



Cystic Fibrosis
Canada

Volunteer Information Package

Welcome

On behalf of the volunteer Board of Directors, thank you for your interest in Cystic Fibrosis Canada – Calgary & Southern AB Chapter. By volunteering, you will be part of a winning team of individuals who generously share their time and skills to help people with cystic fibrosis.

Volunteers are one of our organization's greatest strengths and most valued assets. Enthusiastic and dedicated volunteers help at fundraising events, work on committees, recruit and train other volunteers, write letters of support, and promote the organization and its activities.



What is Cystic Fibrosis?

- Cystic fibrosis (CF) affects the **lungs and digestive system**, and is the most ***common, fatal inherited disease*** affecting young Canadians.
- 1 in 25 Canadians carry the defective gene responsible for CF.
- In Canada, 1 in 3,600 children are born with cystic fibrosis, only half will live to see the age of 40.
- Every week, in Canada, two children are diagnosed with cystic fibrosis and one person dies from the disease.
- Most CF related deaths are due to lung failure.
- *There is no cure.*



History of Cystic Fibrosis Canada

In the late 1930s, cystic fibrosis didn't even have a name. Canada first joined the battle against cystic fibrosis in the late 1950s, with a meeting of concerned and anxious parents.

By the early 1960s, the Board of Directors drafted by-laws and created a strong medical advisory committee. They overcame obstacles for obtaining federal status, and on July 15, 1960, our organization was born.

On February 1, 2011 our organization changed its name from the *Canadian Cystic Fibrosis Foundation* to *Cystic Fibrosis Canada*.



About Cystic Fibrosis Canada

Cystic Fibrosis Canada is a national health charity consisting of more than 50 volunteer-organized Chapters.

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

Our purpose is to:

- Fund research towards a cure or control for cystic fibrosis.
- Support specialized clinics and transplant programs.
- Educate the public on cystic fibrosis.
- Raise and allocate funds for these purposes.



About Our Chapter

The **Calgary & Southern AB Chapter** consists of volunteer members who are individuals, families, friends, medical professionals, donors and partners all dedicated to finding a cure for cystic fibrosis. The Chapter employs two part-time staff.

Our members volunteer their time to:

- organize events and campaigns to raise funds to support critical cystic fibrosis related research and care.
- promote public awareness, understanding and acceptance for people living with this devastating disease.
- support people and affected families through their daily, and life-long challenges of cystic fibrosis.

Signature Events:



Local Initiatives

Last year, volunteers throughout Calgary & Southern AB contributed to \$550,940 being raised.

Cystic Fibrosis Canada has a **strong, local focus**. In 2010/2011 our organization provided:

- \$486,760 to research initiatives at the University of Calgary consisting of four (4) research projects; two (2) research fellowship awards and four (4) student research grants.
- \$110,616 to support specialized cystic fibrosis clinics at the Foothills Medical Centre and Alberta Children's Hospital and a Pediatric Outreach Clinic for Southern AB.

Together with critical research, the two local and specialized clinics are vital to the delivery of care to persons with cystic fibrosis as it is a highly complex and challenging disease.



Chapter Volunteers

A local volunteer Board of Directors oversees the activities and daily operation of the Chapter. These volunteer positions are for a term of two (2) years.

2011/12 Board Members:

- | | |
|----------------------------|----------------------|
| ■ President | Jeanette Demers-Weir |
| ■ VP Volunteers & Partners | Deb Laval |
| ■ VP Publicity & Promotion | Debbie Carver |
| ■ Treasurer | Carol O'Connor |
| ■ Secretary | Laura Read |
| ■ Risk Manager | Steve Peplinski |
| ■ Newsletter Editor | Cara Wiley |
| ■ Director-at-Large | Susan Godfrey |
| ■ Director-at-Large | Tammy Hironaka |



Chapter Volunteers Cont...

Other director positions include:

- | | |
|-----------------------------|-----------------|
| ▪ Children's Clinic Liaison | Trevor Phillips |
| ▪ Adult Clinic Liaison | <i>Vacant</i> |
| ▪ Shinerama Liaison | Karen Yurkiw |
| ▪ KIN Liaison | Davina Thuroo |

Committees:

- 65 Roses Ladies Golf Classic
 - Wrapping for a Cure
 - Great Strides Walk
 - Ride for Cystic Fibrosis
 - Charitable Giving / Fund Development
 - Community Engagement
- ...other AdHoc committees



Volunteer Activities

Each member of our Chapter, from the President to the newest family, is a volunteer.

You can give as much or as little time as you like, doing things such as:

- joining an event committee
- speaking to community groups about cystic fibrosis
- generating fundraising ideas
- planning and organizing a future fundraising event or campaign
- developing publicity, or using your contacts to raise awareness
- speaking with friends, family and colleagues about cystic fibrosis and encouraging them to get involved
- helping out at an event, or other fundraiser throughout the year
- setting up an ongoing coin collection program with your favourite stores



Volunteer Recognition

We value the efforts, time and commitment of our volunteers. Cystic Fibrosis Canada has a comprehensive and rewarding volunteer program including:

- Local Chapter Awards for Volunteers
- Regional Volunteer Awards
- National Volunteer Awards
- Invitation to the Calgary & Southern AB Chapter's Volunteer Appreciation Reception and Annual General Meetings



Delivering Results

Funding by Cystic Fibrosis Canada has directly contributed to Canada becoming a world leader in cystic fibrosis advancements and we have seen tremendous results including:

- Increased median age of survival for patients with CF from four to beyond 40 years – ***the survival rate of persons in Canada with CF is the highest in the world;***
- Pioneered the world's first successful double-lung transplant with a CF patient; and
- Discovered the gene responsible for cystic fibrosis.

Researchers across Canada are exploring all aspects of the cystic fibrosis puzzle; from investigating *new methods of fighting infection and inflammation in the lungs* to finding *new therapies that target the basic defect* at a cellular level.



Volunteers Make a Difference

It is with the continued support of all Canadians, and generous support of our volunteers and community partners, that we will enable the necessary research and quality care for people with cystic fibrosis.

Together, we can set our sights on a future where cystic fibrosis is no long a progressive, life-shortening disease.

For more information, please contact:

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