

# A Cure in Our Lifetime



*Carys Nurse, Advocacy Champion, Nova Scotia*

2013/2014 Annual Report



*Breathing life into the future®*



## VISION

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

## 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

## Cystic Fibrosis

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 the digestive system. In the lungs, where the effects are most devastating, a build-up of thick mucus causes severe respiratory problems. Mucus and protein also builds up in the digestive tract, making it difficult to digest and absorb nutrients from food. As improved therapies have helped to address the malnutrition issues, ultimately most deaths related to cystic fibrosis are due to lung disease. There is no cure.

## Cystic Fibrosis Canada

Cystic Fibrosis Canada is one of the world's top three charitable organizations committed to finding a cure for cystic fibrosis and is an internationally-recognized leader in funding CF research, innovation, and clinical care. We invest more funding in life-saving CF research and care than any other non-governmental agency in Canada. Since 1960, Cystic Fibrosis Canada has invested more than \$150 million in leading research and care, resulting in one of the world's highest median survival rates for Canadians living with cystic fibrosis.

**For more information, visit [www.cysticfibrosis.ca](http://www.cysticfibrosis.ca)**

# LEADING THE WAY

## Board of Directors

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

**Ron Anderson**, Richmond Hill, Ontario

**René Coutu**, Montreal, Quebec (resigned April 2013)

**Ross Drake**, Dartmouth, Nova Scotia

**Douglas Ingersoll**, Edmonton, Alberta

**Carol Ann Kairns**, Montreal, Quebec

**Mitch Lepage**, Whitby, Ontario

**Stephen McCourt**, Toronto, Ontario (appointed September 2013)

**James Mountain**, Vice Chair, Toronto, Ontario

**Miles Nagamatsu**, Toronto, Ontario

**Leona Pinsky**, Vancouver, British Columbia

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## MESSAGE FROM OUR CHAIR

**Debra Berlet**

Thanks to our incredible volunteers, partners and donors, we continue to turn hope and dreams into reality for Canadians



who battle cystic fibrosis. The positive impact we are making in the lives of Canadians with cystic fibrosis is evident day after day in my own family. As the parent

of two adult children with cystic fibrosis, 2013 was a milestone year as I became a grandparent to two beautiful sets of twins. I never dreamed this would be possible when my children were diagnosed in the 1970s.

This also marks my final year as Chair, an experience I cherished. My hope for the future has never been stronger. Together we will continue to breathe life into the future of Canadians with cystic fibrosis. It has been an honour to serve as your Chair.

## ROADMAP TO A CURE 2012-15 Strategic Directions

Our strategic directions provide a roadmap for Cystic Fibrosis Canada as we continue to deliver on our mission and in achieving our vision. The strategic directions put CF patients, donors and volunteers first.

Six key directions form the basis of our corporate goals, objectives and priorities in 2013 and beyond. Every action and initiative we undertake for Canadians with cystic fibrosis finds its inspiration in our strategic directions.

- 1** Build and achieve sustainable revenue growth in order to invest in research, care and advocacy
- 2** Influence health policy and government decision-making in order to enhance the quality of life for CF patients
- 3** Support excellence in CF care in order to ensure patients receive improved quality of CF care
- 4** Support and enable advances in CF research in order to achieve the goal of a cure or control for cystic fibrosis
- 5** Bridge the gap between research and clinical care through knowledge translation in order to improve the health of CF patients
- 6** Align our organizational resources in order to deliver on our mission





## MESSAGE FROM OUR PRESIDENT AND CEO

**Maureen Adamson**

Together, with the outstanding support of our donors, partners and volunteers, we continue to pave the way to a cure or control for cystic fibrosis — and are making tremendous progress as we complete the second year of our three-year strategic plan in 2013.

**This is a year marked by proud accomplishments as we continue to improve the lives of almost 4,000 Canadians with cystic fibrosis through the roadmap provided by our strategic directions. These include:**

- Almost \$17 million was raised, as we continue to build and sustain revenue to invest in CF research and care. Chapters exceeded their overall fundraising targets and increased major gift revenues.
- Our assertive advocacy efforts in influencing health policy and government decision-making resulted in the commitment of Nova Scotia and Newfoundland and Labrador to implement CF newborn screening.
- Leading in quality improvement and CF care by connecting Canadians with cystic fibrosis through the *My Cystic Fibrosis Canada* online network, making key clinic-specific data available on our website, launching a quality improvement learning and leadership initiative, and hosting the first-ever multidisciplinary clinical conference.
- Continuing to support and enable advances in CF research, by investing more than \$5 million in innovative research.
- Bridging the gap between research and clinical care through knowledge translation with new investments in clinical project grants, and a Clinician Scientist position.

Some of the issues we faced this year included a challenging fiscal environment and continued pressure on the research landscape in Canada. We once again rose to the challenge through the strength and support of our incredible CF community.

Canadians with cystic fibrosis are living longer, healthier lives than at any other time in history. Our Canadian CF Registry in 2012 reported that the median age of survival is 49.7 years old.

This outstanding progress is the direct result of the investment of our donors, partners and volunteers who tirelessly support our important work. Cystic Fibrosis Canada does not receive any government funding; all funds are raised through donors and strategic alliances.

Together, we have set our sights squarely on finding a cure or control for cystic fibrosis.

# 2013/2014 A YEAR IN REVIEW

## Our Investments



## 2013/2014 Highlights

### Fundraising

- Great Strides™ walk raised \$3.2 million
- \$1.1 million raised by Kin Canada

### Research

- More than \$5 million in research grants and training awards

### Healthcare

- More than \$1.8 million to CF clinics
- *My Cystic Fibrosis Canada* social network for CF patients launched
- First-ever Quality Improvement Learning and Leadership Collaborative (LLC)

### Advocacy

- Two more provinces committed to CF newborn screening
- Céline Dion raised her voice for CF newborn screening

## The CF Community



### OUR IMPACT

Median age of survival in 2012 was 49.7 years

Influence health policy and government decision-making in order to enhance the quality of life for CF patients

## Raising Our Voice ADVOCACY

- Nova Scotia now screens newborn babies for cystic fibrosis
- Newfoundland and Labrador announced the province will include cystic fibrosis in its newborn screening program
- Cystic Fibrosis Canada's online petition for newborn screening in Quebec gained more than 3,000 signatures
- Our online petition calling on health ministers to provide access to KALYDECO® gathers almost 45,000 signatures
- Cayston® listed in Quebec following patient input from Cystic Fibrosis Canada

### Policy Advisory Panel on Access to Medicines

The Policy Advisory Panel on Access to Medicines, comprised of CF health experts, helps us drive our strategic priority of advocating for equitable access to prescribed therapies for every Canadian living with cystic fibrosis. The volunteer advocacy panel provides invaluable guidance and professional support to Cystic Fibrosis Canada. The panel contributes to key submissions in the drug review and approval process, and provides critical advice about emerging issues, trends, challenges and opportunities regarding access to medicines.

**Daniel Cortes**

**Dr. John Gjevre**

**Dr. John Hawboldt**

**Dr. Harvey Rabin**

**Joan Tabak**

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process, and provides critical advice about

emerging issues, trends, challenges and

opportunities regarding access to medicines.

### Adult Cystic Fibrosis Advisory Committee

The Adult Cystic Fibrosis Advisory Committee (ACFAC) is a standing committee of Cystic Fibrosis Canada. Members include adults with cystic fibrosis who represent different regions across the country and two professional advisors. The committee provides perspective and advice on CF-related issues, and advocates for public policies and programs to help people with cystic fibrosis. Members also foster and support an engaged and knowledgeable CF community.

**Paulette Boston**

**Jessica Carver**

**Nathan Fish**

**Hughes Leclair**

**Lisa Legros**

**Megan Parker**

**Dr. Harvey Rabin**

**Joan Tabak**

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for public policies and

programs to help people with

cystic fibrosis. Members also foster and support an

engaged and knowledgeable CF community.



## Nova Scotia adopts CF newborn screening

Thanks to the efforts of our advocates and public support, Nova Scotia has implemented newborn screening for cystic fibrosis. Nova Scotia joins British Columbia, Alberta, Saskatchewan, Manitoba and Ontario in offering this life-saving test that allows early CF intervention and treatment and brings us steps closer to universal CF newborn screening in Canada. In the weeks and months leading up to the announcement, nearly 2,000 Canadians signed our online petition.



Newfoundland and Labrador announced that cystic fibrosis screening will be included in the province's newborn screening program. We continue to advocate for cystic fibrosis to be added to newborn screening in Quebec, and monitor progress in Prince Edward Island and New Brunswick.

## Céline Dion raises her voice for newborn screening



Our long-time champion and Celebrity Patron, Céline Dion, lent her famous voice to our CF newborn screening Public Service Announcement (PSA) campaign, "Raise Your Voice," that aired in Newfoundland and Labrador and Quebec — provinces without CF newborn screening in their provincial screening programs. The television, radio and digital ads ran throughout these provinces for more than four weeks, sending a powerful message to families to urge legislators to support CF newborn screening so that all Canadians born with cystic fibrosis can get a healthier start in life. The campaign kicked-off in May, Cystic Fibrosis Awareness Month, receiving strong public support, media coverage, and many more signatures on our online petitions in these provinces.

## Provincial Advocates

Provincial CF Advocates serve to implement the goals and objectives of the National Advocacy Program. They identify provincial-specific advocacy priorities and together with Cystic Fibrosis Canada, develop strategies to address these priorities. Provincial CF Advocates build relationships with elected and

appointed officials in order to increase support for the programs, services and policies that can improve the quality of life for people with cystic fibrosis. Each of the Provincial Advocates coordinates advocacy efforts and builds volunteer advocacy capacity for the province they represent.

**Erick Bauer**  
**John Bennett**  
**Christine Black**  
**Stefanie Cali**  
**Cori Carey**  
**Bob Fortier**  
**Melvin Jay**  
**Tim McKay**  
**Denis Mouton**  
**Caroline Warren**

## New Provincial Advocates to fight for better CF care

The new National Advocacy Program launched in 2013, brings together a group of devoted and outspoken volunteer advocates from across Canada to fight for better care for Canadians living with cystic fibrosis. The Provincial Advocates identify provincial and territorial advocacy priorities; advocate to local legislators and other government decision-makers; and recruit and coordinate advocacy efforts for the province they represent. The goal of the new program is to enhance support for the programs, services and policies that can improve the quality of life of Canadians living with cystic fibrosis.

## Access to KALYDECO® reaches next phase

Gaining affordable and equitable access to KALYDECO®, the breakthrough drug for CF patients with the G551D mutation of the CF gene, remains one of our key advocacy priorities. In 2013, Kalydeco received a positive recommendation from the Canadian Drug Expert



*Carys Nurse, Cystic Fibrosis Canada  
Champion for KALYDECO®*

Committee, in part due to a comprehensive and compelling patient input submission from Cystic Fibrosis Canada. They recommended that Kalydeco be listed on the formulary of publicly funded drug plans.

We launched an online petition directed to all health ministers involved in the Pan-Canadian Pricing Alliance (PCPA). Almost 45,000 people have signed this petition urging the health ministers and the drug manufacturer to come to a resolution as soon as possible.

Once a pricing agreement is reached, it will be up to each province to fund Kalydeco — the final phase in getting access for CF patients.

## Support excellence in care in order to ensure patients receive improved quality of CF care

### Connecting for better care CLINICAL CARE

- Nine Accreditation Site Visits completed. The program now includes CF Nurse Coordinators
- New My Cystic Fibrosis Canada social network for CF patients launched
- More than \$1.8 million in support to CF clinics
- Key Canadian CF Registry data made public on our new website
- Eight clinics participate in the new Quality Improvement Learning and Leadership Collaborative

#### First National Cystic Fibrosis Clinical Conference

More than 200 Canadian healthcare professionals participated in Cystic Fibrosis Canada's first-ever multidisciplinary clinical conference held in Ottawa in May 2013. Together, with clinical representatives from the United States, the United Kingdom and France, CF healthcare professionals had opportunities to collaborate, network and learn about excellence in CF care in the two-day conference focusing on "Quality Improvement in CF Care".

#### Accreditation Site Visits get a new perspective

Not only do CF Clinic Nurse Coordinators play a pivotal role in the health of CF patients, they now bring their unique perspective and hands-on clinical experience to the Accreditation Site Visit Program. In 2013, members of Cystic Fibrosis Canada's Nursing Advisory Group volunteered to participate in the program which had previously been conducted with Directors and physicians from CF clinics. Nine Accreditation Site Visits were completed.

The recommendations brought forth following site visits help CF clinics identify areas for improvement, such as personnel and space availability and other important CF clinical services. Accreditation Site Visits are a crucial tool in helping to ensure that Canadians with cystic fibrosis have consistent and high-quality CF care across Canada.

# 49.7 years

**The median age of survival for Canadians with cystic fibrosis in 2012.**

**Nearly 60 percent of Canadians with cystic fibrosis are adults.**

## Cystic Fibrosis Canada Nursing Advisory Group

Established in October 2012 to act as a valued source of credible and professional advice to the management group of Cystic Fibrosis Canada, and to the many CF patients across the country and their families, the Cystic Fibrosis Canada Nursing Advisory Group is a partner that recognizes the need to ensure a high standard of nursing practice, education, and research. Comprised of Nurse Coordinators from all CF clinics in the country, the Advisory Group's mandate includes providing nursing and healthcare advice to Cystic Fibrosis Canada; presenting a national nursing perspective on CF-related issues; sharing best practices and knowledge exchange; advocating for CF patients; and providing leadership in establishing the highest standards of nursing care in cystic fibrosis.

## Clinic Incentive Grants

Cystic Fibrosis Canada enhances the quality of care Canadians with cystic fibrosis receive through the Clinic Incentive Grants program. Thanks to the generous support of our donors, we invested more than \$1.8 million in the 42 specialized clinics and 12 outreach centres that serve almost 4,000 CF patients throughout the country.

These grants help support CF clinic personnel salaries and education, and help guarantee that CF care is available when health issues arise outside of clinic times.

## Canadian CF Registry Highlights

For the first time in our history, key data from the Canadian CF Registry is publicly available on our new website. The transparency of the CF Registry brings us one step closer to our goal of establishing national standards for CF care and treatment across Canada, allowing those with cystic fibrosis, clinicians, and others to engage in dialogue about the clinic-specific data.

The Canadian CF Registry 2012 Annual Report reported a promising increase once again in the median age of survival of Canadians with cystic fibrosis. In 2012, it was 49.7 years (up from 48.5 years in 2011).

### **Other important data revealed that:**

- Almost 4,000 Canadians with cystic fibrosis received care at one of the 42 specialized clinics in the country
- 105 new diagnoses were made in 2012
- Half of the 43 CF patients who died in 2012 were under 32 years of age
- 37 CF patients received transplants
- Nearly half of all CF patients are infected in their lungs with harmful bacteria





## The Quality Improvement Learning and Leadership Collaborative

In 2013, Cystic Fibrosis Canada embarked on a major new initiative to improve CF patient care and health outcomes when we partnered with the Dartmouth Institute for Health Policy and Clinical Practice in New Hampshire to bring the new Learning and Leadership Collaborative (LLC) to life.

The first group of Canadian CF clinic teams collaborated in the LLC pilot program to learn and practice hands-on techniques leading to CF patient care improvement. Clinic teams from Vancouver, Saskatoon, Hamilton, Toronto, Windsor, and Quebec City; and individuals from Hamilton, Toronto, Quebec City and Halifax were among the first cohort to participate in the LLC.

Cystic Fibrosis Canada will invest more than \$1 million in the LLC over the next four years.

## The My Cystic Fibrosis Canada Network

Cystic Fibrosis Canada launched Canada's first-ever social network designed for CF patients, by CF patients - *My Cystic Fibrosis Canada Network* in May 2013.

The unique online forum allows people with cystic fibrosis and their families to connect and share important information about living with the disease. The goal of the new network is to help improve CF care through self-management and collaboration.



Users can discuss the treatments, programs and services available in their region, video chat and instant message with others, share stories and personal issues, and receive support for advocacy and fundraising initiatives from a much broader community.

Cystic Fibrosis Canada acknowledges Novartis Pharmaceuticals Canada Inc. for the collaboration that has made The My CF Canada Network possible.

## Healthcare Advisory Council

The purpose of the Healthcare Advisory Council is to provide advice and recommendations to Cystic Fibrosis Canada's management on the implementation of healthcare programs and quality improvement initiatives.

Made up of healthcare professionals and lay members,

**Dr. Candice Bjornson**

**Dr. Mark Chilvers**

**James Cummine**

**Dr. Patrick Daigneault**

**Karen Doyle**

**Nathan Fish**

**Helen Meinzinger**

**Dr. Bradley Quon**

**Dr. Harvey Rabin**

**Dr. Valerie Waters**

the Healthcare Advisory Council will advise on the programs required to successfully implement the organization's strategic directions and business plan specific to CF

care and quality improvement. This Council will also consider issues where specialized input is required such as infection control and the latest advances in clinical care.

## Support and enable advances in CF research in order to achieve the goal of a cure or control for cystic fibrosis

### Racing to a cure RESEARCH INVESTMENTS

**In the race to find a cure or control for cystic fibrosis, we invested more than \$5 million in research grants and training awards in 2013/2014.**

#### Research discoveries bring hope for a cure

Every year, new research discoveries shed light on the mysteries of cystic fibrosis, bringing new hope to Canadians living with the disease that a cure or control will be found in our lifetime.

In 2013, Cystic Fibrosis Canada's funded researcher Dr. Gergely Lukacs and his research team at McGill University unearthed important new information which could result in an exciting new approach for treating cystic fibrosis.

Having shown the distinct structural changes introduced by the common cystic fibrosis F508del mutation in the *CFTR* gene, Dr. Lukacs was able to explain why patients carrying this mutation were unresponsive to VX-809, Vertex's investigational drug which only restores one of these changes. Dr. Lukacs' team has initiated the use of rationally selected combinations of different classes of correctors with the startling result of increasing efficacy of VX-809 by several folds in cell culture models.

#### Supporting Organ Transplantation

Organ transplantation is an important treatment option for end-stage lung disease in people with cystic fibrosis, and it can save lives. Cystic Fibrosis Canada is helping to improve the quality of care available to CF patients who



*Paul Underhill, Victoria, British Columbia (double-lung transplant, 2011)*

are transplant candidates by providing transplant centres with supplementary funding. In 2013/2014 Cystic Fibrosis Canada provided almost \$130,000 in Transplant Centre Incentive Grants to five transplant centres.

In partnership with the Canadian Institutes of Health Research (CIHR), we also invested \$20,000 in the nationwide Canadian National Transplant Research Program (CNTRP). Led by Dr. Lori West at the University of Alberta, the program focuses on increasing organ and tissue donation and improving the outcomes for Canadians who receive transplants.





*Dr. Lap-Chee Tsui, Cystic Fibrosis Canada funded researcher who discovered the gene responsible for causing cystic fibrosis in 1989*

## Scientific Advisory Committee

The Scientific Advisory Committee is composed of members with broad expertise in health research and innovation. Committee members serve in an advisory capacity and provide insights and recommendations for public-private partnerships, collaborations, and opportunities to advance research and funding programs. This committee meets with the Board at least twice a year and is invited to all meetings of the Research Advisory Council and Healthcare Advisory Council as observers.

**Dr. Tak Mak**

**Dr. Lap-Chee Tsui**

## Research Advisory Council

Cystic Fibrosis Canada's Research Advisory Council is composed of scientists and lay members from across the country. The Council provides input and advice to management on the development of new research programs and initiatives, and guidance on the successful implementation of Cystic Fibrosis Canada's research strategic directions and business plan. The Council

**Dr. André Cantin**

**Karen Corraini**

**Dr. Charles Deber**

**Dr. Jonathan Dennis**

**Dr. John-Paul Heale**

**Dr. Larry Lands**

**Maggie McIlwaine**

**Dr. Smita Pakhale**

**Dr. Michael Parkins**

**Max Pinsky**

**Wally Speckert**

**Dr. David Speert**

**Dr. John Wallenburg**

considers issues where scientific input is required, and will provide stewardship of the peer review framework for research funding. Based upon advice from scientific

review panels, the Council will make recommendations on the approval of Cystic Fibrosis Canada grants, awards, and other research funding initiatives.

## Bridge the gap between research and clinical care through knowledge translation in order to improve the health of CF patients

### Clinical Project Grants

Clinical project grants demonstrate Cystic Fibrosis Canada's commitment to clinical research. These grants help move the most important ideas for clinical studies into real and relevant protocols and strategies that can lead to better diagnosis of cystic fibrosis and/or new CF treatments.



PRINCIPLE INVESTIGATOR:

**Dr. Pearce Wilcox**  
(University of British Columbia, Vancouver)

**\$14,800** (2013-2014)

**OBJECTIVE: Identification of novel plasma biomarkers in exacerbations of cystic fibrosis.**

Dr. Wilcox's team is using state of the art technology to recognize and quantify blood-based markers during exacerbations in the lungs. The goal of his research is to identify blood biomarkers that predict lung flare-ups, and to use this information to make timely and better treatment decisions for CF patients.



PRINCIPLE INVESTIGATOR:

**Dr. Grace Parraga**  
(University of Western Ontario, London)

**\$14,600** (2013-2014)

**OBJECTIVE: Imaging pulmonary exacerbations of cystic fibrosis.**

Dr. Parraga's team is using magnetic resonance imaging (MRI) as a tool to study and better understand the clinically-relevant responses to therapy, including regional changes within the lung during an exacerbation. Forced Expiratory Volume (FEV<sub>1</sub>) is still the clinical standard for monitoring response to therapy, and all new CF therapies are directed at improving FEV<sub>1</sub>.





## Cystic Fibrosis Canada and the University of British Columbia invest in a Clinician Scientist at St. Paul's University

Cystic Fibrosis Canada continues to foster the development of up-and-coming clinical researchers. The recruitment of trained respirologist, Dr. Bradley Quon, to St. Paul's Hospital and the University of British Columbia is an investment with long-term benefits for CF patients and their families. The research funding includes \$500,000 over five years, with Cystic Fibrosis Canada contributing \$250,000. Cystic Fibrosis Canada's investment will be matched by the University of British Columbia.

The goals of the program are to cultivate the next generation of CF clinical researchers in Canada, and attract highly-trained, early career CF professionals to Canada.

The areas of clinical research being conducted by Dr. Quon include the use of quality improvement to improve lung function in cystic fibrosis and the discovery of novel blood- and sputum-based biomarkers to guide exacerbation treatment decisions in cystic fibrosis.

Build and achieve sustainable revenue growth in order to invest in research, care and advocacy

## Fuelling the Fight FUNDRAISING, PARTNERS & CHAPTERS

• Kin Canada raises more than \$1.1 million • CARSTAR Automotive Canada Inc. contributes more than \$85,000 • Mac's Convenience Stores Inc. raises \$133,000 • BioGuard® Canada and their dealer network tallies up \$55,000 • Great Strides™ walk raises \$3.2 million • Shinerama raises \$1.1 million • Lawn Summer Nights raises \$310,000 • Danny Gallivan Golf Tournament tees up almost \$80,000 • Ride for the Breath of Life raises more than \$140,000 • Advocis® members contribute more than \$150,000



1. L-R: Chuck Russello and Judy Wilson-Henry with Cystic Fibrosis Canada co-founders Doug and Donna Summerhayes at the 2013 Volunteer Engagement Conference 2. Dr. Neil Sweezey, Cystic Fibrosis Canada funded researcher, presented his CF research at the 2013 Volunteer Engagement Conference

### Engaging Our Volunteers

More than 100 volunteers came together for Cystic Fibrosis Canada's first-ever Volunteer Engagement Conference.

During the conference, volunteers had the opportunity to network, share success stories, best practices and gain skills and knowledge about fundraising, sponsorship, communications and other key areas.

The two-day conference in November was designed to engage, motivate and educate volunteers to enhance their abilities to generate revenue from local and regional fundraising activities and the Great Strides™ walk. Regional awards were presented to a number of our outstanding volunteers to celebrate their accomplishments.

### Shinerama Liaison Committee

The Shinerama Liaison Committee provides input and discussion on policies and directions affecting Shinerama. The committee is made up of an elected Chairperson; four Regional Directors selected through an eligible pool of current Shinerama volunteers; and Cystic Fibrosis Canada personnel for a term of two years. Committee members are selected on a regional basis with each member responsible for the growth and development of Shinerama in their region. Shinerama Liaison Committee members participate in conference calls once a month and host regional conference calls once every four to seven weeks.

- Sara Glover, Chair**
- Stephanie Bagnell**
- Kevin Duquette**
- Teagan Gahler**
- Elizabeth Whitfield**





### Great Strides™ walk

The Great Strides™ walk, Cystic Fibrosis Canada's largest national fundraising event, raised more than \$3.2 million in 2013. More than 60 walks took place throughout Canada, including a first-time Great Strides™ walk in the Yukon. More than 12,500 Canadians participated, including thousands of outstanding volunteers. Since 2005, more than \$18.5 million has been raised for CF research and care through our flagship national fundraiser.



### Ride for the Breath of Life

For the 29th year in a row, the Ride for the Breath of Life took to the streets in support of Cystic Fibrosis Canada, raising another \$143,000 to help Canadians battling cystic fibrosis. Since the first Ride for the Breath of Life, this national motorcycle fundraiser has grown from eight to 12,000 riders. The Ride now spans more cities and provinces than ever before. Rides rolled-out throughout the spring and fall in Regina, Saskatoon, and Assiniboia in Saskatchewan; Edmonton and Calgary in Alberta; Brandon and Winnipeg in Manitoba; Peel Region and Windsor in Ontario; and St. John's in Newfoundland.

### Lawn Summer Nights

Lawn Summer Nights began in 2009, and has raised over \$560,000 in support of Cystic Fibrosis Canada. In 2013, more than 900 people participated in Lawn Summer Nights in Victoria, Vancouver, Ottawa,



Toronto, and London, raising more than \$310,000. Over the past few years the event has grown in popularity, and is slated to take place in seven cities across the country in 2014.



### Shinerama

More than 35,000 student volunteers from 55 universities and colleges across Canada pitched in to support Cystic Fibrosis Canada by raising more than \$1.1 million. Shinerama, Canada's largest post-secondary fundraiser has raised almost \$25 million in support of Cystic Fibrosis Canada since 1964.

### Bell Aliant Danny Gallivan Cystic Fibrosis Golf Tournament

For 29 years, the Danny Gallivan Golf Tournament has been attracting local and national celebrities and avid golfers in Halifax to raise funds for a cure or control for Cystic Fibrosis

Canada. This year was no exception, with more than \$79,000 raised to invest in CF research and care. The tournament, founded by hockey broadcaster Danny Gallivan, Red Storey and a group of Halifax professionals, will celebrate 30 years of dedication to the CF mission in 2014. To date, the event has raised almost \$1.4 million.

Cystic Fibrosis Canada's dedicated partners continue their history of unwavering support in the fight against cystic fibrosis. Their fundraising events and public awareness activities help raise millions of dollars each year for vital CF research and care. Their commitment to our cause enables us to reach more people, recruit more volunteers and raise more funds to enhance the quality of life of Canadians with cystic fibrosis.

## Kin Canada

Our longest-standing partner in the fight against cystic fibrosis, Kin Canada, has raised another \$1.1 million through numerous 2013 fundraisers and the Great Strides™ walk. In 2014 we will celebrate our epic 50-year partnership in the fight against cystic fibrosis. Dedicated Kinsmen and Kinettes have raised a grand total of more than \$40 million for life-saving CF research and care.



2013 Kin Canada National Convention cheque presentation: L-R: Doug Ingersoll, Alice Awweh and Brenda Dineen

## The Kin Canada - Cystic Fibrosis Canada Liaison Committee

The Kin Canada - Cystic Fibrosis Canada Liaison Committee works with Cystic Fibrosis Canada to encourage involvement in fundraising and awareness activities from Kin clubs across Canada. The committee includes Kin Canada Service Directors representing eight regions across Canada, an elected Chair, the Kin National Service Director and staff members from Cystic Fibrosis Canada and Kin Canada. The committee meets every month by phone or web teleconference, and in person at least once a year.

	2012/2013 Outgoing	2013/2014 Incoming
<b>Chair</b>	Brenda Dineen	Davina Thuroo
District 1	Joanne Bint Adrian Helm	Bill Harris Katie McKean
District 2	Tim McKay	Tim McKay
District 3	Jesse Shkuratoff	Jesse Shkuratoff
District 4	Brian Smith	Lisa Maggrah
District 5	Scott Wood	Kelly Woywitka
District 6	Helen Meinzinger	Helen Meinzinger
District 7	Michelle Harfitt	Barbara Yorke
District 8	Deborah Corpe Susan Lafreniere	Mike Croghan Eric Wilson



## Our Major Partners

The commitment and dedication of our partners and friends in the fight against cystic fibrosis allow us to continue to make our important investments in life-sustaining CF research and care.

### Advocis®

In 2013, Advocis members raised a tremendous \$150,000 through charity golf tournaments, Santa Sock Raffles and other community based fundraisers. Advocis has been our committed partner in the fight against cystic fibrosis since 1985.

### BioGuard® Canada

BioGuard® Canada and their dealer network continue to support Cystic Fibrosis Canada through their national fundraiser, *Splash for CF*. The 2013 campaign was their most successful to date, raising an incredible \$55,000.

### CARSTAR® Automotive Canada Inc.

A partner of 16 years, CARSTAR Automotive Canada Inc., and its franchise owners raised \$85,000 for Cystic Fibrosis Canada in 2013 through various fundraising events including an annual golf tournament and the *Soaps It Up* National Car Wash.

### Mac's Convenience Stores Inc.

For more than a decade, Mac's Convenience Stores Inc. has been a partner in the fight against cystic fibrosis. In 2013, Mac's raised more than \$133,000 through their charity golf tournament, in-store coin boxes, and Air for Charity Program.

### Siemens

In 2013, Siemens Canada and their employees raised more than \$80,000 for Cystic Fibrosis Canada. Employees participated in many fundraising activities including the Great Strides™ walk and Siemens Canada matched all employee funds raised.

### HealthPartners

HealthPartners is a unique collaboration of 16 Canadian national health charities that are working together to transform the health of Canadians. In 2013, Canadians contributed over \$270,000 to Cystic Fibrosis Canada through HealthPartners' employee giving campaigns.



**Kin Canada**  
Kinsmen • Kinettes • Kin



**SIEMENS**



# 2013/2014 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

Year ended January 31, 2014, with comparative information for 2013  
(in thousands of dollars)

	2014	2013
<b>Revenue</b>		
Chapter - Operating	\$12,510	\$11,895
Chapter - Bequests	1,132	430
Kin Canada	1,140	1,192
Shinerama	1,117	1,035
Corporations	541	720
Royalties	328	407
Other	151	403
	<b>16,919</b>	<b>16,082</b>
Less direct fundraising costs	4,109	3,761
<b>Net fundraising revenue</b>	<b>12,810</b>	<b>12,321</b>
<b>Expenses</b>		
<b>Program:</b>		
Research grants and awards	5,845	5,553
Special research initiative	131	96
Clinics	2,381	2,024
Advocacy/Education	608	588
Public awareness	1,074	1,228
Other	113	86
	<b>10,152</b>	<b>9,575</b>
<b>Other:</b>		
Administration and Meetings	2,590	2,566
Fundraising	929	895
	<b>13,671</b>	<b>13,036</b>
Excess of expenses over revenue before the undernoted	<b>(861)</b>	<b>(715)</b>
<b>Investment Income</b>		
Realized gains on investment	1,231	489
Unrealized gains on investments	676	542
Derivative loss on foreign exchange contracts	(29)	(48)
	<b>1,878</b>	<b>983</b>
Excess of revenue over expenses	<b>\$1,017</b>	<b>\$268</b>

## STATEMENT OF FINANCIAL POSITION

January 31, 2014, with comparative information for 2013  
(in thousands of dollars)

	2014	2013
<b>Assets</b>		
<b>Current Assets:</b>		
Cash	\$2,203	\$1,773
Short-term investments	2,795	2,440
Receivables and other assets	932	1,198
	<b>5,930</b>	<b>5,411</b>
Contribution receivable	159	132
Capital Assets	136	
Long-term investments	11,589	10,803
	<b>\$17,814</b>	<b>\$16,346</b>
<b>Liabilities and Net Assets</b>		
<b>Current Liabilities:</b>		
Accounts payable and accrued liabilities	447	378
Deferred Revenue	367	310
	<b>814</b>	<b>688</b>
Long-term Deferred Contributions	457	132
<b>Net Assets:</b>		
Endowment	94	94
Internally restricted for research and clinics <sup>1</sup>	11,594	12,221
Unrestricted	4,855	3,211
	<b>16,543</b>	<b>15,526</b>
	<b>\$17,814</b>	<b>\$16,346</b>

<sup>1</sup> The research fund which amounts to \$11,594 as of January 31, 2014 (2013 - \$12,221) represents commitments for research and clinic grants, which are scheduled to be paid out in varying amounts during the next five years, ending January 31, 2019.

During the past year, a total of \$6,987 (2013 - \$6,973) was spent directly on research and clinic grants. In addition, the Board of Directors approved grants in the amount of \$6,493 (2013 - \$7,495) for future years.

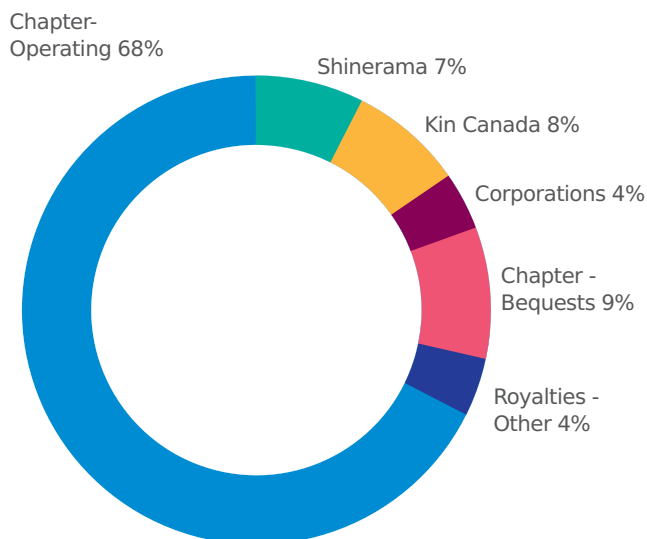
## STATEMENT OF CHANGES IN NET ASSETS

Year ended January 31, 2014, with comparative information for 2013  
(in thousands of dollars)

	Endowment	Internally restricted for research and clinics	Unrestricted	2014 Total	2013 Total
Net assets, beginning of year	\$94	\$12,221	\$3,211	\$15,526	\$15,258
Excess of revenue over expenses			1,017	1,017	268
Transfer between funds		(627)	627		
Net assets, end of year	\$94	\$11,594	\$4,855	\$16,543	\$15,526

## STATEMENT OF FUNDRAISING REVENUE

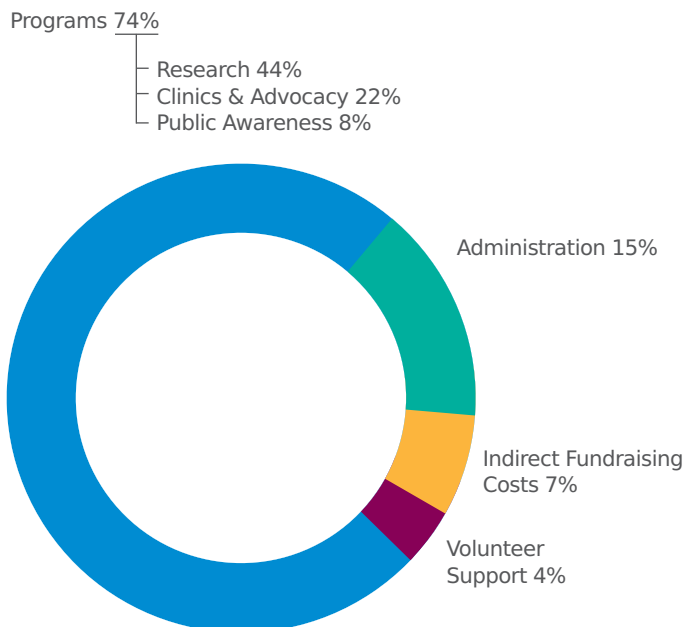
(Net of direct fundraising costs)



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

## USES OF FUNDS

(Excludes direct fundraising costs)



Complete audited financial statements 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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