

The Presidents Corner

From the President

In April, I had the opportunity to attend the National CF Annual General meeting. This meeting brings together representatives from all the chapters to share ideas and help set the direction for the foundation for the upcoming year. There are many different sessions, but I want to focus on one event in particular - the Kin Luncheon. I had the fortune of attending the NAGM in Edmonton last year, so this was going to be my second Kin luncheon - and being "experienced" at this event, I had my Kleenex in tow as I headed to lunch.

This lunch is an opportunity to celebrate our relationship with the Kinsmen and Kinettes around the country and thank them for what they have done for the fight against cystic fibrosis. For those of you that don't know, our relationship with the Kin started on a barstool in 1963, and since then, the Kin have raised over \$32 million in support of CF. At this particular lunch, we heard from a 13 year old girl that received her double lung transplant when she was 11. Her story was incredibly inspiring, she showed more courage and life experience than most of us have as adults. After she spoke, Dave Perkins, Kin Canada President said a few words. He thanked us. He thanked us for giving the Kin a cause to work for and believe in. He thanked us for letting them make a difference to people that suffered from CF. Think about that for a moment...shouldn't we be thanking them? The incredible generosity of the Kin and Kinettes has made a huge difference to the research and treatment of cystic fibrosis - and they are thanking us for that? As I listened to him speak, I realized what an incredible organization Kin Canada is, and how amazing the people are that make up the individual clubs. We have been blessed in Edmonton with extremely supportive Kin clubs, and seeing their commitment to cystic fibrosis has always amazed me. The vast majority of these people do not have a direct connection to CF - just a desire to make a difference. Seeing their president speak at a national level, thanking us, showed me that we are not just blessed in Edmonton, but across the country with amazing support and strength. At the end of the Kin luncheon, there wasn't a dry eye in the room - emotion brought on by the strength and courage of a 13 year old, and the commitment and dedication of Kin Canada.

So, on that note, I want to personally thank the Kin clubs in Edmonton and across Canada for their incredible support in the fight. You have never wavered in your support for us and you have made a difference - a bigger difference than can ever be quantified in a "thank-you". I also encourage anyone that knows a Kinsman or Kinette to take a minute and personally thank them - their support is priceless.

Caroline Warren (formerly Van Dorp)

Motorcycle Run 2006

Ride for the Breath of Life

On Saturday, June 24, 2006, 50 motorcycle riders joined our chapter's first annual motorcycle run. The riders met and registered at the Husky Station just off Highway 16 at Acheson. Before departure, Parade Marshall Deb Grey called all the riders together for an official send-off, and then riders followed lead rider Don Bouclin on a 150 km. route of secondary roads and around the south end of Pigeon Lake to end at the Falun Community Hall. Riders were served a fantastic lunch, thanks to sponsors Alberta Pork, the Falun Coop, Stony Plain IGA, Safeway, TGP Warehouse, Sobey's, and the Swedish Bakery in Wetaskiwin. Special thanks to our sponsor Alberta Cycle. Publicity for the event was provided by the 97.3 K-Rock and Big Earl 96.3 radio stations. The weather was picture perfect, the ride was beautifully organized, and the event raised over \$9000. The top fund-raisers for the event were Don Bouclin at \$1975.00, Jerry Gordon at \$1500.00, and Brad Bouclin at \$1385.00. Many thanks to all the volunteers on the planning committee, at the registration tables, and at the Falun Community Hall.



Deb Grey, Nurse Lisa Semple (Calgary) and daughter Libby

Great Strides in Edmonton and Northern Alberta!

After registration and an energetic warm-up, our Great Striders for 2006 walked their laps around West Edmonton Mall on Sunday, May 28. Our CF Chapter recognizes the participation difficulty faced by CF supporters living outside Edmonton. However, this was one event where people from outside the city made a huge contribution. Four out of five of the top fundraisers drove in from outside the city (two from Hinton, one from Mayerthorpe, and one from Wetaskiwin) to participate. The top-fundraiser, Allan Bartman, is an Edmontonian and a Kin Canada member. Without Allan, Edmonton would have come in second after Wetaskiwin for donations collected. Other northern Alberta locations represented by walkers were Leduc, Sherwood Park, Bonanza, Spruce Grove, Barrhead, Fort Saskatchewan, and New Sarepta. Way to go, Northern Alberta!

65 Roses Eskimos Dinner

On Tuesday, July 11, the 65 Roses Sports Club will host its annual Eskimos dinner. Corporations and individuals are invited to attend and to sponsor one or more Eskimo home game. Each sponsorship costs \$750, and includes two tickets to the dinner with honorary chair Chris Morris and special guests Coach Dan Maciocia and his wife, a Eskimo memento, a tax receipt for \$600, and a pair of tickets to the sponsored game. If you did not receive an invitation and would like more information about attending or sponsoring, please call the CF office.

Hockey Draft 2006

The 18th Annual CF Hockey Draft of Hope is just winding up and we had another successful year. Although the Oilers were unable to bring home the Stanley Cup, this fund raising project brought in approximately \$8,000 for CF research in the Province of Alberta. Since its inception, this project has now raised over \$185,000 and that is a tremendous achievement.

While this year's profit was slightly less than planned, this was primarily attributed to the loss of more past entrants than expected due to last year's NHL Players strike. Fortunately, we realized a lot of new entrants this year and believe we are well positioned to increase our profit in 2007.

The 2006 CF Hockey Draft of Hope owes a lot to three companies who continued their strong support for this project: Edmonton Sun, Primrose IDA Pharmacy and Speedy Muffler, Brake & Wheel.

The Chapter would also like to thank the following volunteers, who donated their time to help make this project a success:

Marcel, Jacquie & Jennifer Fontaine Caroline Warren Lisa Taylor Michelle Hauch & friend Chris Small Tracy Clevely Matthew Christiansen Mary Sawchyn Toni Saccomani Doris Gordon Heidi Bidwell Eugenia & Joe Nimchuk Michael Buttrey	Betty & Ken Orchard Kyle Zroback Lori & Scott Hanna Jordan Milne Sue Burnham Eugene Trepanier Patti & Chantelle Magnan Jane, Larry & Verity Filipow & friend Carey Losinski Marty Van Happen Jackie & Richard Peden Marcia Zroback & Doug Milne
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Lastly, congratulations to Dr. Brian Banks for winning the \$6,000 top cash prize in 2006. Brian has generously supported CF over many years and his margin of victory was the largest in the history of the Draft.

Step by Step

Step by Step is a dance school in Sherwood Park. Every dance class from this school donated its prize money from recent competitions to Cystic Fibrosis. Thank you , Step by Step. With many "steps" like yours, we are able to make great strides towards improved care and hopefully a cure for cystic fibrosis. Along with this school, several others have stepped forward. Our appreciation and thanks go to the following schools, each having raised and contributed over \$300.00:

- St. Kevin School, Edmonton – which donated the proceeds from an Easter basket raffle.
- Wye Elementary School, Sherwood Park – staff donation.
- Barrhead Elementary School – grade 5/6 French class did a penny collection.



Barrhead Elementary

**** News from the CF Clinic ****

Outpatient Pharmacy is now being managed by Rexall. The hours of operation have been extended, they are Monday to Friday 8-6 Saturday 8-1.

Soap it up for CF



Saturday, June 10 was THE day to get your car washed at one of the three Carstar locations in Edmonton: Borrelli's on the corner of St. Albert Trail and Yellowhead Trail, Champagne next to the Mayfield Inn, or Glacier off Calgary Trail South on 72nd Avenue. Each location

provided both a carwash and extras. Borrelli's was host to Elvis and Marilyn Monroe impersonators and to Shane Neil with his tractor-pull truck.

At Champagne, Edmonton Eskimo offensive tackle Patrick Kabongo signed autographs, and the Glacier's location had former Eskimo Willy Pless signing autographs and a visit from "Marilyn Monroe". All three locations had barbecues and sold raffle tickets for a 2-weekend pass to the Grand Prix. The Borrelli location alone raised enough to contribute over \$2500 to CF. Thank you Carstars!!



*This is not snow, it's bubbles!!
Fundraising Coordinator Tammy Turko
and her daughter Aspen.*

Golf Tournaments

Akita:

On August 10, Akita Drilling Ltd. will hold its 5th Annual Charity Golf Tournament for Cystic Fibrosis. Registration payments and sponsorship payments have been arriving in the mail steadily since May. Yvonne Wupori at Akita does most of the organizing work and we appreciate Yvonne and Akita so much.

65 Roses Ladies Golf Classic:

August 21 will be the date of the 21st annual 65 Roses Ladies Golf Classic. As usual, the tournament will be at the Mill Woods Golf Course, and will include lots of food and fun at the holes as well as a lovely meal and prizes afterwards. This year we are so pleased to welcome J'Lyn Nye, Global's 11:00 p.m. news anchor as our honorary chair. As of the writing of this article, we still have a few spaces left for golfers so please contact the office if you are interested. Registration cost is \$220.00.

Laperle Jam IV

The 4th Annual LaPerle Jam Charity Fundraiser, held on Saturday May 6, was a huge success! The addition into the silent auction of two Edmonton Oiler jerseys, signed during the playoffs, brought in \$2,600 on its own! Overall an amazing \$9,262.51 was raised during this event! The night would not have been possible without our wonderful volunteers selling raffle tickets and working at the door and the bar. Everyone got on their feet dancing thanks to the music of "Section 69"! A wonderful evening was had by all and we hope this event will only get better in the future!

Amazing Award Winners

Our Chapter has some amazing volunteers, and to their surprise, three of them were recognized at the June 24 Motorcycle Run program. They were all part of the organizing committee for this event.



Carey and Joan Losinski of Wetaskiwin were presented with the Celine Award. Named after the CCFF's Celebrity Patron, the Celine Award acknowledges a volunteer individual, couple or family who has made indispensable and sustained contributions to the chapter at the non-executive

level. Joan and Carey have contributed in many substantial ways in Chapter and National events and in Wetaskiwin events since the birth seven years ago of their first grandchild with CF. They are a regular presence at many of our fundraisers and rarely miss an AGM. They are part of the organizing group for the Kinette Christmas craft auction in Wetaskiwin, they make items for the Edmonton Christmas craft sale and for some of our silent auctions, they sell Grey cup pool tickets, they helped with Christmas gift wrap when that was one of our fundraisers, they sell bracelets, and magnetic car ribbons, they promote the Hockey Draft in their area, and they walk – for 6 years the Zellers walk, and now Great Strides. They were a huge part of the success of the first Motorcycle Run.



Darlene Bouclin of Edmonton was presented with the Breath of Life Award. This award recognizes outstanding and long-term contributions to a CCFF chapter in a leadership capacity. Darlene has been very active (and energetic!) in the Edmonton Chapter for

over 20 years, and there are very few board positions that she has not served in. She joined the board in 1985 and in true Darlene fashion jumped right in as the fundraising chairman. In 1986 Darlene began her first term as president. Once her two year commitment was completed, Darlene remained on the board as past president until 1996. When it was necessary to release our office manager four years ago, Darlene returned to the position of President and brought her experience and enthusiasm to a board in need of encouragement. At the following AGM, she took on the role of fundraising chair once again and was a contributing factor to our chapter receiving the "Chapter of the Year" award in 2004. Darlene exemplifies the criteria for the "Breath of Life" award. It is not her style to seek recognition or to self promote; her actions are solely to make a difference in the lives of those who struggle with CF. She is a committed volunteer and has been an enormous asset to our chapter.

Darlene chaired the committee which planned the first annual Motorcycle Run in June 2006. She is pictured with her husband Don Bouclin, who also served on the organizing committee and was the lead rider for this event.

Clinic News - CF Related Diabetes (CFRD)

What is CF RELATED DIABETES (CFRD)?

CF Related diabetes is thought to be caused by damage to the pancreas. Thick mucus clogs the tubes in your pancreas making it hard for it to function. The pancreas is an organ that has 2 main jobs. The first is to make and secrete insulin, and the second is to make and secrete enzymes and other digestive juices. As people with CF are living longer, the number of persons who have diabetes is increasing. The type of diabetes that develops as a result of CF is different from other types of diabetes.

Common Symptoms:

- very thirsty
- weight loss
- urinate often
- very hungry
- lack of energy
- unexplained decrease in lung function

If symptoms of CFRD are left untreated, it can lead to problems with your CF including:

- thick mucous that is difficult to clear
- trouble keeping a healthy weight
- muscle loss

- less able to fight infection
- high blood sugar over time may damage blood vessels in your eyes and kidneys which could lead to blindness or kidney failure

Testing For CFRD

A random blood glucose (sugar) level is done with routine blood work yearly. Fasting blood glucose levels are followed if random levels are elevated. Hemoglobin A1C is done to follow long term glucose levels.

Treatment

The treatment varies but many people with CF need injections of insulin one or more times a day. They also need to check their blood sugar at different times during the day. The CF related diabetic diet is much different from the diabetic diets other people are given. There is still a need to eat high calorie, high fat foods and not to cut back on the amount of calories taken a day. "Simple sugars" such as soft drinks and candies should be avoided. The CF clinic usually consults the diabetes specialists for their expertise

Submitted by Joan Tabak CF Clinic Coordinator
Adapted from CF Health Matters prepared
by CF Dietitians of Canada.

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CF 65 Roses Liaison:	Geoff Thornell
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Newsletter Editor Needed

Karen Bateson, our current newsletter editor, is expecting her second child and is stepping down from this position. We wish her and her family good health and happy times ahead, and thank her for continuing to do this from her B.C. home. But that means we need a new editor. If you are familiar with Microsoft Publisher and would be willing to format each issue of the newsletter, please call Emily at the office. (The articles and photos will all be supplied)

Calling All CF Adults

The Board is still looking for a CF Adult who would be willing to step into this role. If this is something you could do, call Emily at the office for a description of the roles and responsibilities.

Upcoming Events

July 8	Bingo
July 11	65 Roses Eskimos Dinner
Aug 1	Board meeting
Aug 10	Akita Golf
Aug 21	21st Annual 65 Roses Ladies Golf Classic
Sept 5	Board meeting
Sept 13	Oilers Alumni Golf
Sept 16	Keith's 50-50-50 Bike Ride
Sept 17	Run for the Lung

Wayne Lee

Wayne Lee, Empowered for Life speaker, author, and hypnotist, reveals how you can become the master hypnotist of your own life. His next Edmonton workshop will be on Saturday, September 30. If you mention you heard about him through our CF chapter when you order your tickets, Wayne will make a \$40.00 donation for each ticket purchased. For more information about his workshops, please see his website at www.waynelee.com.

HBC Points

Are you collecting points with an Hbc card (Zellers, Bay, Home Outfitters)? You could donate those points to Cystic Fibrosis. The Canadian Cystic Fibrosis Foundation receives a quarterly update of all donation totals and redeems the points for an annual cash contribution from Hbc. Here is what you need to do to donate this way:



1. Make sure you have the Hbc Rewards card. You can apply for one either in person at one of the stores or by going on-line to www.hbc.com/hbc rewards, clicking on the Enroll tab, and continuing to follow the instructions.
2. Once you have the card, you can choose to donate a portion or all of your points to a number of charities including CF. To donate your points, again either visit your nearest Zellers, Bay, or Home Outfitters and complete a donation designation form, or you can go on-line (same address as above), click on the Community Program tab, and search for the CCFB account. You will need to have your card so you can enter its number when you are donating.

Raffles in Calahoo

What can you get for \$1.00 these days? It could be a lot if you shop at the Calahoo General Store. Esther Szatmary, storeowner, has been promoting small raffles through her store in support of cystic fibrosis. Tickets are only \$1.00 apiece. K. Johnson won an 8.4" widescreen portable DVD player with car kit for her dollar in the raffle which ended March 31. Wes Rideout won a 7.0 megapixel digital camera with a camera case in the raffle ended June 5. And this local effort helps make everyone with CF a winner since the raffle proceeds are all used in the fight against CF.

Keith Shaw's Red Deer 50-50-50 Bike Ride

When I was born in 1956, the doctors told my parents that I had cystic fibrosis and would only live to around four years of age. Well here it is 2006 and I am turning 50 years old on September 22. This is due to the generosity of Canadian individuals and corporations for their donations towards research into and treatment of Cystic Fibrosis.

So in celebration of my 50th birthday, on Saturday, September 16, 2006, I am hosting Keith's 50-50-50 bike Ride for CF. 50 friends – to raise \$50,000.00 for CF by bicycling 50 kilometers each! All money raised will be sent to the CCFB. There will be a BBQ to follow and exciting prizes for ride participants. So please, join me in my celebration by participating in the 50-50-50 bike ride for CF. Sign up by emailing sjshaw@shaw.ca or by phoning 403-886-2384. Thank you for your support.

Summer Student

With the help of a government grant, the Chapter has hired Hannah Chan to work for us for the summer. Hannah has completed three years of a University of Alberta Bachelor of Arts program with a double major, English and French. Her education, her previous work experiences, and her personal goals made her a great match for our needs this year. She is a valuable addition to our staff, taking on a number of tasks for the office, the board, and fundraising committees, and also pitching in where needed at fundraiser events. In her photo, Hannah was at the St. Albert Rainmaker Rodeo to assist with taking Candid Cowboys photographs.