

CF GOES TO THE SAHARA DESERT

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President	Caroline Warren
VP Fundraising	Patti Magnan
VP Publicity & Promotions	Salima Nurani
Secretary	Michelle Husch
Treasurer	Judy Quathamier
CF Adult Director	** vacant **
CF Clinic Liaison	Joan Tabak
Director at Large	Julie Hornig
Director at Large	Julie Mitchell
Past President	Sue Zukowsky
CF Kin Liaison	Gerry Boehm
CF 65 Roses Liaison	**vacant**
Chapter Manager	Emily Westwood
Fundraising Co-ordinator	Yvonne Wupori
Newsletter Editor	Patrick Lépine

Blain Davis, former board member of the Edmonton and Northern Alberta Chapter is embarking on his own unique CF fundraiser. The Sahara Race, 250 kilometers across the Sahara Desert, will be held in October 2007, and will last 7 days. Blain has several corporate sponsors and is seeking donations for CF through this event. His story was published in a brochure promoting his marathon journey.



Blain will run through the Sahara desert in October 2007 to help raise research money to find a cure for Jack's CF and for the thousands of other children who have this disease.

The Sahara race is a self supported footrace across 250 kilometres, in six stages over seven days in western Egypt. Blain must carry all his own food, gear, and clothing throughout the race. Please see our Chapter's website, www.cfedmonton.ca for more information about the Sahara Race. Please become a "Pledge Partner" with Blain in his run by making a donation to Cystic Fibrosis.

Jack is 3 years old, full of energy and life. He loves to wrestle with his dad and colour with his mom. On the outside, Jack looks like any other 3-year-old boy. However, on the inside there is a battle for his life." Jack has a fatal genetic disease called Cystic Fibrosis. The disease primarily attacks his lungs and digestive system.

Three times a day, Jack endures a one-hour session of inhaling medications and physiotherapy to help keep his lungs free of infection. He takes over 20 pills a day to help him digest his meals.

"As a father of a son with a fatal disease, I struggled to find something tangible to help. My wife and I are diligent in giving him therapy and medication. But I have found something more that I feel I can do – Run."

Chapter Awards Presented at AGM

CF Clinic Nurse, Joan Tabak, was this year's recipient of the Ron Moore award. President Caroline Warren presented it to Joan on Sunday, March 4 at the Chapter AGM. The award was first presented in 2006 and is given to someone in the chapter whose approach to life and to the fight against cystic fibrosis reminds us of Ron and his "Give Life All You've Got" attitude. Not only do CF patients and families appreciate Joan, but so does the Edmonton and Northern Alberta Chapter of the Foundation. Joan goes above and beyond her job by supporting the Chapter board and many CF fundraisers and events.

The Volunteer of the Year award was presented to Esmond and Shirley Warren. They volunteer frequently and can be counted on to pitch in whenever there is a need.

A Certificate of Appreciation was presented to one individual, Allan Bartman, for his ongoing work on behalf of CF.



PRESIDENT'S CORNER

Budgets! What an event a budget is! I have experienced budgets in my home and at work, but I have learnt in the last couple of years that neither of those budgets are near as important as the CCFF budget...not even close! So, what is our budget process and why is it so important? In the October time frame, a group of us get together to determine what our budget should be for the next fiscal year. We go through each of the fundraisers and determine the

income and the expenses for each. Then we add in our operating costs (such as rent and utilities), divide everything appropriately into the quarters and ta-da! We have a budget. Pretty straight forward! Then the budget is presented to the local board, and after it's approved, it is sent to the national office. They accumulate the budgets from all the chapters and from there, they determine how much money is available for research projects. That's where the accuracy of our numbers becomes critical. If we don't meet our budget, then we are short

money that's committed to research. If we exceed our budget, then a research project that could have been funded, may not get the resources it needs. So, an accurate chapter budget is very important in the search for a cure or effective control.

After all of that, our budget for the Edmonton chapter is \$225,000. We are responsible for providing \$225,000 to our Foundation office to support the foundation and its research projects. Sound like a lot? It is! Will we do it? With your help – of course!

Caroline

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? Wednesdays: April 11, May 9, June 13, 6:30-8:00 pm

Where? Edmonton and Northern Alberta CF Office located on the 2nd floor of St. James School 7814 – 83 Street, Edmonton.

RSVP: Please call the office at (780) 466-2265 to confirm your attendance.

Live Web Cast – April 28

During the Foundation's annual meeting and conference, two sessions will be made available through live webcasts to anyone interested. These two sessions are the "Annual Day for Adults with Cystic Fibrosis" (8:50 am – 12:30 pm EDT) and the Medical/Scientific Conference (2:20 pm – 5:00 pm EDT). Please visit the home page of the Foundation's website, (www.cysticfibrosis.ca) prior to April 28 for further information and for instructions.

Message from the Regional Director – Beverly Van Horne

I have made a promise for my second term as Regional Director to write not just reports to the Alberta Chapter Presidents but also an article to the Newsletters after each Board of Directors meeting. If you would like more details than provided in this very brief look at highlights of the February 24 meeting, your Chapter Presidents have my full report or you can contact me at bgvanhorne@shaw.ca.

Congratulations to everyone! By far the most excitement was over the news that we had the highest ever gross income in the history of the CCFF! We were able to fund two extra research projects that the Medical/Scientific Advisory Committee (M/SAC) had considered very promising but could not afford according to the budget. Our 2007-2008 research budget is set at \$6,253,587! That's a \$400,000 increase from last year. The M/SAC clinical budget is \$1,914,749 for a

total program budget for 2007-2008 of \$8,168,336. Our fundraising dollars are working very hard at the very best research and clinical support.

Thanks to a Medical/Scientific visioning day, a meeting with the Adult CF Committee and a strategic planning workshop with the Executive Committee and senior office personnel, we now have a Three-Year Plan. It includes increasing the investment in CF research, improving the care and treatment for young Canadians with CF, strengthening the Foundation, targeting new audiences and planning the funding of the goals. It also includes a new direction: bringing new therapies for CF to market. The Canadian Cystic Fibrosis Consortium will go through key phases of development in order to translate research

discoveries into novel therapies for CF.

I would like to say congratulations to all of the Kin Clubs who received a 5 year or 10 year Kevin Denbok Kin Care Crest which celebrates the number of continuous years of donations to cystic fibrosis. Your continued donations to CF mean so much. I will conclude by sharing last year's total for the Great Strides™ walk: \$640,000! That is a 27% increase from 2005 and includes \$38,000 from Kin walkers. Good luck to the committees who are planning this year's walk. I am hoping for good weather for all on May 27.

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Edmonton and Northern
Alberta Chapter

CF Stinks**Calendar**

April 3	Board meeting
April 11	Hockey draft: dead line for ticket purchases
April 11	Parent Support Group meeting
April 27-29	National Annual General Meeting
April 28	Live Webcast – Annual Day for Adults with CF
May 1	Mail campaign mailout
May 1	Board meeting
May 9	Parent Support Group meeting
May 27	Great Strides Walk at WEM
June 5	Board meeting
June 10	Original Joe's Run for the Lung
June 9	Parent Support Group meeting
June 22	Advocis golf tournament
June 23	Ride for the Breath of Life Motorbike Ride
June 24	65 Roses Night at the Races with Edmonton Eskimos
July 3	Board meeting

AN EVENING AT THE CITADEL

The biggest and best ever Evening at the Citadel was held on February 10, 2007. Tickets sold out well in advance, and the few who purchased last minute tickets did so only when others had to cancel. The 2007 evening made just under \$22,000.

When the Tucker Amphitheatre opened at 6:45 for the wine and cheese reception and the silent auction, people had already started to gather. The auction featured a varied assortment of items – paintings, jewellery, a signed Oilers jersey and stick, tickets to Oilers games, Via Rail tickets to Vancouver, beautiful quilts and pottery, a Cancun condo for a week, and many, many others. The string quartet, "String Beans," provided music for the reception.

As always, the Citadel Theatre provided a very entertaining, and well-staged and acted theatre production, "The Constant Wife". During the intermissions, bidders returned to check on their auction items. Finally, during the reception which followed the play, the "String Beans" played music once again, and guests enjoyed desserts, Grand Marnier, coffee, and punch. Door prizes were announced, the silent auction ended, and the raffle of the Inuit sculpture closed. The winner of the raffle was M. Fata of Edmonton. We'd like to thank the organizing committee, especially Julie and Ralph Hornig, for a wonderful evening and for raising such a significant amount for CF.

Voices of Hope

The Canadian Cystic Fibrosis Foundation extends heartfelt thanks and congratulations to all Kin Clubs that received the Kevin Denbok Kin Cares Crest. Kevin, who lost his battle with cystic fibrosis, helped forge a long-lasting relationship between Kin Canada and the Foundation.

Five Year**Zone One**

Spirit River Kinettes

Zone Two

Camrose Kinsmen
Edmonton Kinettes
Edmonton Kinsmen
Leduc Kinettes
Leduc Kinsmen
Spruce Grove Kinsmen
Wetaskiwin Kinsmen

Zone Three

Vegreville Kinettes
Vegreville Kinsmen
Wainwright Kinsmen

Zone Four

Innisfail Kinsmen
Ponoka Kinettes
Red Deer Kinsmen
Stettler Kinettes

"0" Zone

Calgary Kinettes
Hanna Kinettes
High River Kinsmen
Stamper City Kinsmen

Zone Six

Brooks Kinsmen
Medicine Hat Kinsmen
Milk River Kinsmen

Zone Nine

Drayton Valley Kinettes
Mayerthorpe Kinettes
Mayerthorpe Kinsmen

Zone Eleven

Fort Saskatchewan Kinsmen
St. Albert Kinettes

Ten Year**Zone Two**

Fort Edmonton Kin
Wetaskiwin Kinettes

Zone Four

Red Deer Kinettes

"0" Zone

Kinsmen Club of Calgary
Claresholm Kinettes
Stamper City Kinettes
Vulcan Kinettes

Zone Six

Brooks Kinettes
Medicine Hat Kinettes

Zone Eleven

Fort Saskatchewan
Kinettes

Correction

The final sentence of the article about the 65 Roses Oilers dinner in the January issue of the newsletter was missing. It stated the event raised over \$20,000. Once again, our sincere thanks go out to sponsors of this event.