Issue 49

July-Aug

2010

Canadian Cystic Fibrosis Foundation

THE EDMONTON & NORTHERN ALBERTA CONNECTION

Contents

Calendar

July–Sept. 2010

July 27

Chapter Board Meeting

July 28

Akita Golf tournament for CF

August

Grey Cup pool mailouts to ticket sellers begin

August 29

Original Joe's Run for the Lung

Sept. 7

Chapter Board Meeting

Sept. 7

Draw for Trip Voucher raffle at board meeting

Sept. 8

Raffle begins for Grey Cup game tickets Nov. 28 in Edmonton

Great Strides Grows by Leaps and Bounds

The Great Strides Walk 2010 took several giant steps forward in the Edmonton & Northern Alberta Chapter. The first step was the expansion of the walk to a total of five different locations. In Edmonton, for the third year, the Snow valley Ski Centre was our hospitable home base for a walk on Terwillegar area river valley trails and for pre and post walk activities. New this year were Leduc (Telford Lake), St. Paul (Sobey's), Grand Prairie (Muskoseepi Park), and the Ekati Diamond Mine in the Northwest Territories.

The second big step was the expansion of the organizing team to include a local chairperson and committee for each site. Fundraising Manager Kathy Irvine worked with all the site committees to book venues and trails, to plan for registration, to obtain supplies, to organize family-friendly activities or entertainment and to complete all the other details involved. The Edmonton Snow Valley committee was chaired by Stacy Hipkin. The Leduc Kinettes and the Grande Prairie Kin organized the walks in their communities. In St. Paul, Helen Chapdelaine chaired the planning committee, and at the Ekati Diamond Mine, Graydon Chretien was the organizer. Needless to say, this represents a group of very busy people.

Continued on Page 4

Team captains registered a day early to speed up registration.

Volunteers from the World Health Club led the Edmonton walkers in warm-up exercises before the walk.

New Name and Logo Adopted

By Patti Magnan

For several years now, the CCFF has been looking at better ways to promote itself to the public. Work has been done on developing a brand, vision, values statement and corporate image that would enhance recognition of the foundation and would help people understand the mission that we all share.

While working on this project, it became apparent to the national branding committee that using one logo in Quebec and another completely different logo in other parts of Canada was confusing. Market studies showed that only a small percentage of the population actually recognized our current logos. Work on finding a new logo that could be used across the whole country began. At the same time, participants in both internal and external surveys commented that the names "Cystic Fibrosis Canada" and "Cystic Fibrosis Quebec" were shorter, simpler and easier to say and remember than our current name.

At our annual meeting of the Edmonton and Northern Alberta chapter these issues were discussed at length. Half of all members from our chapter in attendance were in favour of a name and logo change, while the other half were against it.

After consulting members of our foundation across the country through on-line surveys, meetings and conference calls, a motion was made to change both the name and logo of the foundation. This motion was formally made at the National Annual General Meeting of the CCFF in Ottawa this spring. 59 delegates in attendance were eligible to vote. 45 were in favour, 13 against, and 1 abstained. The motion was passed and the CCFF will have a new name and logo as of February 1, 2011.

Although change can be hard to accept, now that this decision has been made, let's move forward, continuing to work together toward a time when CF is no longer a progressive, life-shortening disease.

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THE EDMONTON & NORTHERN ALBERTA CONNECTION

CF Connection is a free newsletter for members published bimonthly by the CCFF Edmonton & Northern Alberta executive committe with offices in Rm 205 of St. James Elementary Catholic School at 7814-83 St., Edmonton.

Issue 49 was issued July 9, 2010. It was edited by Patrick Lépine with contributions by Pat Magnan, Emily Westwood, Sherri Selby, the 2010 Ride Committee, and Patrick Lépine.

Mission

The Canadian Cystic Fibrosis Foundation (CCFF) helps people with cystic fibrosis. The Foundation funds research towards the goal of a cure or control for CF, supports high quality care, promotes public awareness of the disease, and raises and allocates funds for these purposes.

President	Pat Magnan
Past President	Allan Bartman
VP Fundraising	Julie Mitchell
VP Publicity & Promotions	Scott Hanna
Secretary	Stacy Hipkin
Treasurer	Carolyn Grono
CF Adult Director	Megan Parker
CF Clinic Liaison	Joan Tabak
Director at Large	Lisa Taylor
Director at Large	Jocelyn Gillis
Director at Large	Sherri Selby
CF Kin Liaison	Gerry Boehm
Chapter Manager	Emily Westwood
Fundraising Manager	Kathy Irvine

Traveling with CF

By Sherri Selby

I am an adult with CF and have been lucky enough to be well enough to travel throughout my life. When I was 14, I had a six week family adventure that included travels through some of the US (Idaho, Montana, Wyoming, Nevada, California, Oregon, Washington), and back to Vancouver and to the interior of B.C. which we called home. I also went on a class trip to Spain and Portugal when I was in high school. My husband and I have visited England and Scotland. Our most recent trip has been to Italy. All trips, even within Canada, involved some previous and contingency planning (such as having a list of my clinic and doctor's contact numbers) in order to be successful. These tips from "Cystic Fibrosis Education – Seeing the World with CF" (http://www.cfeducation.ca/en/travelworld.aspx) are helpful for how to travel with CF.

The key to any successful vacation lies in planning. Having CF means taking extra care in making arrangements ahead of time, and being realistic about where you should or shouldn't go. Some countries or places may be off limits simply because they lack adequate health care resources. To determine if an area is right for you, speak to the people at your local travel clinic. They are a wealth of information on such matters as available health resources and immunizations appropriate to the travel area. https://www.travmed.com/clinics/ lists locations of these clinics in Canada.

Medications, equipment, contacts

Get a letter from your doctor stating that you have CF, and need certain medications. Make sure you list them in detail - in English and the language of the country (or countries) you will be travelling to. Since trade names of medications differ from country to country, list both the trade and generic name. Always carry this letter on your person, so that it's readily available for customs and border personnel.

Not all medications are available in all countries. Speak to your doctor about taking extra medications and/or antibiotics with you and guidelines for their use.

Take everything you need for your treatment with you. Your medications should be labelled and in their original bottles. For electrical equipment, find out about the plug-ins, voltage/power that is used in the country you're going to. You may need an adapter to use your equipment. Also, think about your medications. Do any need refrigeration? What plans can you make to accommodate this? Nebulizers must be cleaned as specified by the manufacturer so you have to consider how this might be achieved. It might be useful to take more than one mask/pipe in case it is humid – you want to make sure things are thoroughly dry before use or they will become a breeding ground for germs. Check with your health care provider for the best information.

Finally, always try to carry as much of your medications as possible in your carry-on bag to ensure you have them in case your luggage is delayed or lost.

Get a list from your CF Clinic of the CF centers or hospitals in the areas you will visit (just in case). Check into medical insurance to see what is covered and what is not.

Continued on Page 4

President's Corner

By President Patti Magnan

I am honoured to have been chosen as president of this chapter. I strongly believe that the medical research sponsored by the CCFF is crucial to improving quality of life for those affected by CF. All of us need to continue working hard to raise the funds for this research.

With amazing office staff, and very dedicated board members and event chair people, I am optimistic about our fund raising for this year. We have recently experienced tremendous success with the five locations of the Great Strides Walk and also did well with the Ride for the Breath of Life. Special thanks to Allan Bartman who has shown such commitment to our chapter , first as a volunteer, and recently as president for the last two years, and to Caroline Warren who has just completed her final year as past president, after many years of excellent service to the board. Together they continue to be a source of help to all of us. ●

Two Wheels Move the Soul

By The 2010 Ride Committee

On Saturday June 19, sixty motorcycle enthusiasts made the fifth Ride for the Breath of Life a tremendous success again this year. J'lyn Nye, of Joe FM, led the 150 km ride from the Acheson Husky along the scenic west side of Pigeon Lake to our final destination at Falun Hall. Though our ridership was down slightly from last year, the ride raised over $43,000.

Thanks to our Volunteers

We thank everyone who helped with this year's ride with special thanks to the following:

All our volunteers who ran the registration booth, sold 50/50 tickets, assisted the riders and helped make the day run so smoothly. They were Madeleine Bosnyak, Susan Cox, Kathy Irvine, Andrea Hoppe, Monica McGrath, P.K. McKenzie, Emily Westwood, Sue & Ted Zukiwsky, and Shelley Properzi.

Darcy McLaren for driving the chase vehicle.

Joan Losinski and her Falun crew who prepared a fantastic BBQ lunch for all to enjoy.

Show & Shine judge Bob Gillies and his crew.

Photographers Shannon Gaucher, Gary & Lorie Leighton, Alex Lépine, and James Wayne.

J'lyn Nye for being our honorary chairperson, ride leader and emcee at the dinner.

Dave Lumley for emceeing the prizes at the dinner.

This year's organizing committee – Madeleine Bosnyak, Darlene Bouclin, Les Cox, Shannon Gaucher, Kathy Irvine, Patrick Lépine, Joan Losinski Monica McGrath, David & Bliss Robinson, Abe Van Dorp, and Emily Westwood.

Thanks to our Sponsors

Our major sponsors and their generous donations that make this ride possible – main sponsor Alberta Cycle, Provincial Home Oxygen (food), Northwest Rentals (T-Shirts), Western Dispatch (several prize packages), Sutton Place Hotel (several prize packages), MacDonalds (gift certificates), Canadian Brew House (top team prize), The Comic Strip (top individual prize), 92.5 Joe FM (advertising), Falun Community League (hall), and Acheson Husky (start location). Please consider patronizing their businesses as they contribute to our community.

Thanks to our Riders

We appreciate all the fund raising efforts of every rider. Several received special recognition at the end of the ride:

Show & Shine – Ian Schlinker of Drayton Valley rides in memory of his brother Jason using Jason's motorcycle)

Carey Losinski trophy – Babes on Bikes (team with most members present at ride - eight)

Top Fundraising Team – Team Sierra Thunder $18,900

Youngest rider – Keith Stenger (20 years old, from Drayton Valley)

Oldest rider – Clem Champagne (64, who rides in memory of his son Vincent)

Oldest bike – Don Bouclin (a 1977 BMW)

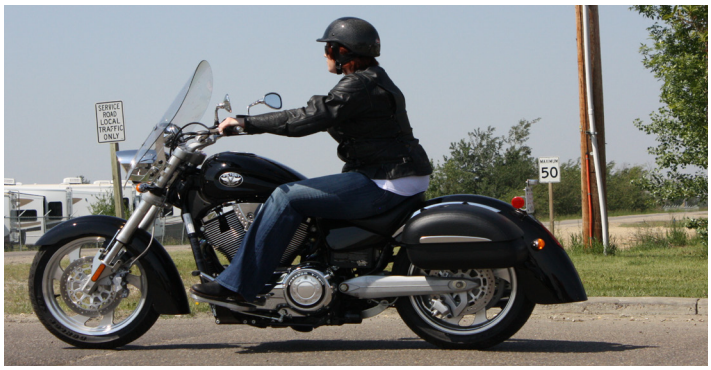
50/50 Raffle – Fred Fishburne (who promptly donated the $177.50)

2nd & 3rd highest fundraisers – Mike Hughes ($4,360) and Warren Gaucher ($2,651)

Top Fundraising Individual – Abe Van Dorp ($10,125)

We are in the process of compiling a book of this year's Ride, which will be available soon. Please check the website at http://www.cfedmonton.ca for updates and instructions on how to order the book.

We hope to double the number of riders next year. Please let your family and friends know about next year's Ride for the Breath of Life tentatively scheduled for June 18, 2011. We leave you with this thought: four wheels move the body; two wheels move the soul. ●



J'Lyn Nye leads the 60 pack of motorcyclists out of the parking lot at the Acheson Husky on the start of their 150 km ride to Falun Hall along the west side of Pigeon Lake.

Alberta Cycle Rides in to Help

By Patrick Lépine

Monica Hoppe-McGrath, owner of Alberta Cycle Motorsports, first got involved with CF because of people she knew, but has kept coming back because of the people she met along the way.

" My son went to school with someone who had a family member with CF, so that was the first connection," she says.

The owner of Edmonton's best family-run motorsport shop soon learned something new about people she already knew.

"Some of the people I have met on the ride were already customers of ours. I had no idea they had someone dear to them with CF. "

Being involved with the ride for the past four years has opened her eyes to the disease.

"I knew virtually nothing about CF before I became involved. Now after meeting so many people through this motorcycle ride, I have learned a lot about it."

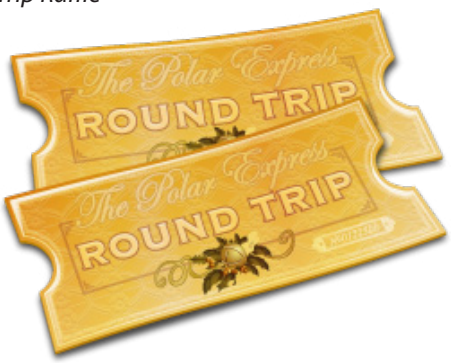
Alberta Cycle Motorsports has several events throughout the year. They receive donations for CF at their events and give out brochures for the Ride for the Breath of Life. She'll continue to help with the ride, but Hoppe-McGrath wishes she could do more.

"I wish there was more money to turn their way to assist them with their goal of finding a cure or control for CF."

THE EDMONTON & NORTHERN ALBERTA CONNECTION

Destination Anywhere

Trip Raffle



Where would you go if you won a travel voucher worth up to $4000? Disneyland? Mexico? Maui? Las Vegas? Buy a ticket for $10 on our Destination Anywhere Raffle. The winner will consult with a travel expert at Argyll Travel to explore their options and plan a trip to the destination of their choice.

See our website, www.cfedmonton.ca, for official rules. Raffle tickets are available at the CF office. Call us to buy tickets or if you are interested in selling tickets on behalf of the chapter. The draw for the winner will be made on September 7, 2010. ●

Carstars Soaps It Up

Edmonton's four Carstar Collision autobody shops joined the company's national Soaps It Up carwash campaign on Saturday, June 12.

Over half of the proceeds will be donated to the Canadian Cystic Fibrosis Foundation.

Tina Perkins, our volunteer at the Borelli's Carstar location, said her kids had fun last year and again this year, and they really want to go back again next year.

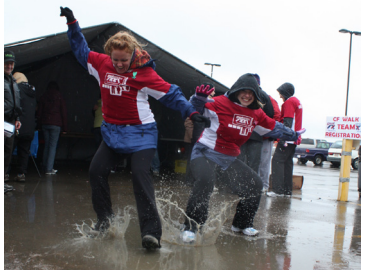
They joined the enthusiastic students from Ross Shepherd's High School rugby team to wash cars and to thank customers for their support of the fundraiser.

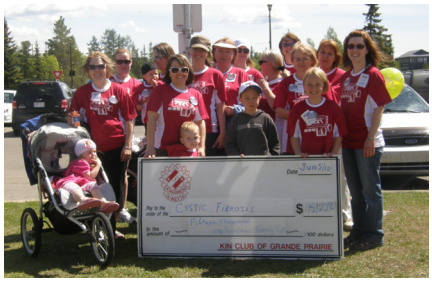
Our thanks go to all the Edmonton Carstar shops for their support- Borelli's, Glacier, Champagne, and Capital. Together with the other Carstar locations across Canada, they raised more than $117,000. ●

Continued from page 1

For the Edmonton, Leduc, and St. Paul locations, the weather was the coldest and wettest we have ever experienced for this event. In spite of that, our chapter took another great stride forward, and raised the most ever, approximately $200,000.

To all walkers who collected donations, whether big or small, we extend our thanks. You are the ones who made the day a success as we keep up the fight to control cystic fibrosis. We especially want to thank Tom Matthews in St. Paul, whose Team Dragonfly was one of the top ten fundraisers in Canada. Finally, we would like to thank all of our wonderful sponsors who help make these walks as successful as they are for the families and individuals who come out to participate. ●





Left: Sarah and Andrea showed the spirit that made the St. Paul walk successful. Right: The Kin Club of Grande Prairie led in organizing the walk in the city.

Traveling with CF

by Sherri Selby

Continued from Page 2

Make a thorough check of the elevation, pollution level and temperature in the country or city you'll be going to. If it's hot and sunny, pay special attention to your salt and water and electrolyte intake. As well, speak to your pharmacist if you are taking antibiotics. Some can make you hypersensitive to the sun, so take appropriate precautions.

Note: If you will be traveling through different time zones, the schedule you follow to take your medication may have to be adjusted. Discuss your travel plans with your doctor and get advice on when to change the time you take your medication, especially on the day of travel. It's important that you not skip doses nor take too much medication. Your doctor can help you make the necessary but temporary changes to your medication schedule based on whether you will be losing or gaining time as you travel.

Travelling with oxygen

Special arrangements and permission will be needed to ensure oxygen is available en-route and at your destination. This could prolong your planning time and cost you more money. Speak with your local oxygen supplier for assistance. Also, keep in mind that some airlines will not allow you to use your own oxygen equipment. Contact the airline (or airlines, if you are taking connecting flights) about their oxygen policies.

Travel advisories

Check this government website: www.TravelHealth.gc.ca

Travel Insurance (information obtained from our national website):

It can be difficult for people with cystic fibrosis (or any chronic illness) to obtain travel insurance. Explore possibilities and apply early. Insurance companies may ask for a letter or specialized form/questionnaire from your CF specialist with details of your health status, medications and treatments. Read the fine print of travel insurance policies carefully. TravelAbility® is a travel insurance company providing travel information and insurance to Canadians with disabilities and their families. It was initiated by March of Dimes and INGLE International, call 1-866-637-9798.

More information

Thorough travel tips are also available from "Tips for Travelling with CF" at the following link: (http://www.cysticfibrosis.ca/assets/files/pdf/TreavelTipsfor_cystic_fibrosisE.pdf).

Have a great, healthy and safe holiday! ●