROVED BY HEALTH CANADA

Cystic Fibrosis Canada continues to build capacity in our advocacy activities, including lobbying for access to medicines. One of our key priorities is KALYDECO™ (ivacaftor), a breakthrough drug designed for CF patients with the G551D gene mutation. KALYDECO™ is the first drug to address the underlying cause of cystic fibrosis rather than the symptoms.

On November 30, 2012, Health Canada announced a Notice of Compliance (NOC) had been issued for KALYDECO™, approving the drug for use in Canada. This was an important first step in gaining access for Canadian CF patients.

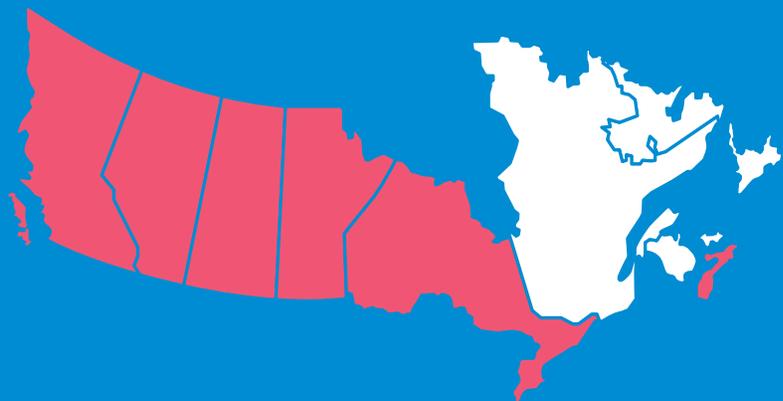
On March 26, 2013, the Canadian Drug Expert Committee, as part of the Common Drug Review process, recommended that KALYDECO™ be listed on the formulary listing of publicly funded drug plans for cystic fibrosis patients aged six and older who have the G551D mutation in the Cystic Fibrosis Transmembrane conductance Regulator (CFTR). Cystic Fibrosis Canada's mandate remains to call upon

provincial drug plan administrators and the drug manufacturer to work together to ensure equitable and affordable access to KALYDECO™.

### Other successes in gaining access to medicines

- Cayston® in British Columbia and Ontario: On September 17, 2012, Cayston® was listed by Pharmacare as Limited Coverage Drugs in British Columbia and subsequently made available through the Special Authority Request program. On September 28, 2012, Cayston® was included on the Ontario Drug Benefit Formulary and made available through the Exceptional Access Program for the treatment of the *pseudomonas aeruginosa* infection.
- TOBI® and TOBI Podhaler® in British Columbia: On September 13, TOBI® and TOBI Podhaler® were both made available through Pharmacare in British Columbia as Limited Coverage Drugs. Access is now granted by Special Authority Request.

- May 2012 - Manitoba announces the expansion of its newborn screening program to include cystic fibrosis
- November 2012 - KALYDECO™ approved by Health Canada
- September 2012, B.C & Ontario include Cayston® on their coverage programs
- September 2012, TOBI® & TOBI Podhaler® made available through Pharmacare in B.C.



**SIX** out of **TEN**  
provinces have committed to  
screen newborns for cystic fibrosis.

## POLICY ADVISORY PANEL ON ACCESS TO MEDICINES

In 2012, Cystic Fibrosis Canada announced the formation of our first Policy Advisory Panel on Access to Medicines. The panel's volunteer membership is comprised of pharmacists, physicians and nurses, who will lend their expertise and guidance to our efforts to advocate for equitable and affordable access to prescribed therapies for every Canadian living with cystic fibrosis.

## BC GOVERNMENT GRANTS \$100,000 TO DEVELOP PROVINCIAL CF PROGRAM

In 2012, Cystic Fibrosis Canada took action to respond to a call from CF patients and their families in British Columbia, who were asking for the establishment of a provincial CF program. As a result of our leadership, the British Columbia Ministry of Health provided a \$100 thousand grant for Cystic Fibrosis Canada to develop a business case for a potential provincial CF program.

Now, with the help of advisory firm KPMG, Cystic Fibrosis Canada is working closely with all four CF clinics in British Columbia, patients, families and health professionals to develop a comprehensive plan that addresses the needs of the Canadians living with cystic fibrosis in B.C. Work is ongoing through 2013.



Ashlee Voortman-Macdonald with CF clinicians at SickKids in August 2012

# SETTING THE STANDARD EXCELLING IN CLINICAL CARE

## ACCREDITATION SITE VISITS

Cystic Fibrosis Canada continued our commitment to quality improvement and raising the bar for the national standard of CF care by completing five more Accreditation Site Visits in three regions of the country. Clinics in Toronto, Quebec and Calgary hosted visits from members of the Cystic Fibrosis Canada team and volunteer experts. 2013 began with a visit to Halifax.

Accreditation Site Visits are the cornerstone of Cystic Fibrosis Canada's Quality Improvement Initiative as outlined in our Strategic Directions 2012-2015. Meant to create a nation-wide standard of excellence in CF care, the program sees experts in the clinical field visit with Clinic Directors, Nurse Coordinators, multidisciplinary team members, hospital officials and local Chapter representatives to gauge the quality of the health services offered to Canadians living with cystic fibrosis.

## NURSING ADVISORY GROUP FORMED

In October of 2012, the Canadian Cystic Fibrosis Nurses Interest Group took a momentous step for CF care across the country and joined forces with Cystic Fibrosis Canada, becoming a crucial facilitator of our mission to improve the quality of care for CF patients.

The newly formed Nursing Advisory Group holds a mandate to:

- Provide nursing and healthcare advice to Cystic Fibrosis Canada
- Present a national nursing perspective on all things related to CF care
- Share best practices and facilitate knowledge exchange
- Advocate for CF patients across a range of issues
- Provide leadership in establishing the highest national standard of CF care

The members of the Nursing Advisory Group bring to the table more than 20 years of experience in the realm of cystic fibrosis-related health issues. Their unanimous decision to join together under the Cystic Fibrosis Canada banner was a bold recognition of the changing landscape of CF care.

## CLINIC INCENTIVE GRANTS

From educational opportunities, to professional development, to outreach health services in less accessible parts of the country, our Clinic Incentive grants are

there to help our CF clinics serve their patient communities.

As the only national organization for cystic fibrosis, Cystic Fibrosis Canada is the leading funder of CF-focused research and clinical care. Nearly 4,000 patients across the country receive care through a network of 42 clinics and 18 outreach clinics, and the multidisciplinary teams that staff them.

The nurses, physicians, and multidisciplinary team members working in these facilities rely on the support of Cystic Fibrosis Canada, which is in turn created through the generosity of our donors and volunteers across Canada. In 2012-2013, we invested \$1,726,200 in in Clinic incentive grants.

### CANADIAN CF REGISTRY HIGHLIGHTS

The newly-rebranded Canadian Cystic Fibrosis Registry debuted its new name in the 2011 Annual Report—released in March of 2013.

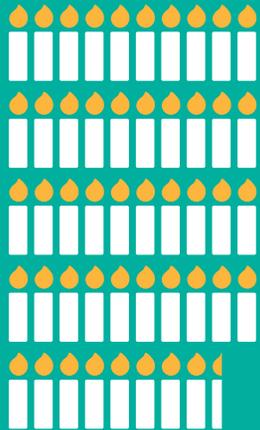
According to the latest data, the median age of survival is 48.5 years -- a promising stability in the median age of survival for Canadian CF patients.

Other critical insights include:

- Approximately 4,000 Canadians received care at one of 42 CF clinics across the country.
- Of the 45 patients who died in 2011, half were under 34 years old.
- A significant portion of CF patients are underweight; more females than males are underweight.
- 114 more people were diagnosed in 2011.

2013 marks an important milestone in the history of this resource—clinic-specific data will be made available to the public, and CF patients and their families, for the first time in our history. This is a positive step forward for our community, one that brings us closer to our goal of establishing national standards of CF care across the country. That data will be available beginning July 2013.

- Five more Accreditation Site Visits completed
- Nursing Advisory Group brings more than 20 years of cystic fibrosis-related experience
- In 2012-2013, we invested \$1,726,200 in Clinic Incentive grants
- For the first time in our history, clinic-specific data will be made available to the public, patients, and their families



According to the latest data, the median age of survival is

**48.5 YEARS**

A promising stability of survival for Canadian CF patients



Nearly

**60%**

of all people with cystic fibrosis in Canada are

**ADULTS**



Researchers in Dr. Christopher H. Mody's research lab, funded by Cystic Fibrosis Canada at the University of Calgary.



Dr. Stuart Turvey, is the leader of research at the Child & Family Research Institute (CFRI), in B.C.

# LEADING THE WAY RESEARCH INVESTMENTS

## DR. LAP-CHEE TSUI INDUCTED INTO MEDICAL HALL OF FAME

On March 22, 2012, Dr. Lap-Chee Tsui, the scientist responsible for the discovery of the cystic fibrosis gene, was inducted into the Canadian Medical Hall of Fame.

Dr. Tsui's discovery in 1989 has been hailed as one of the most important breakthroughs in human genetics of the past half century. Cystic Fibrosis Canada is proud to have been one of the key funders of Dr. Tsui's work.

"I am grateful for Cystic Fibrosis Canada's support from the very beginning," Dr. Tsui said at the induction ceremony. "I'm glad that our identification of the cystic fibrosis gene has paved the way to new drugs and treatment of cystic fibrosis."

Dr. Tsui's discovery continues to unlock the mysteries and contribute to our progress in the fight against cystic fibrosis. Newborn screening for cystic fibrosis, carrier testing for parents, and a first-ever drug targeting the root cause of the disease (KALYDECO™) were all made possible by the work of Dr. Tsui and his team nearly a quarter century ago.



Debra Berlet, Dr. Lap-Chee Tsui, Maureen Adamson and Ken Chan.  
Photo Credit: Alan Flores

## RESEARCH PROJECTS

The fourth mandate of our 2012-15 Strategic Directions directs us to "support and enable advances in CF research in order to achieve the goal of a cure or control for cystic fibrosis."

We delivered on that commitment by earmarking more than \$5 million for research grants and training awards in 2012-2013. Our research and training grants were given to principle investigators, fellows, and students in British Columbia, Saskatchewan, Alberta, Manitoba, Ontario, Quebec and Nova Scotia, representing the truly pan-Canadian effort we are leading in the fight to find a cure for cystic fibrosis.

## CYSTIC FIBROSIS CANADA FUNDED DISCOVERIES BRING HOPE

Rarely does a year go by without news of an intriguing new development in the fight against cystic fibrosis. Of the carefully-selected list of researchers funded by Cystic Fibrosis Canada, a number of achievements stood out this year, offering new reasons for hope.

### Under the sea

As one co-author described it, "In the past, people have looked under the streetlight for lost keys, but we choose to search for our keys using a flashlight in other untapped areas." It was that mentality which led to the discovery of a chemical, found in sea sponges, which has a corrective effect on the defective gene that causes cystic fibrosis.

The work, supported in part by Cystic Fibrosis Canada and carried out in a joint effort between the team of Dr. John Hanrahan (a Cystic Fibrosis Canada funded researcher) of McGill University and the University of British Columbia, was published in the journal *Chemistry and Biology*.

### Pathways to health

While cystic fibrosis is a multi-system disease, the majority of deaths result from lung

disease caused by years of inflammation and infection. But in late 2012, research was published in the *Journal of Immunology* on work conducted by teams from the Child & Family Research Institute (CFRI) at the BC Children's Hospital, the University of British Columbia, and the Providence Heart + Lung Institute at St. Paul's Hospital that suggested a new cellular pathway that leads to lung inflammation had been discovered.

According to the CFRI, researchers found that by decreasing the pathway's activity, lung inflammation was reduced. Dr. Stuart Turvey, the leader of the research, is a Cystic Fibrosis Canada funded researcher.

### Tackling infection

Finally, new research published in January 2013 suggested that by addressing a specific cellular protein, the *B. cenocepacia* infection—a highly transmissible and dangerous infection among CF patients—could be more easily cleared.

The study was co-authored by a Cystic Fibrosis Canada funded researcher, Dr. Miguel Valvano of the University of Western Ontario.

## TARGETED RESEARCH PROGRAMS AND PARTNERSHIPS 2012-2013

Total investment: \$225,389

### **Pseudomonas Team Grant**

Principle investigator: Dr. Valerie Waters (The Hospital for Sick Children, Toronto)

**OBJECTIVE: Investigating the role of transmissible *Pseudomonas* in Canadian CF patients.** One quarter of adult CF patients in Canada have transmissible strains of *Pseudomonas*, a bacterium associated with increased risk of death. This finding prompted a revision of Cystic Fibrosis Canada's Infection Control Policy. The intended result of the work done by Dr. Waters and her team is a better understanding of the magnitude of the bacterium in Canada and how its spread can be controlled.

### **The Cystic Fibrosis Technology Initiative (CFTI)**

Principle investigator: Dr. Robert Hancock (The University of British Columbia, Vancouver)

**OBJECTIVE: Accelerating research ideas into innovative and commercially viable therapies for children and adults with cystic fibrosis.** The CFTI could significantly impact the lives of people with cystic fibrosis by moving CF discovery research closer to commercialization. There is potential in the CFTI project to markedly advance research in the areas of infection and inflammation, and to develop innovative treatments against antibiotic resistant bacteria in the general population.

### **Canadian Institutes of Health Research Partnerships**

By working with our partners at the CHIR Institute of Infection and Immunity and Institute of Genetics, we leveraged a \$300,000 investment into more than \$6.3 million in additional funding to CF research. Those supported projects include:

- Dr. Felix Ratjen (The Hospital for Sick Children) and his team's work on developing new therapies for patient care.
- Dr. David Guttman (University of Toronto) and his team's work on characterizing the bacteria in the CF lung during cycles of health and respiratory illness.
- Dr. Gerard Wright (McMaster University) and his work on understanding the complex outer membrane of bacteria to overcome antibiotic resistance.
- Dr. Jonathan Dennis (University of Alberta) and his team's work on eliminating the *B. cepacia* infection.



Lawn Summer Nights 2012, Vancouver, B.C.



Opening ceremonies for the annual Shine Day, Saint Mary's University, Halifax, N.S.

# OUR FOUNDATION FUNDRAISING, PARTNERS & CHAPTERS

## KIN CANADA'S MILESTONE

In 2012, Cystic Fibrosis Canada was pleased and proud to congratulate Kin Canada on crossing the \$40 million threshold after more than 48 years as our dedicated partner. This achievement is the result of years of Kinsmen and Kinettes joining together across Canada to raise the voice of Canadians with cystic fibrosis, and to raise funds in support of crucial CF research and care.

In 2012 Kin Canada raised nearly \$1.2 million through countless fundraising events and by supporting the Great Strides™ Walk; a staggering amount that speaks to the dedication of the Kin throughout the country.

Cystic Fibrosis Canada presented Ian F. McClure with the Queen Elizabeth II Diamond Jubilee Medal at the 2012 National Kinvention in Peterborough. Ian is a dedicated Kinsman who was instrumental in cementing the Kin Canada partnership with Cystic Fibrosis Canada and continues to passionately support the cause.

## CARSTAR AND MAC'S CONVENIENCE STORES REACH MILESTONES OF THEIR OWN

Two of Cystic Fibrosis Canada's long-time partners also achieved significant milestones in 2012.

**CARSTAR Automotive Inc.** marked \$2 million raised in support of Cystic Fibrosis Canada's mission over the course of a 15-year partnership. Cystic Fibrosis

Canada presented CARSTAR President and CEO Sam Mercanti, and Vice-President, Marketing and Client Services Lisa Mercanti-Ladd, with Queen Elizabeth II Diamond Jubilee Medals to honour their commitment to the cause throughout the years.

**Mac's Convenience Stores Inc.** celebrated \$1 million raised in the fight against cystic fibrosis, as well as 10 years of partnership with our organization. A Queen Elizabeth II Diamond Jubilee Medal was presented to Rick Pasemko, Director of Franchise, in recognition of his dedication to raising awareness and funds for cystic fibrosis.

## GREAT STRIDES™ WALK

The Great Strides™ walk in a very short time has become our organization's largest fundraising event. In 2013, it had a remarkable year raising \$3.22 million. The event across the country brought out families, friends, co-workers and neighbours to lace up their shoes to raise funds for critical CF care and research.

As the event continues to grow in communities all across Canada from North West Territories to Newfoundland it proves that we as an organization are increasing not just revenue but awareness as well.

Cystic Fibrosis Canada thanks our sponsors Abbott, Advocis, Gilead, Kin Canada and Via Rail for their generous support.

• Kin Canada reaches \$40 million • CARSTAR Automotive marked \$2 million • Mac's Convenience Stores celebrates \$1 million • Great Strides™ events raised \$3.22 million nationwide • Shinerama volunteers fundraised \$1.06 million • Lawn Summer Nights rally \$150,000 • Danny Gallivan Golf Tournament shoots for \$93,000 •

## CÉLINE DION

In 2012, Céline Dion marked 30 years as our marraine and Celebrity Patron. For three decades she has championed our CF mission, raising awareness internationally and generating public support. We are very grateful to Céline and her husband René Angélil who continue to generously contribute funds for our important work. Céline's recent benefit concert, "Adding Tomorrows", in Las Vegas raised over \$200,000 for Cystic Fibrosis Canada.

## SHINERAMA

In 2012, more than 35,000 student volunteers took part in Shinerama, Canada's largest post-secondary fundraiser with more than 65 participating universities and colleges across Canada.

The event raised more than \$1.06 million by the time the final dollars were counted. More than \$23.7 million has been raised since 1964, all in support of Cystic Fibrosis Canada.

## LAWN SUMMER NIGHTS

The Vancouver-based event, Lawn Summer Nights expanded east to Toronto after three successful years on the west coast. The event brought its own brand of

panache to Toronto's Leaside Lawn Bowling Club in July, raising \$50,000 for Cystic Fibrosis Canada. In Vancouver, the event raised an amazing \$100,000 at the Granville Park Lawn Bowling club.

Lawn Summer Nights has raised more than \$240,000 to date. The success of the 2012 events has prompted a call for even more locations, and expansion is planned for 2013.

## DANNY GALLIVAN GOLF TOURNAMENT

One of the longest-running charity golf tournaments in Atlantic Canada had another successful year of networking and raising funds for Cystic Fibrosis Canada. The Danny Gallivan Golf Tournament, founded by hockey broadcaster Danny Gallivan, Red Storey, and their friends in the Halifax business community, brought in a remarkable \$93,000. Participants hit the links and enjoyed a banquet dinner and BMO Harris Private Banking silent auction with local celebrities.

To date, this continually sold-out event has raised more than \$1 million for cystic fibrosis care and research.

# GALA EVENTS FUNDRAISING, PARTNERS & CHAPTERS

## 12TH ANNUAL 65 ROSES GALA (Vancouver)

Over 360 guests gathered at the Pan Pacific Hotel for an evening of fun and philanthropy set to the theme All You Need is Love. With the help of Gala Chair Jackie Bevis, Honorary Chair Dale Boniface, presenting sponsors Canaccord Financial and B2Gold, the event raised \$300,000 for the fight against cystic fibrosis.



## 65 ROSES GALA (Ottawa)

Guests gathered together in Ottawa with a single goal in mind: raising funds for CF care and research. The result was \$120,000 raised in a single event, with the help of host Max Keeping and Celebrity Chair Nick Foligno of the Ottawa Senators. A big thank you to the evening's sponsors Insight Communications, TD Bank, Advocis, Dundee Wealth Management, Mackenzie, Johnny Farina, Fidelity and many more.



**VANCOUVER** 1 Dale Boniface and Pam Burns 2 Bill and Jackie Bevis 3 Amy and Bart Corbett 4 Fred Lee and Gloria Macarenko  
5 FRESHH **OTTAWA** 1 JW Jones 2 Martine Legault, Nick Foligno, Janelle Foligno, Manon Vachon and Marielle Brunet  
3 Dr. Shawn Aaron and Lisa Lawrenson 4 Nick Foligno, Janelle Foligno, John Kelleway, Nadine Imbleau-Redman and Rob Redman

## FUSION: PUTTIN' ON THE RITZ

(Toronto & District Chapter)

On October 13, 2012, over 300 guests joined the Toronto & District Chapter at Angus Glen Golf Course in Markham, Ontario for a swanky evening right out of the 1920s. Guests enjoyed a cocktail reception, dinner, casino games, keynote speakers and the Key to a Cure auction. The event brought in \$334,000 for CF care and research. Special thanks to presenting sponsor TEAM Solutions and all other participating sponsors.



THANKS TO OUR MAJOR PARTNERS!



SIEMENS



**TORONTO** 1 Ron Anderson, Bonnie Griffin, and Clint Griffin 2 Erick Bauer and Stefani Cali

3 Jackie Bloom, David Gilmer, Ron Anderson, Bonnie Griffin and Jim Mountain

4 Supporting a Key to A Cure

# 2012 FINANCIALS

**Cystic Fibrosis Canada was ranked among the top three Health Services Charities in the *MoneySense 2012 Charity 100*. We remain in a strong financial position as we continue to strategically invest generous donor dollars into vital CF research and care.**



## Cystic Fibrosis Canada

### STATEMENT OF OPERATIONS

Year ended January 31, 2013, with comparative figures for 2012  
(in thousands of dollars)

	2013	2012
<b>Revenue <sup>1</sup></b>		
Chapter - Operating	11,975	13,789
Chapter - Bequests	430	564
Kin Canada	1,192	938
Shinerama	1,035	1,117
Corporations	620	770
Foundations	100	144
Royalties	407	217
Other	323	3
	<b>16,082</b>	<b>17,542</b>
Less direct fundraising costs	3,847	4,863
<b>Net fundraising revenue</b>	<b>12,235</b>	<b>12,706</b>
<b>Investment Income</b>		
Realized gains on investments	489	389
Unrealized gains on investments	542	(357)
Derivative gain in foreign exchange contracts	(48)	32
	<b>983</b>	<b>64</b>
	<b>13,218</b>	<b>12,770</b>
<b>Expenses</b>		
<b>Program:</b>		
Research grants and awards	5,553	5,814
Special research initiative	96	445
Clinics	2,024	2,110
Advocacy / Education	566	458
Public awareness	1,228	1,355
	<b>9,467</b>	<b>10,182</b>
<b>Other:</b>		
Administration	1,961	2,013
Meetings	627	625
Fundraising	895	869
	<b>12,950</b>	<b>13,689</b>
Excess of revenue over expenses (expenses over revenue)	<b>\$ 268</b>	<b>\$ (919)</b>

## STATEMENT OF FINANCIAL POSITION

Year ended January 31, 2013, with comparative figures for 2012  
(in thousands of dollars)

	2013	2012
<b>Assets</b>		
<b>Current assets:</b>		
Cash	1,773	1,633
Short-term investments	2,440	3,687
Receivables and other assets	1,330	870
	<b>5,543</b>	<b>6,190</b>
Long-term investments	10,803	9,868
	<b>\$16,346</b>	<b>\$16,058</b>
<b>Liabilities and Net Assets</b>		
<b>Current liabilities:</b>		
Accounts payable and accrued liabilities	378	520
Deferred contributions	442	280
	<b>820</b>	<b>800</b>
<b>Net Assets:</b>		
Endowment	94	94
Internally restricted for research and clinics <sup>2</sup>	12,221	12,123
Unrestricted	3,221	3,041
	<b>15,526</b>	<b>15,258</b>
	<b>\$16,346</b>	<b>\$16,058</b>

<sup>1</sup> Donations receipts for income tax purposes amounted to \$7,923 (2012-\$7,834)

<sup>2</sup> The research fund, which amounts to \$12,221 as at January 31, 2013 (2012-\$12,123) 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 \$6,973 (2012-\$7,591) was spent directly on research and clinic grants. In addition, the Board of Directors approved grants in the amount of \$7,495 (2012-\$8,094) for future years.

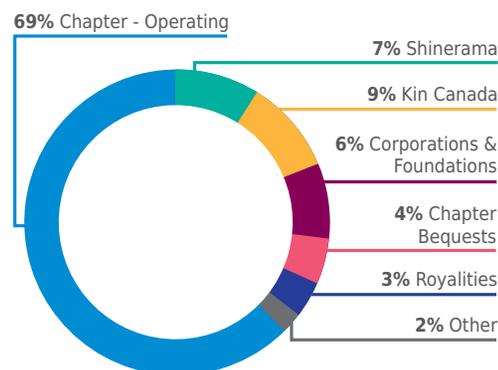
## STATEMENT OF CHANGES IN NET ASSETS

Year ended January 31, 2013, with comparative figures for 2012  
(in thousands of dollars)

	Endowment	Internally Restricted for Research and Clinics	Unrestricted	2013 Total	2012 Total
Net assets, beginning of year	94	12,123	3,041	15,258	16,177
Excess of revenue over expenses (expenses over revenue)	-	-	286	268	(919)
Transfer between funds	-	98	(98)	-	-
Net assets, end of year	94	12,221	3,211	<b>\$15,526</b>	<b>\$15,258</b>

## STATEMENT OF FUNDRAISING REVENUE

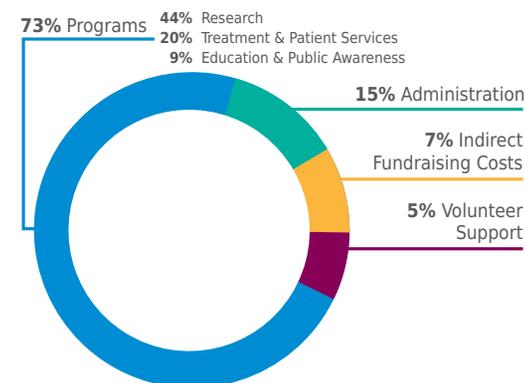
(Net of direct fundraising costs)



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

## USES OF FUNDS

(Excludes direct fundraising costs)





Cystic Fibrosis  
Canada

*Breathing life into the future®*

2221 Yonge Street, Suite 601, Toronto, ON M4S 2B4  
2013-04 | Cette publication est aussi disponible en français.  
Charitable registration: 10684 5100 RR0001

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

#### OUR BOARD OF DIRECTORS

**Debra Berlet, Chair** . *Calgary, Alberta*

**Ron Anderson** . *Richmond Hill, Ontario*

**Paul Arsenaault** . *Durham, Ontario*

**René Coutu** . *Montreal, Quebec*

**Ross Drake** . *Dartmouth, Nova Scotia*

**Douglas Ingersoll** . *Edmonton, Alberta*

**Carol Ann Kairns** . *Montreal, Quebec*

**Mitch Lepage** . *Whitby, Ontario*

**James Mountain** . *Toronto, Ontario*

**Miles Nagamatsu** . *Toronto, Ontario*

**Leona Pinsky** . *Vancouver, British Columbia*



This document is made from 100% recycled paper. Join us in reducing our impact on the environment by choosing to recycle.