

January—March 2008 Issue 39

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**BOARD OF DIRECTORS:**

President	Caroline Warren
VP Fundraising	Patti Magnan
VP Publicity & Promotions	** vacant **
Secretary	Julie Mitchell
Treasurer	Judy Quathamer
CF Adult Director	Sherri Selby
CF Clinic Liaison	Joan Tabak
Director at Large	Julie Hornig
Director at Large	Charlene Keller
CF Kin Liaison	Gerry Boehm
CF 65 Roses Liaison	Rob Sokil
Chapter Coordinator	Emily Westwood
Fundraising Coordinator	**vacant**
Newsletter Editor	Patrick Lépine

**65 Roses Oilers Dinner**



Steve Staios, Tom Gilbert, Andrew Cogliano, and Sam Gagner were the four Oiler guests of honour at this year's 65 Roses Oilers Dinner. Our honorary chair, Ethan Moreau and his wife Ornella were not able to attend due to medical appointments in Los Angeles. We missed having them in attendance at our dinner, but it's great to see Ethan back on the ice. Bryn Griffiths of Team 1260 Radio emceed the program for the evening. Chapter President Caroline Warren announced the CF Julia award for Ethan and Ornella Moreau. This award is given to acknowledge someone who has made a significant, ongoing (at least three years) contri-

but ion to the CCFF through a chapter. Steve Staios accepted the award on behalf of the Moreaus. Guests included representatives from sponsoring corporations as well as Steve's wife Susanna and the Staios children. The guest speaker for the evening, Blain Davis, shared his personal story of learning that his son has cystic fibrosis and his recent project to raise money to help find a cure or control – the Sahara Desert ultra-marathon. Everyone, children and facility staff included, enjoyed a wonderful evening and the event raised \$19,200 for CF. Our Chapter thanks 65 Roses Chair Rob Sokil and all the volunteers and participants for this success.



Honored guests at the 65 Roses Oilers Dinner. L - R, Oilers Tom Gilbert, Sam Gagner, Andrew Cogliano, CF dad and ultramarathon runner Blain Davis, and Oiler Steve Staios

## Message from the Regional Director – Beverly Van Horne

Here is a very brief look at the September 2007 Board of Directors meeting:

We were told by Cathleen Morrison, our CEO, about Dr. Land's ibuprofen study and how it appears that there is a small effect in the rate of decline in lung function at the beginning of treatment and that the effect becomes larger over time.

The Alberta Aids to Daily Living has removed air compressors from their coverage. Kelly Gorman, our Manager - Social Action, along with Alberta Clinic Directors are looking into the potential impact this decision will have.

Adax is taking its water soluble vitamin K off the market three years before approval of a new product. The Foundation is concerned since the crushing of tablets is not good for children under the age of one.

Debra Berlet, our Vice President, Publicity & Promotion, and Edna Cahill, the Regional Director from Newfoundland & Labrador, presented to the Board the CCFF

Branding Project Core Recommendations.

These core recommendations include: CCFF positioning and vision statements, a vivid description with six goals, four core values and a new English tagline. The Board of Directors approved the recommendations and the new CCFF brand will be rolled out to Chapters across the country this fall.

Kim Steele, our Consultant for Special Projects, gave an update and recommendations concerning the CF Drug Coverage Project. The project goal is:

To use the research findings to encourage provincial governments, in jurisdictions in which it is difficult to obtain identified medications, to modify policies and/or practices around drug listing and prescription drug coverage, for the benefit of individuals with cystic fibrosis.

The Atlantic Region was identified as a first target of focus.

There is a multi-clinic study proposal in which High Frequency Chest Com-

pression (The Vest) vs. positive expiratory pressure (PEP) is being considered.

There will be an article in Circle of Friends on airway clearance techniques as well as information on our website, [www.ccff.ca](http://www.ccff.ca).

I will conclude with this wonderful news: gross revenues for the 2007 Great Strides™ walk are up 45% from the previous year at \$1,157,875.

There were \$400,000 verified online donations which was \$300,000 greater than 2006 and there were over 6,000 online donors. 58% of Hbc cards were donated back to the CCFF. Congratulations to organizers, donators, volunteers and walkers on a job very well done!



## PRESIDENT'S CORNER

Wow – this is my last “President’s Corner!” After being your chapter president for three years, it’s hard to imagine not doing some of the tasks of the president, but I’m sure I’ll adjust! What to talk about in my final corner? That’s easy!

As president, I had my fingers in a lot of pies and there were definite challenges in the role. As luck would have it, the two VP’s of Fundraising, Marcia and Patti, were simply amazing in their roles and without their dedication, I would have gone crazy! So, I have to offer up a special thank-you to them for their leadership in the fundraising. I also have to say a special thanks to Judy, our Treasurer for the last three years. When

it came to budgeting, she knew exactly what to do, and I’ll be forever grateful for her lead on that process! A special thank-you to the board members. Each of them has been involved in fundraisers and helped to set the direction of the chapter and made some tough decisions. They attended the meetings with enthusiasm and have been a huge support for me in my role. I couldn’t have done it without them.

Another important thank-you is for Sue, our past president. Whenever I needed her input, she was always there. She was a great support to help with the stuff that I thought I knew, but I really didn’t, so she set me on the right path. Sue will officially be off the board now, and her presence at the

meeting will certainly be missed. I save my final thank-you for someone that never ceased to amaze me. She joined our chapter part way through my tenure as President and I can’t imagine our chapter without her. Her work ethic, her passion, her dedication, her willingness to step in, her ability to communicate and lead, have all been a huge asset to our chapter, and I know I could not have done my job without her. A huge thank-you to Emily for her continual support. I know the new President will appreciate her as much as I have! I know the chapter will continue to thrive and raise funds and awareness for cystic fibrosis. It’s been my pleasure to be your President. I look forward to the next year as Past President!

## Streamlining Risk Management

The Edmonton & Northern Alberta Chapter has decided to take a step forward in eliminating the risks involved with events. A Control Checklist will be created that will encompass the many facets of planning and creating a successful fundraising event. This document will be for use by all planning committees. The Checklist will

be based on the one already developed by our national office, but will also include questions related to local issues. An example of a question on the checklist is: "Have signs been posted to indicate that parents or guardians are responsible for their children?" Thinking through these questions will help us remember to check on important details

that we may have overlooked. Categories to be included in the checklist are:

- Insurance Requirements
- Finances
- General Safety
- Alcohol
- Medical and Sanitation
- Minors
- Vehicles
- Volunteers

## Treasurer Needed

The term for our current treasurer ends March 1, 2008, and we are in need of someone who is willing to assume this volunteer position.

The position involves important responsibilities, much of this is in the nature of monitoring and supervising the work of the chapter manager. She handles chapter revenue (making bank deposits, reporting deposits of funds to National, maintenance of all records), chapter expenses (requisitioning transfer of funds for chapter expenses, monitoring chapter expenses to be in line

with budget, issuing cheques, reconciling bank accounts, maintenance of records) and preparation of tax receipts.



As treasurer your specific responsibilities would include: completion of the Quarterly reports which are

submitted to the national office (revenue, expenses, bank account reconciliations); reports to the Alberta Gaming and Liquor Commission for major gaming events such as the hockey draft, the casino, and the Grey Cup raffle; preparation of the chapter's annual budget, in consultation with the chapter's executive committee; attendance at chapter monthly board meetings to provide financial reports.

Please contact Caroline, the Chapter President, or Judy, Chapter Treasurer, if you would like more information or are willing to volunteer for the position.

## CF Sahara

Last October, Blain Davis ran and at times shuffled his way through the six gruelling stages of the Sahara Race to raise awareness of the disease that afflicts his son Jack. He has raised over



\$26,000 to date, and we are still receiving donations! We are so proud of Blain. He has accomplished so much even when faced with some of the biggest obstacles imaginable!

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 School  
 7814 - 83 Street  
 Edmonton, AB T6C 2Y8  
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Websites: [www.cfedmonton.ca](http://www.cfedmonton.ca)  
[www.ccff.ca](http://www.ccff.ca)

Clinic: University Hospital  
 (780) 407-6745



Edmonton and Northern  
 Alberta Chapter

Calendar  
 January – April, 2008

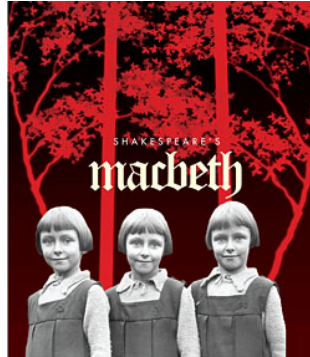
- Jan. 25 CF Information Night
- Jan. 26 Garneau Safeway Miles Bring Smiles
- Jan. 29 Board meeting
- Feb. 9 Evening at the Citadel
- Feb. 9 Garneau Safeway Eating Right Charity Checkout
- Feb. 12 Parent support group meeting
- Feb. 16-17 Kin Corporate Cup
- March 1 Garneau Safeway We Care Day: Coupon Book Launch
- March 2 Chapter Annual General Meeting
- March 4 Board meeting
- March 11 Parent support group meeting
- April Hockey Draft
- April 8 Board meeting
- April 8 Parent support group meeting
- April 24-26 National Annual Gen. Meeting, Banff

## EVENING AT THE CITADEL

The Edmonton chapter of the Canadian Cystic Fibrosis Foundation invites you to an evening of theatrical entertainment, plus much, much more! The "Evening at the Citadel" fundraiser will take place on February 9, 2008 at the Citadel theatre.

This event includes a wine and cheese reception, the performance of "Macbeth", a Grand Marnier and dessert reception following the play, plus a silent auction. When Macbeth is told that he will one day become King of Scotland, he is

urged by his ambitious wife to take destiny into his own hands. Referred to by some as



the ruby in the crown of Shakespearean tragedy, *Macbeth* is a brilliant and vivid portrait of a couple's willing descent into evil.

Tickets for this event are only \$65.00, an outstanding bargain. This would make an excellent gift for those on your list who have everything! Tickets will be available at the CF office after December 1, 2007 (466-2265). We would also greatly appreciate donations for the silent auction for this event, if anyone has restaurant or hotel connections, these make great silent auction items! Please help us in the fight against CF, plus have a fun evening out!

## Hockey Draft: Chairperson needed



For 20 years Doug Milne has chaired

the Hockey Draft to

raise money for cystic fibrosis. This will be the last year that he will be able to lead this fundraiser.

If you have an interest

in helping or leading in the future, please let us know as soon as possible, so Doug can show you the ropes this year.

## MiniQuad /Pocketbike – Winners



Jeff Grimson, Edmonton

Suzuki QuadSport Z50 (mini quad)  
 Donated by Alberta Cycle  
 Retail value \$2649

We held the draw for raffle winners for the Suzuki QuadSport mini quad and Repsol pocketbike on November 30, as scheduled. Both winners were excited to receive the call notifying them that their names had been drawn and both have claimed their prizes. Both prizes for this raffle had been donated, the miniquad by Alberta Cycle, and the pocketbike by Gingerbread Racing. Thanks to these two businesses, we were able to raise \$4558.15.



Todd Kitagawa, Blackfalds

Repsol Pocketbike  
 (mini bike with gas engine)  
 Donated by Gingerbread Racing  
 Retail value \$399.00

## CF Support Group

“Physio, calorie intake, enzymes, antibiotics, clinic, nebulizers, Tobi, fat content, pancreatic discomfort, stool textures....”

Those are not words that most parents or caregivers have in their daily vocabulary! But for those of us with children who have CF, we are all too familiar with our daily obsession with

these terms!! In response to many, many requests, the Edmonton and Northern Alberta Chapter for Cystic Fibrosis is pleased to initiate it's first ever **CF Parent Support Group!!** This initiative is an attempt to provide a helpful way for parents and family members (or caregivers) to express thoughts,

questions, and get helpful tips about CF from others facing the same issues.

Who? Parents and other caregivers of those with CF. In order to provide the best environment, children will not be able to attend. When? **Tuesdays: Feb. 12, Mar 11, Apr. 8, 6:30-8:00pm** Where? **Edmonton and Northern Alberta CF Office** located on the 2<sup>nd</sup> floor of St. James School 7814 – 83 Street, Edmonton. RSVP: **Please call the office at (780) 466-2265 to confirm your attendance.**



## Garneau Safeway We Care Program

The Safeway We Care program is a program wherein the employees at each Safeway store in Western Canada choose and raise funds for a local charity. The employees then work with their chosen charity

from January to April to develop a fundraising and awareness program for that organization. In 2008, the Safeway We Care program will focus on raising funds for children and families living with physical, develop-

mental and neurological disabilities.

The Garneau Safeway has selected our CF chapter as its charity this year.

The first event will be a “Charity Check-Out” on January 26.

## CF Fundraising Casino

Our CF Fundraising Casino took place on August 29 & 30, 2007 at the Century Casino. It was our first time at this particular casino.

It was great to see the usual crew of volunteers and equally great to see some new faces. Thank you to all the volunteers, from Marcia Milne,

Casino Chairperson, for taking time from their busy summer schedules to work the long shifts and sometimes even two shifts.

Our casino earned the chapter \$ 78,282.07 !!!!

We will see you at the next one in the second quarter of 2009.

Eugenia & Joe Nimchuk

Patricia Rollison

Terrill Buttrey

Vic Rudkowski

Patti Magnan

Greydon Chretien

Arnold Erickson

Marcel Fontaine

Julie & Ralph Hornig

Sue & Ted Zukiwsky

Laura Krefting

Abe Van Dorp

Bob Rennie

Charlene Keller

Charles Pratt

Conrad Michael

Barb Jensen

Jane & Larry Filipow

Rod Sherman

Caroline Warren

Ken Orchard

Doug Milne

Cathy Gaida

Ashley Galloway

Chris Small

Vic Freire

Christie Braden

## GREY CUP RAFFLE

Leading up to the November 23, 2007 Grey Cup game, our army of volunteers was busy selling tickets for our annual Grey Cup raffle. Thank you to every one of you who



accepted and sold tickets. We have been operating this raffle for 36 years, since 1971, and 2007 was our second most successful year ever. The raffle raised \$7,560.23.

## Biking Canada for Cystic Fibrosis

Allison Watson and her brother Davey are two university students who are biking across Canada this summer to raise awareness about CF and how it affects Canadians. Allison who has CF herself wishes "to encourage other people with Cystic Fibrosis that anything is possible and that Cystic Fibrosis does not define who we are or what we can do".

To learn more about this trip, the people involved, the route, and the itiner-

ary, please check out [www.bikecanadaforcf.weebly.com](http://www.bikecanadaforcf.weebly.com).

If you are close to the route through Alberta (Jasper across to Lloydminster), you can help by providing a place to stay or to stop for a meal, or by riding along with Alley and Davey for part of the trip. Let them know if you can help. You can reach them through connections given on their website.



## CCFF Policy: Burkholderia cepacia complex

Some adults and children with cystic fibrosis who acquire Burkholderia cepacia complex suffer very serious health consequences. Furthermore, strong evidence exists indicating that some B. cepacia complex strains can be transmitted from one individual with CF to another. Although it is not possible to eliminate the risk that persons with CF may acquire B. cepacia complex, the Canadian Cystic Fibrosis Foundation (CCFF) is seeking to reduce this risk as much as possible. It is therefore with great regret, that the CCFF has adopted the policy outlined below, concerning the participation of persons colonized with B. cepacia complex in meetings and events organized by your Foundation, and by its associations, chapters, partners and supporters. This policy was adopted after considerable discussion and review of all available scientific data and the policies of other jurisdictions and countries.

*We want to say clearly to adults and children colonized by B. cepacia complex that you are valued members of your Foundation and of the CF community at large. To the extent your capacity to contribute is constrained, the whole CF effort in Canada is diminished. Your Foundation is committed to exploring all possible means of permitting your continued participation – short of personal attendance – in Foundation, association and chapter affairs.*

It is the policy of the CCFF that persons who know they have tested positive\* in the last 12 months for B.

*cepacia* complex shall not attend, in person, CCFF meetings and events where other persons with CF may be in attendance. Persons with CF should be aware that some individuals who have CF may be in attendance at a meeting or event without knowing that they have B. cepacia complex or other potentially harmful bacteria. These bacteria can be passed from one person with CF to another person with CF. Some individuals with CF can experience a serious decline in health if they become colonized with these bacteria. It is believed that persons with CF face a relatively low risk of acquiring B. cepacia complex by attending a meeting or meetings at which other individuals with CF are present. However, persons with CF are strongly cautioned to avoid prolonged, close physical contact with each other. Anyone with CF who attends a meeting does so at his or her own risk, and the CCFF accepts no responsibility for any risk to health involved in attendance, or in any social contact between persons with CF. Please contact your CF clinic director or the Foundation's office for further information.

\*The Medical/Scientific Advisory Committee clarified that, for those who have tested positive for B. cepacia complex in the past, it would be necessary that the four most recent, successive sputum cultures – taken at three-month intervals – not culture positive, in order for an individual to be considered "no longer positive" for B. cepacia complex.

The Edmonton and Northern Alberta Chapter Annual General Meeting will be held on Sunday, March 2, 2008 at the Kinsmen River Valley Place in Edmonton at 2:00 pm