THE EDMONTON & NORTHERN ALBERTA CYSTIC FIBROSIS
CONNECTION
Canadian Cystic Fibrosis Foundation

April — June 2008 Issue 40

INSIDE THIS ISSUE:

New President Elected at AGM

On Sunday, March 2, at the Kinsmen River Valley Place, Caroline Warren chaired her last Annual General Meeting as Chapter President. Our chapter's newly elected president is *Allan Bartman*. Allan attended board meetings for years as a non-voting but interested and supportive member, and we are grateful to have him sharing his skills and wisdom with the chapter in a leadership role.

Three people stepped down from the board. *Sue Zukiwsky*, now being past past president, no longer has a board position, but she is chairing one of our major events, the Rose & Thorn Golf Classic. *Judy Quathamer* has stepped down as treasurer but agreed to be elected as auditor. *Julie Hornig*, chairperson of the annual "Evening at the Citadel" event, will continue to chair this event, but will no longer be a director at large on the board. The members of the Edmonton & Northern Alberta Chapter greatly appreciate the service Sue, Judy, and Julie have provided during their years on the board, and we appreciate their continuing service in other capacities.

Three new members were elected to the board, and we are pleased to welcome Directors at Large *Scott Hanna* and *Jocelyn Gillis*, and Treasurer *Carolyn Grono*. *Charlene Keller*, who was appointed in July, 2007 to fill a vacancy has moved from Director at Large to VP Publicity and Promotion.

While Caroline is moving officially into the role of past president, she is not stepping down at all from her amazing efforts to improve the lives of those living with CF. She already has new projects in the works. Her many years of service combined with her "Energizer bunny" keep-on-going attitude made her the perfect candidate for this year's ***Ron Moore Award***. Past-President Sue Zukiwsky presented the award to Caroline at the AGM. In speaking to this presentation, Sue read the Mother Teresa poem, "Do It Anyway", very apt for the perseverance and dedication of the award's namesake as well as of Caroline, the award recipient.

Caroline chairs her last AGM as Chapter President at the Kinsmen River Valley Place early last March

Caroline presented another award at the AGM, the ***Volunteer of the Year Award***. This was given to Blain Davis, our Sahara Desert Ultra-marathoner, who raised over $33,300 for CF with this project. Blain was also the speaker for the AGM and he shared his moving story as both a CF parent and a runner of the Sahara ultramarathon.

The recipients of **Certificates of Appreciation** were not able to be present at the AGM, but the Chapter wishes to acknowledge Betty Orchard and J'lyn Nye with these certificates as a small thank you for all they have done for the chapter. Betty spent many hours making phone calls to talk with people about being volunteers, this on top of other smaller volunteer tasks she has done. J'lyn has served as honorary chair, as a speaker, as a guest of honour, and as a resource person.

Clinic News

Our CF team hosted the western Canadian clinics meeting in Edmonton in March which was a great success. Topics included CF newborn screening, lung transplants, vitamins, diabetes, airway clearance and much more. It was a wonderful time to get together learn and share information.
Since Newborn screening started in April 2007, we have received no extra nurse coverage or secretarial assistance and the past 6 months in particular have been extremely busy in the office.
We have discussed how to deal with the volume of work that comes our way constantly and have come up with the following. Messages and phone calls will be prioritized and the most urgent situations dealt with first. If it is urgent, please let us know - otherwise we may not be able to get back to you for a day or so.
Please allow a few days for reorder of medications. We are hoping to do more reordering at clinic visits to cut down on the phone calls so ask the nurse/ doctor in clinic if you need to reorder medications.
Remember paediatric routine medications are reordered for the year in outpatient pharmacy. Please call there first (407-6990) to see if you have refills and get them transferred to a local pharmacy if needed.
Pulmozyme must be obtained from this pharmacy as well as enzymes and antibiotics for children. They can then be covered under the provincial program.

Travel- Please let Yvonne know 3 weeks in advance if you need a travel letter.
Other travel concerns (immunizations and questions etc) can be directed to the travel clinic. International travel line is 413- 7677.

We appreciate your patience and assistance as we try to take care of all 235+ of you.
On the brighter side we have hired a new casual nurse, Marcella Kosinski, who has many years of experience and we welcome her.

A butterfly lights beside us, like a sunbeam...
and for a brief moment it's glory
and beauty belong to our world...
but then it flies on again, and although
we wish it could have stayed,
we are so thankful to have seen it at all.

-author unknown

Condolences go to family and friends of Kayley Chrumka and Casey Selinger-Dowd.
Co-workers say Kayley put a splash of light in every day and made everyone feel special. Her smile will not be forgotten.
We will long remember Casey's laugh and sense of humour and the "superman" he was.

President's Corner

Well to start with, I will introduce myself. My name is Allan Bartman and I come to you via the Edmonton Kinsmen Club. I have been a Kinsmen for just over 10 years now, and have been visiting/ hanging out/disrupting the Chapter board meetings for last 3 years or so. Kin Canada (our National Association) has partnered with the Canadian Cystic Fibrosis Foundation in one form or another since 1964 and hence my connection.
I must start off by thanking the Chapter for the opportunity to be President. Caroline has done a stellar job in her 3 years at the helm and Sue was amazing before her. I owe them both a great debt of gratitude for teaching / enlightening me, both in the past and certainly in the future.
This chapter does amazing work at raising funds and awareness for CF and is always considered one of the flagship chapters amongst the foundation.
Although the fiscal year is only a couple of months old, the initial signs indicate that this is going to be another great year. Several events have already taken place or will be occurring in the very near future: An Evening at the Citadel, Safeway We Care, Hockey Draft of Hope, Red Dress Run, and last but certainly not least, Great Strides. And this is just the first 3 months of the year and doesn't even mention some of the ongoing projects like the mail campaign, coin boxes, Skelly skunk sales etc….This chapter is truly amazing at what it has on the go and I am certainly proud to be a small part of it.
Over the year the phone may ring with the intent of gathering volunteers for one of the many projects – please help out where you can and remember, usually the work isn't too hard, it can even be fun at times, and every little bit we do adds to that little bit done by someone else, and all of a sudden those little bits aren't so little anymore.
Again, thank you for the opportunity, and I look forward to the challenge of trying to fill Caroline's shoes (I mean that in a metaphorical way of course, as she really doesn't have big feet).

Allan Bartman

Signature Event—We're at the Starting Line

A **signature event** is an event whose brand recognition in the market is equal to or greater than the brand recognition of its sponsoring organization. Also, an event whose "production values" carry the "genetics" of the sponsoring organization's mission.
"Signature event" is a term encountered, most frequently, in the nonprofit sector to describe an organization's major fundraising event. The term "signature event" was coined in 1984 by Biondolillo Associates, a Wellesley, MA-based marketing and development consulting firm.
Some examples include: The Big Cheese Reads, The Pan-Mass Challenge, Girl Scout Cookies Campaign.
Many charities have signature events, but our chapter of the Canadian Cystic Fibrosis Foundation is not yet one of them.

We are going to change that and you can help us get to the next level.
Several of our chapter members have met with the board to discuss some possibilities for our signature event, after exploring several exciting possibilities we came up with the … ***Signature event.***
Now we need volunteers for a planning committee which will work under the leadership of the Fundraising Coordinator to provide input and direction and assistance in developing it.

Are you interested in volunteering for this committee? If you would like to volunteer, or if you would like more information, please contact Kathy Irvine, Fundraising Coordinator, at the CF office. You can phone 466-2265 or e-mail Kathy at ecfs.fundraising@telus.net

CF Info Night

Thirty-five people attended the CF Information night held at St James school on Friday, January 25 where CF Team members shared information obtained at the North American CF Meeting in October. At this meeting approximately 3400 attendees gather to present, learn, network and collaborate in all aspects of CF care from gene delivery to CF mice to bedside care, antibiotics, and new drugs. It is the biggest CF meeting held in the world.
Joan attended a short course on Newborn screening in CF which talked about different types of programs currently in the US.
Catherine brought us information about glucose intolerance in CF and diabetes.
Dr Zuberbuhler talked about the CF Foundation Therapeutics Pipeline and new drugs that are in trials.

Catherine, paediatric dietician, speaks about diabetes in people with CF at CF Info Night.

Dr Jackson Wong spoke about the *Edmonton Journal* article saying Lung transplants are not much help for children with CF and noted it was US data taken from years ago when people in the US went on the transplant list early as it was their only hope (first come- first transplanted).
Dr Wong spoke about the paediatric lung transplant program at the Stollery.
The team urged caution with the use of the vest systems for physio. There aren't any studies that prove they are better or as good as regular physio and many people are not doing postural drainage which could be very important. The national airway clearance group, which Joan was a member of, will have information out shortly on their work.
The night ended with questions and networking and hope for the future.

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Websites: www.cfedmonton.ca
www.ccff.ca

Clinic: University Hospital
(780) 407-6745

Edmonton and Northern Alberta Chapter

Calendar
April – June, 2008

Apr. 8	- Chapter Board Meeting
Apr. 8	- Parent support group Meeting
Apr. 9	- Hockey Draft entry deadline
Apr. 24-26	- National AGM at Banff
May	- CF Month – Mail Campaign - CF Month – Skelly skunks in area Shoppers' Drug Marts
May 6	- Chapter Board Meeting
May 10	- Red Dress Run (Hash House Harriers)
May 13	- Parent support group Meeting
May 25	- Great Strides Walk
June 3	- Chapter Board Meeting
June 9	- Leduc Kinsmen golf tournament
June 10	- Parent support group Meeting
June 14	- Aerobathon (World Health Club)
June 20	- Advocis golf tournament
June 21	- Ride for the Breath of Life Motorcycle Ride

Evening at the Citadel

The Edmonton chapter of the CCFF held its 11 annual "Evening at the Citadel" on February 9, 2008, at the Citadel Theatre. The event was a great success and raised approximately $25,000 for CF research!
The Citadel Theatre is a major sponsor for this event, and has supported this event for the past 11 years. Our evening started with a wine and cheese reception in the Tucker amphitheatre, in which our guests enjoyed an amazing variety of cheeses, provided by Jan K. Overweel, a major cheese importer. The play this year was Shakespeare's "Macbeth", following which a post reception of Grand Marnier and desserts was enjoyed by all.

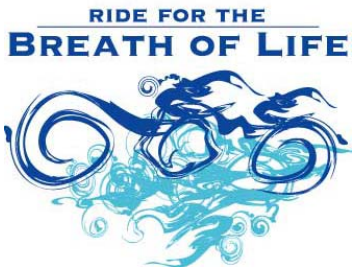
An exciting addition to this year's event was a draw for a 50" Panasonic Plasma T.V., which was won by John Tabak. I know that both Joan and John Tabak were absolutely thrilled with their win, congratulations John!
As in previous years the event also included a silent auction. We would like to thank all those individuals and companies who donated auction items.
In conclusion, I think our theatre evening was enjoyed by all our guests, and we look forward to seeing you all next year!

Hockey Draft of Hope

The 20th annual Hockey Draft of Hope moved ***online*** with a website at www.cfhockeydraft.ca. For those who preferred to send their entries by mail or fax, this option was still available. Entrants are now carefully watching their player picks to see if they still have a chance to be the winner of one or more of the cash prizes for this event. A total of $25,000 will be paid out in prizes. Deadline for submitting entries was 6:00 p.m. on April 9.
Thanks go to Doug Milne and Marcia Milne for all the organizing work, to Paul Filipow for website design and management, and to the team of volunteers who processed all the entries.

Breath of Life Motorcycle Ride for CF

On June 21, our chapter will be holding its third Ride for the Breath of Life Motorcycle Ride. The riders meet at the Acheson Husky station, ride as a group along a scenic back country route west of Edmonton down to the Falun Community Hall near Pigeon Lake, and then enjoy a BBQ lunch and brief program.



We have appreciated tremendous support from riders who collect pledged donations for CF. Alberta Cycle, Alberta Bison Producers, and other corporate sponsors are also contributing to the success of this event.
For more information or to get a brochure, please call us at the office at 466-2265 or contact David and Bliss Robinson, planning committee co-chairs.

Great Strides Moves to New Venue

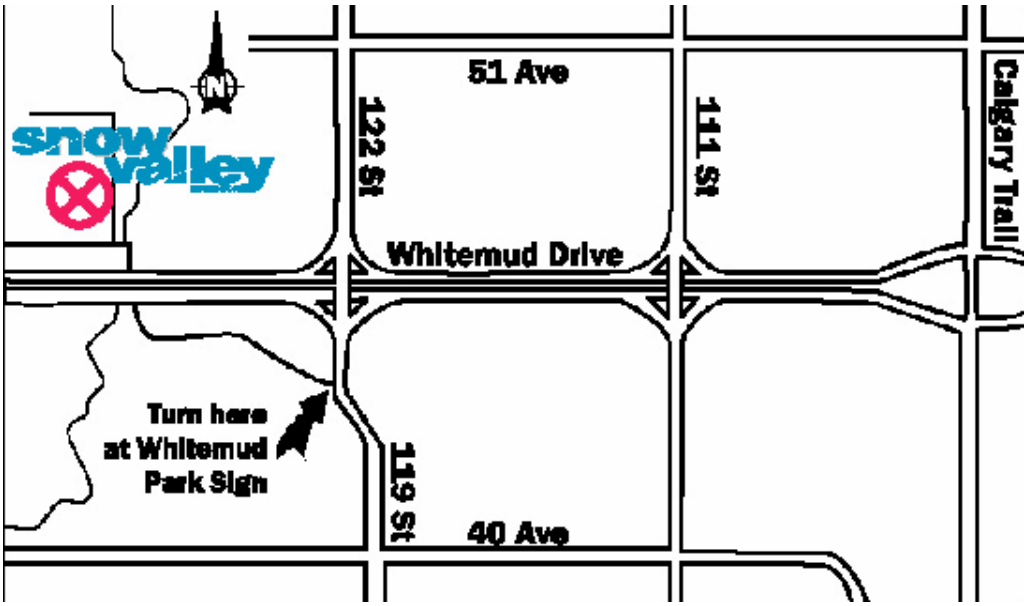
The Edmonton and Northern Alberta Chapter of the Canadian Cystic Fibrosis Foundation is taking Great Strides outdoors this year! We are moving to Snow Valley Ski Hill at 119 St just off the Whitemud Freeway in Edmonton. We will take a beautiful walk through Rainbow Valley, have a scavenger hunt and games for the kids, and celebrate with a picnic lunch afterwards.

Last year, across Canada, almost $1.2 million was raised, with $35,254 raised in Edmonton. We want to top that this year – so our goal is $50,000! We invite you to join us on **Sunday, May 25, 2008** – registration is at 9 am!

The Great Strides™ website is at www.cysticfibrosis.ca/greatstrides - where registering is easy and fast! You can create your own personal page and you can instantly begin collecting pledges or inviting others to join your team. You can log on with your 2007 user name and password to get instant access to your previous profile. If you can't remember this information, please contact us at info@cysticfibrosis.ca or (800) 378-2233. If you prefer to collect donations in person, enclosed you'll find an official Great Strides™ pledge form. If you do not register on line, please call the Edmonton office at (780)466-2265 to let them know you are walking so there will be a picnic lunch for you!

Lace up your sneakers! We look forward to seeing you on Sunday, May 25th!

Sunday May 25 at Snow Valley Ski Hill



Upcoming Fundraisers

Advocis® Edmonton

Advocis Edmonton's charity golf tournament is scheduled for June 20th back at Jagare Ridge Golf Course. Start putting together your team early. This is a fun tournament with all the proceeds again this year going to the Canadian Cystic Fibrosis Foundation.

WORLD HEALTH CLUB

World Health Club will be holding its Aerobathon in support of Cystic Fibrosis on June 14.

For more information or to participate, contact the CF Office or any of the four Edmonton World Health Club locations.

Red Dress Run

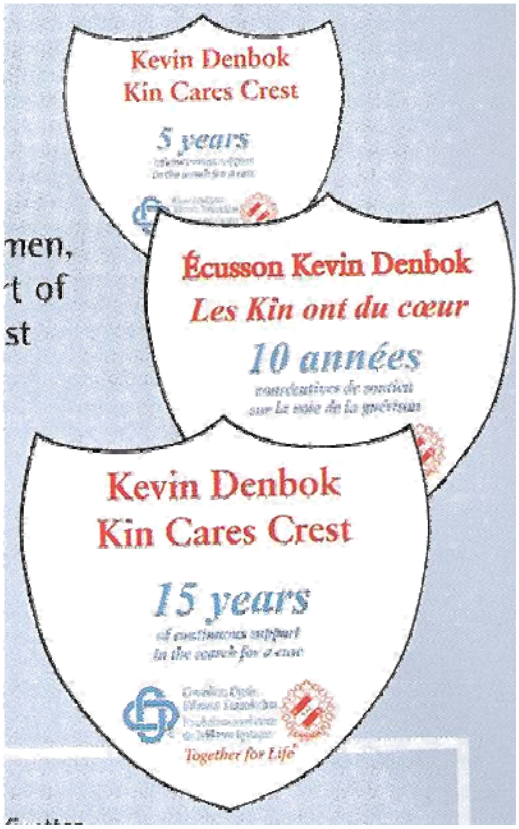
If you should be in the Old Strathcona area or along Whyte Avenue during the afternoon of Saturday, May 10, and you see a bunch of "crazy" people running wearing red dresses, run — toward them — to say hi and a big thank you. The Red Dress Run is the annual fund-raising event for the local Hash House Harriers, a running club. This year the Harriers selected our Foundation as the charity to support with the funds they raise.

Live Webcasts from National AGM

Two sessions held at the National AGM & Conference are the *Annual Day for Adults with Cystic Fibrosis*, and the *Medical / Scientific Conference*. As the name indicates, the first session (morning) is of particular interest to adults with CF. The afternoon session is a collection of presentations about different aspects of CF research – this session is broadcast in both French and English. Anyone not able to attend these sessions in person can catch them live via a link from the CCFF web site. Individuals are also able to participate in the question and answer period following the presentations.
These conference sessions will be held on Saturday, April 26, 2008.

Visit the home page of the Foundation's Web site (www.cysticfibrosis.ca) after April 18 for further information and instructions if you would like to catch either of these sessions.

Voices of Hope — The Kin Clubs



The Canadian Cystic Fibrosis Foundation (CCFF) is pleased to congratulate the Kinsmen, Kinette and Kin clubs, who in 2006-2007, reached a new milestone in their support of the CF cause. These clubs are the proud recipients of a Kevin Denbok Kin Cares Crest for continuously supporting the work of the CCFF.
Kevin, who lost his battle with cystic fibrosis, helped forge a long-lasting relationship between Kin Canada and the Foundation.

District 4

5 Years of continuous support to cystic fibrosis

Zone B	Edmonton Kinettes
Zone G	Spruce Grove Kinsmen

15 Years of continuous support to cystic fibrosis

Zone B	Fort Edmonton Kin
	Wetaskiwin Kinettes
'O' Zone	Calgary Kinsmen
Zone F	Brooks Kinettes