

The Presidents Corner

On the first Tuesday of every month, a group of dedicated people get together for an hour and a half and talk about what can be done in the fight against cystic fibrosis. They talk about fundraisers – upcoming ones, completed ones, potential ones and even resurrecting old ones. They talk about publicity of the cause – through newspapers, television and radio. They talk about what’s happening at the national foundation level and other chapter successes. Thankfully, they don’t have to talk about finding space for the office anymore, but they do talk about what is happening in the office. Sometimes, they go off topic; most of the time, there are goodies; and all the time, they share a few laughs.

Who are these people? These are your Board of Directors. There are seven board positions - President, VP of Fundraising, VP of Publicity and Promotion, Past President, Secretary, Treasurer and Directors at Large. And, there are four liaisons - Adult liaison, clinic liaison, Kin liaison, and a 65 Roses liaison. Finally, we cannot forget our very talented and skilled staff - our Chapter Coordinator and Fundraising Coordinator - who also attend the meetings. Each one of these people participate in sharing ideas, as well as take on responsibilities that fit within the time and skills they have available.

This is the time of year when we start looking for new blood to join the board. Many of our board members have been on the board in one capacity or another for 10 years or more. They have worked hard and the advances in CF care that we all appreciate are partially due to their efforts. But, they deserve a break. I know that thinking about becoming a board member can be daunting because the illusion is that you will be asked to do 100 additional things in an already busy life, or you will struggle on your own to get something done. But truly, many people start on the board as a Director at Large - which is probably a time commitment of 30 hours a year. And, our staff and other board members will always be there to help.

So, what does it take to be a board member? A little time, a lot of enthusiasm and the desire to make a difference. If you think you might like to try it, or if you have questions, please call me at 417-1153 and I'll be happy to answer them. CF cannot be beaten without the help of people like you - so please, take some time to figure out if you can help.

From everyone on the board and in the office, have a great 2006!

Caroline

65 Roses Oilers Dinner



Ethan Moreau, Edmonton Oilers hockey player, and Honorary Chairman chaired this year’s Oilers Dinner held on October 30 at the Royal Glenora Club. In the photo he is presenting an Oilers puck which he had signed to *Jerry Gordon*, one of the dinner guests. Before the dinner, guests had the opportunity to chat with Ethan and his wife Ornella. After a superb dinner, J’Lyn Nye, newscaster for Global TV, gave a very

moving talk about living with CF and the need to continue to support the cause financially. Each guest sponsored one game of this year’s Oilers season. Sponsorship means that during their Oilers game, the sponsor’s name will be posted on the reader board above the rink. Provision of this reader board announcement is a donation from the Edmonton Oilers, so each paid sponsorship becomes a donation to CF. Thanks to Medallion Marketing for the wine, to donors of auction items (including both Ethan Moreau and Georges Laraque), to the Kinsmen Club of Edmonton for a donation to cover part of the dinner cost, and a big thanks to the game sponsors for supporting this event. When financial records are complete, this event will have raised almost \$18,000.

AGM

You are invited to the 2006 Annual General Meeting of the Edmonton and Northern Alberta CF Chapter

Date: Sunday, March 5, 2006
Time: 3:00 p.m.
Place: Kinsmen Clubhouse
Directions: Across the field and north of the Kinsmen Sport Centre in the river valley.

Car Magnet Ribbons

Help spread awareness about CF and at the same time support research funding by purchasing one or more magnetic car ribbons. Stick them on your car, and you will be “on the job” with no effort at all every time you go to the mall parking lot. The cost of each magnetic ribbon is \$10.00. Please call the office at 466-2265 to place your order.



Recent Fundraisers



Jerad & Eric Bergheim

Candid Cowboys

Lots of cute cowboys came to the Canadian Finals Rodeo for the weekend of Nov. 13, 14, and 15, but none so cute as the ones who supported CF by having their photos taken at our Candid Cowboys booth. Led by Fundraising Coordinator Tammy Turko, a group of volunteers manned a photo booth equipped with western style props. The event raised \$805.00. Thanks to volunteers Esther Szatnary, Chris Small, Shirley Warren, Esmond Warren, Amanda Criss, John Tabak, Abe Van Dorp, Erica Van Dorp,

Brent Van Dorp, Suzanne Wiebe, Kara Clancy, Beth, and Monica Perras for helping out. And extra thanks to all those who had photos taken to raise funds for CF, especially the cowboys in this photo, Jerad and Eric Bergheim.

Christmas Craft Sale

The Strathcona Farmer's Market was the site this year for our Christmas Craft sale. We had quite a varied assortment of items, some of which sold very quickly and had people asking for more. The volunteers who manned our table for the two Saturdays, Nov. 26, and Dec. 3 found that too much variety seemed to hinder sales a bit so we may want to focus on several specific items next year. However, in the two days, we made over \$1000.00! Thanks to all the crafters who made and donated items and to the volunteers who sold them.

Grey Cup Raffle

What an exciting football game between Edmonton Eskimos and Montreal Alouettes on Sunday, November 27! There was extra excitement for a few people, the winners of our annual Grey Cup Raffle. Thanks to the many people who sold tickets. Congratulations to the raffle winners.

Clinic News

Recognizing persons with CF for their accomplishments and celebrating with their families was what it was all about on December 22, 2005. Winners of Creon awards from the past 2 years, their families and some of the CF team members met at the Century Grill to honor the 5 winners.

Here are the winners for 2004

Verity Filipow 12 years old

Verity won for her creativity. At clinic she frequently gave us pictures that she made for us. One of the things she has done is create a children's booklet on CF.

James Tapankov 32 years old

James won in the category for Leadership. He is currently chair of the Canadian Adult CF Committee and a participant in CF Worldwide Board. He is a frequent contributor of Circle of Friends the Canadian adult newsletter.

Melanie Bouclin 23 years old

Mel is an artist and won an award for creativity. She works in oils, acrylics, clay and wood sculpture. She has sold some of her work.

Submitted by Joan for the CF Team

Winners for 2005

Kylie Bain & her sister Shaley



Kylie Bain 13 years old

Kylie loves to make crafts, paint, draw, play the piano but especially she loves to write. For this she won an award for her creativity. The Royal Canadian Legion awarded her in the local, Command and provincial levels. She has also composed piano music and received gold at the Canadian Composers Festival.

Sherry Selby 41 years old

To know why you are sick and to find a cure has pushed Sherry to pursue her life long dream, to be a scientist, do medical research and teach. Sherry has excelled all though school completing her M.Sc in Biochemistry and is working on her Ph.D., despite being ill and having a lung transplant in 2000. Sherry won an award for Education.



We congratulate these 5 winners.

Do you have Cystic Fibrosis?

You too can apply. Creon Awards are sponsored by Solvay.

4 winners are awarded in each category: Leadership, Creativity, Education, and Sports. Ask at the CF Clinic for more info.

An Evening at the Citadel

Saturday, March 25, 2006

6:45 p.m. Private Reception & Silent Auction
- wine, cheese, door prizes -

8:00 p.m. *Trying*

Joanna McClelland Glass' gentle play pays tribute to the unlikely and touching relationship that evolves between a brilliant legal giant and an equally determined young woman.

"One of the finest pieces of theatre in many years."
CHICAGO SUN TIMES

"The most entertaining, wholly engaging play you'll likely have the pleasure of seeing this season."
THE WINNIPEG SUN

10:00 p.m. Private Reception - desserts, Grand Marnier

Tickets are only \$55.00 each. Limited number of tickets available. Phone Cystic Fibrosis Office at 466-2265.

Wetaskiwin Kinette 7th Annual Craft Auction

The Wetaskiwin Kinette Club held their 7th Annual Craft Auction on November 4th, 2005. What a night!!! With all the disasters in the world this year, and charitable dollars being stretched to the fullest, who would have thought that the Auction would see a 20% increase over last year's total. But that is what happened! The Kinette Club of Wetaskiwin through a lively night of bidding raised \$8,500.00. The evening began with an interesting presentation by Doug Milne. The audience was captivated by his slide presentation and description of the Mt. Kilimanjaro climb. So much so, that the framed prints that Doug graciously donated to the auction brought in almost \$200. The smile on Doug's face said it all. He was so happy to contribute to our club and to C.F, long after the climb has been finished. Each year, more and more men are attending and joining in on the fun and bidding wars. The mystery bags seems especially interesting to men. It was so nice to see Kin from

Edmonton, members of the Edmonton C.F. community, as well as C.F. office staff come out to support our fundraiser. I hope they still have some money left to do their other Christmas shopping. Thanks again. Our auctioneer Leighton Sorenson does a fantastic job in bringing in top dollar for all items auctioned. He is not only an auctioneer, but a fabulous entertainer. We couldn't pull off the evening without him. This year Meredith Bongers from the National C.F. office passed C.F./Kin thankyou notes on to us and we were able to hand write and hand deliver thankyou cards to all sponsors and contributors. These cards were very well received and appreciated. It is important to let people know how much their support contributes to the success of the event. Hope to see you next year.

*Joan Losinski
Wetaskiwin Kinette Club*

Jessie McQuitty

On November 9, 2005, 22-year old Jessie McQuitty celebrated the first anniversary of her successful lung transplant by choosing a recipient for the physio Vest she no longer needed. In our last newsletter, she let the CF community know about her offer to give the Vest to someone. As she said in her announcement, "Selling the Vest just wouldn't be right, so I want to give it to another young CF adult trying to live more independently". Jessie received 10 applications for the vest, and as she started to read them, she realized just how incredibly difficult it would be to make a decision. Every single applicant deserved the vest. She could relate to each one and recognized each individual's need.

However, one particular applicant grabbed Jessie's heart because of her struggles with her health and school while developing a relationship with her boyfriend, and just trying to maintain a normal life. The applicant's name was Deanna Kneeland, and at a CFRN press conference, Jessie presented Deanna with the Vest. Jessie's gift had no strings attached, but she did ask Deanna to make one promise – should Deanna ever need a lung transplant, Jessie asked her to promise to in turn pass the vest on to someone else.

Jessie said in her announcement that she wanted to do a little "payback". She accomplished both "payback" and "pay forward" with her gift. The Chapter wishes both Jessie and Deanna all the best.

Motorbike Ride for the Breath of Life

We are excited to be in the midst of planning our first annual Motorbike Ride fund-raiser. It will be held Saturday, June 24, 2006. Entrants in the Ride will be required to obtain pledges. The event will begin at Husky Car and Truck Stop 26304 Twp 531a Acheson Industrial Park (Highway 60 south of the Yellowhead Highway), and end at Falun Community Hall near Pigeon Lake. At the finish line, we will have a barbecue, special guest speakers, and a show and shine.

We are modeling this event after the one done by the Canadian Cystic Fibrosis Chapters in Regina, Saskatoon, the Maritimes, and Chicoutimi. Regina has held a Motorbike Ride for the past 21 years. Canada wide this event has been a great success.

Right now, we are looking for free advertising, prizes, and individuals interested in being on the planning committee. For more information, please contact:

Tammy Turko
CF Fundraising Coordinator
Office: 466-2265
Email: ecfs.fundraising@telus.net

Darlene Bouclin, Volunteer
Committee Chairperson
Office: 488-6683
Email: dbouclin@telusplanet.net

Skelly the Skunk

One of our beloved long-time chapter volunteers is personally NOT a skunk. In fact he is helping us once again. Thanks Bill for letting us use your name for a new project which will remind everyone that "CF stinks". Watch for news about how we can help de-scent the "stinker".

IMPORTANT NUMBERS, NAMES and ADDRESSES

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CF Clinic:
 University Hospital
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 Fax: 407-3112
 Medical Secretary - Yvonne Lysko

Board Members:

President:	Caroline Van Dorp
Past President:	Sue Zukiwsky
VP Fundraising:	Marcia Zroback
VP Publicity/Promotion:	**vacant**
Secretary:	Salima Nurani
Treasurer:	Judy Quathamer
CF Adult Liaison:	Michelle Thornell
CF Clinic Liaison:	Joan Tabak
Directors at Large:	Jerry Gordon Michelle Husch
CF Kin Liaison:	Gerry Boehm
CF 65 Roses Liaison:	Geoff Thornell
Volunteer Coordinator:	Jane Filipow

Web Site: www.cfedmonton.ca
www.ccff.ca

Newsletter Editor & Webmaster:
 Karen Bateson Phone: 604-465-1357
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Did you know???

That last year, the Canadian Cystic Fibrosis Foundation received nearly \$210,000 in memorial donations, or approximately 5% of all chapter core revenue.

A Memorial Donation is a fitting way to remember a special person, while at the same time helping others. Every year, Foundation chapters are fortunate to receive many such donations enabling our important research to continue.

The Foundation has recently updated the design of the bilingual Memorial Donation card. If you would like more information, or to order your supply of memorial cards, please contact the Foundation's office at jmccarthy@cysticfibrosis.ca.

Calling All CF Adults

A wonderful opportunity awaits you! Become involved with your local chapter of the Canadian Cystic Fibrosis Foundation. Meet fascinating people and make a difference. Help find a cure!

I have been active on the Edmonton and Northern Alberta Cystic Fibrosis Board of Directors for the last eight years. It has been a wonderful experience and I have learned so much. I was given the opportunity to travel to other provinces and meet other adults with CF as well as numerous other volunteers. We all share the same dream and our contribution can make a difference. I would like to encourage you to join the board, either as Adult Director or as a Director at Large. The time commitment for the Adult Director is approximately two hours per month at the monthly meetings and whatever else you decide to get involved with. It is much the same for a Director at Large. Please contact the CF office if you are interested. Elections are during the Annual General Meeting in March.

CF Adult Director – Roles and Responsibilities

1. Must be an adult with CF (at least 18 years old).
2. Will serve as a member of the Chapter's Executive Committee and/or will communicate, as appropriate and feasible, to the Chapter Executive's deliberations, and/or Chapter meetings – either in person or by proxy.
3. Make contact with adults with CF in chapter area through such means as e-mail, telephone and in-person attendance at clinics and events.
4. Responsible to advocate on the part of adults with CF to the chapter.
5. Communicate to adults with CF what the chapter is doing and how chapter activities impact on persons with CF (postings at CF clinics, contributions to newsletters and to Circle of Friends).
6. Work with Adult CF Committee Regional and Vice-Regional representatives on concerns of adults with CF in their area. Report on Adult CF Committee activities to chapter (information obtained through Regional Representatives).

Join in the fight for a cure – get involved.
Michelle Thornell

HIGH FREQUENCY CHEST COMPRESSION/ OR USING A VEST FOR PHYSIOTHERAPY

The Edmonton CF clinic has a long history of interest in a vest system used for chest physiotherapy. Our patients along with Dr Jones and Dr King worked on some of the early research in the 1990's and are cited in the reference list.

There are three vest type devices on the market. We know of another being developed in Quebec and another type in Alberta.

- The VEST Airway Clearance System by Hill-Rom www.thevest.com (the original system)
- Smart Vest Airway Clearance System by Electromed www.electromed-usa.com
- InCourage System by RespirTech www.respirtech.com (the newest system using a different wave form)

Which is the best system? We don't know as yet. Some people who have tried the

two systems like one better than the other but it is an individual thing.

Are they better than conventional physiotherapy? Not necessarily. They may be more convenient to use but there is no research saying they are better than other types of physiotherapy. The bottom line is you still need to use it.

The cost of these systems varies from 10 to 17 thousand dollars US. They are very expensive.

In the United States, where insurance companies pick up the cost, they are standard of care. Speaking with nurses at conferences in the US, they are aware of many machines that are gathering dust in the closets. At this time we do not know of any person in Alberta whose insurance has paid for a system.

In the Edmonton CF clinic, we have 2 types of vests for trial. If you go to our clinic and would like to trial them please call the clinic office.

Submitted for the CF team by Joan

Upcoming Events

January 10	Board Meeting
February 7	Board Meeting
	Bingo
Feb. 17 - 20	Kin Corporate Cup

February 23	Bingo
March 5	Chapter AGM
March 7	Board Meeting
March 25	Citadel

The calendar will be back next newsletter!