THE EDMONTON & NORTHERN ALBERTA CYSTIC FIBROSIS

CONNECTION

Canadian Cystic Fibrosis Foundation

July — September 2008 Issue 41

INSIDE THIS ISSUE:

GREAT STRIDES TAKES GIANT STEPS

greatstrides Taking Steps to Cure Cystic Fibrosis

Cloudy skies didn't stop our Great Strides walk from taking giant steps. On May 25, 300 people walked through our new trail at Whitemud Park. The new venue was well received, and everyone enjoyed a picnic lunch after the walk. There were candy guessing jars, photos with Skelly, and lots of laughter.

The team concept for the walk really took off this year with over 90 per cent of our walkers in teams. With so many walkers, we have to say a huge thank-you to all the volunteers who made the event run so smoothly.

Finally, I know you want to know our fundraising numbers. They were off the charts! We raised just over $35,000 last year and set our sights high with a goal of $50,000 this year. Final numbers will not be available for a while yet due to some National Foundation costs that need to be allocated out, but we will be close to double our goal. Next year our goal is to beat Calgary.

Since 1986, Canadian Cystic Fibrosis Foundation (CCFF) chapter members have teamed up with community partners to participate in an annual family-oriented walk campaign to raise funds in support of vital CF research and treatment programs. Great Strides™: *Taking Steps to Cure Cystic Fibrosis* is fast becoming one of the Canadian Cystic Fibrosis Foundation's largest national fundraising event. Thousands of co-workers, friends, and family come together each year as one community to help find a cure or an effective control for CF. In 2008, $1.5 million was raised across Canada to support vital programs. Thanks so much to everyone that participated and we look forward to seeing you again next year.

On the day of the Great Strides walk, Team Saltsticks was listed as the fourth-highest fundraising team in Canada. Members of the team include Lisa and Shawn Grono, parent support group facilitators, and Carolyn Grono Mills, chapter Treasurer. The Edmonton chapter had 3 of the top 10 Great Strides teams in Canada with Team Hyperflex being second highest in the country.

Carter's Crew was listed as the eighth highest fundraising team on walk day. Kim and Dave Laframboise and friends not only collected pledges but ran events at the Lone Spruce Driving Range in St. Albert before the walk to add to their pledges.

Red Dress Run

With over $35,000 raised, the Red Dress Run held on May 10, 2008 was a huge success. The Edmonton Hash House Harriers donates the proceeds of this event to charities, and the amount raised this year was a record high. The Edmonton and Northern Alberta Chapter of CCFF extends its thanks to this group for their generosity, and particularly to David Hopkins, a former board member with our chapter, who proposed Cystic Fibrosis as the cause for the group to support.

The most visible and fun portion of the event was the Run which started and ended at the Granite Curling Club, and wound its way through the Whyte Avenue area. Following the actual Run, the event included a dinner, a live auction, a silent auction, and a dance.

Aerobathon

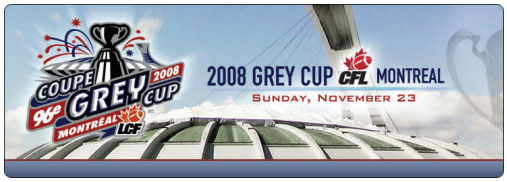
Three years ago, Volunteer Christine Frank organized her first Aerobathon at the World Health Club to raise funds for the fight against CF. Adding together the amounts raised in these three years, she has already contributed over $20,000 to the fight! Now, that's really promoting good health.

This year's Aerobathon, held on June 14 outdoors at the west end World Health Club, managed to scare the rain away and met the goal of matching the amount raised the previous year. The 55 enthusiastic participants included the Sherwood Park U16 soccer team who came in support of a member of their team who has CF. Thank you, everyone who participated – whether as an organizer, as an "exerciser", or as a donor.

Safeway We Care

In February and March, over three different weekends, crews of CF volunteers sold raffle tickets and promoted the Safeway We Care program at Garneau Safeway. The total amount raised for CF by this one store location was $5859.00! We thank Wendy Derdak and the staff of the store for all the work they did on behalf of CF. The store staff also expressed their thanks and appreciation for the number and dedication of the CF volunteers who really raised awareness of CF by their presence in the store. Safeway will no longer be running the We Care campaign after this year.

Grey Cup Raffle

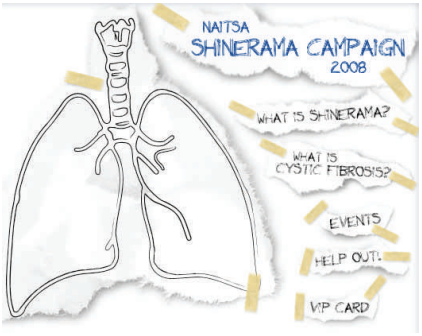


We will be selling Grey Cup raffle tickets again this year! If you helped to sell them last year, we will be contacting you to see if you are able to help out again. We will also be looking for volunteers to help out with sealing tickets into individual envelopes, as well as getting the tickets ready for mailing out. If you are interested in helping out, please give us a call at the office.

Schools Hold Tribute Fundraisers

Two schools held fundraisers as tributes to students with cystic fibrosis.
In January and February of this year, St. Kevin Catholic Junior High School in Edmonton ran some fun activities in honor of Verity Filipow. The fundraiser was concluded at a school assembly attended by several guests, including Verity's aunt from England. In May, Global TV came to the CF office to film a Health Matters story about the St. Kevin tribute. At that time, teacher Patrice Teveniuk presented the cheque to the CF Foundation and Charlene Keller, VP Publicity & Promotion received it on our behalf.
In June, Wes Hosford School in Sherwood Park planned a Treat Day in honor of Drew and Sydney Husch. This event was organized by Leanne Jorgenson, a parent at the school. At both schools, the funds raised through the events were enhanced by additional donations from some of the parents. We'd like to say thank you to our friends and supporters at St. Kevin and Wes Hosford Schools for your thoughtful generosity.

NAIT Shinerama



Our Shine day will be September 13.
We will have volunteers located throughout the city in Blue Shinerama T-shirts.
We will also be selling lollipops at bars throughout the city during the summer; dates and locations will be posted on both the Shinerama Facebook, and our website.
So please visit our website: http://shinerama.naitsa.ca/
and don't forget to join our facebook group: NAITSA SHINERAMA to keep up to date on all of our Shinerama events!

U of A Shinerama

University Of Alberta Shinerama
STUDENTS FIGHTING CYSTIC FIBROSIS

Our Shine Day will be held on Saturday, September 6. The registration time will be between 9:00-10:00 at which time our volunteer breakfast will be served. The Pep rally is from 10:00am-10:30am and we are hoping to get the mayor and President Samarasekera to speak (we are waiting for responses). The events will be held in Celebration Plaza (in front of the Administration building) at the University of Alberta. Please come out to join us!

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Canadian Cystic Fibrosis Foundation

Edmonton and Northern Alberta Chapter

Calendar
July– September, 2008

July 30 - Akita Drilling Golf Tournament

Aug. 5 - Chapter Board Meeting
Aug. 18 - Rose & Thorn Mixed Classic
Aug. 24 - Original Joe's Run for the Lung

Sept. 2 - Chapter Board Meeting
Sept. 6 - U of A Shinerama
Sept. 13 - NAIT Shinerama

Rose And Thorn Golf Classic

23rd Annual Cystic Fibrosis Rose & Thorn Mixed Classic 2008

We invite you to register as a golfer or as a sponsor for the 23rd Annual Cystic Fibrosis Rose and Thorn Mixed Classic. The purpose of the tournament is to raise funds that support the many programs which help to find a cure or control for cystic fibrosis. It will be held at The Links in Spruce Grove on August 18, 2008. Once again the committee has planned a wonderful day filled with fun, super prizes, and a great round of golf. Many were excited last year about the change from the ladies-only format and it was great to see regular participants out golfing with their spouses and family members. It was also great to see several teams of ladies maintaining their annual tradition of supporting this event. As part of the re-structuring of this event, the committee has tried to take the emphasis away from winning to make the day more about sharing time with family or friends, having a round of golf and supporting a worth while cause. Entry fees will remain at $220.00 per golfer and the cost includes your cart, breakfast, green fees and lunch as well as each player's mulligan. There will be other opportunities to buy a drive or get in on some amazing raffle prizes; these expenses are purely optional and are at your discretion to purchase. To get a registration form, please visit the chapter website at www.cfedmonton.ca or call Kathy or Hannah in the CF office at 780-466-2265.

Monday, August 18th, 2008
The Links Golf Course, Spruce Grove

Registration $220.00	**7:30 am**
Continental Breakfast	**7:30 - 8:30 am**
Shotgun Start	**8:30 am**
Buffet Luncheon	**1:30 pm**

Original Joe's Run for the Lung

Run for the Lung – the Trilogy is scheduled for Sunday, August 24, 2008. Join Blain Davis, runner in 2007 of the Sahara Desert ultra-marathon, and continue the journey as a runner or as a walker to finding a cure for CF. To register as an individual or couple, as a walker or as a runner, go online to www.runningroom.com. On this site, choose "Races", "AB", "Aug 08", and scroll down to "Sunday, August 24, 2008". The Run will be held at the Original Joe's Terwillegar parking lot at 2323 Rabbit Hill Road. For more information, including the tribute to Jessie McQuitty, in whose honor and memory this race is planned, you can visit the website www.originaljoes.ca/runforthelung/.
If you know someone who is registered for this Run and you would like to make a pledge on their behalf, you can also do that on the Running Room website or by going to any Original Joe's location to pick up a pledge package.

The schedule for the day is as follows:

10:30 a.m.	Registration
11:00 a.m.	Orientation and warm-up with World Health Club
11:30 a.m.	Race start
12:30 p.m.	Awards and BBQ

New National CF Advertising Campaign

In May 2008, the Canadian Cystic Fibrosis Foundation is launching a new national advertising campaign that will run until April 2011. Awareness of cystic fibrosis is low in Canada. The campaign is aimed at potential donors and supporters who know very little about cystic fibrosis. There are many challenges to consider when creating an ad campaign about cystic fibrosis. The greatest challenge of all is to explain CF to the public in a manner that will get their attention, without delivering a difficult message to members of our community.

We have tried very hard to strike a balance between a message of urgency and one of hope. Too much hope suggests that we don't need help. Too much urgency negates advances that have been made in CF research and care.

As parents of children who have cystic fibrosis, we know how painfully difficult it is to hear that cystic fibrosis is a fatal disease. We live with this reality every day and it's hard to be reminded. We also know that if we expect people outside our very small community to help us fight this battle, they must be aware of cystic fibrosis and aware of how serious CF can be.

The overall campaign goal is to raise awareness of cystic fibrosis and to communicate our urgent need for help. Our strategy is to create empathy, an emotional impact, and to let viewers know that their support can make a difference.

The Foundation is very mindful of how children, teens, and adults with CF and their families might receive the campaign. Members of a committee who represent CF clinicians, parents of children with CF and adults with CF have been consulted every step along the way. The committee worked with advertising professionals to guide the creation of television, radio and print ads.

You will find campaign materials on the Foundation's Web site: www.cysticfibrosis.ca.

Our greatest hope is to see our loved ones thrive and grow into healthy, happy individuals. This is not yet guaranteed for people with cystic fibrosis; it remains only a hope. There is an urgent need to create greater awareness of cystic fibrosis in order to transform this hope into reality. The ultimate benefit will be longer, healthier lives for our loved ones.

The new national advertising campaign is available for several media including television, radio, a digital ad, flyers, posters, and magazine ads like the one pictured above.

President's Corner

Well it has been a hectic 3months….but only in a good way. The national AGM was held at the end of April in Banff and was attended by Julie Mitchell, Caroline Warren and myself. As always, it is great to hear about the advances being made medically and scientifically in finding a cure for CF, and it is also wonderful to meet with people from other chapters, where inevitably the conversation turns to our successful projects.

On that note, since April we have been involved in several large fundraisers which have turned out to be fantastically successful. A few of these were the Playoff Hockey Draft, the Red Dress Run, the Motor Bike Ride, and certainly last but not least the Great Strides Walk. Adding the rough numbers together for only these projects comes to a total in the $200,000 range for our chapter. I would like to personally thank all of the chairs of these committees, and volunteers who work with them to make our chapter a success.

With the summer now here we also have several golf tournaments and other events lined up to raise awareness and funds for curing or controlling CF. If, or perhaps when, the phone rings please consider coming out to help with these events – normally the work is not hard and usually it ends up being quite a lot of fun.

I hope all of you get a chance to rest and relax over the summer and spend some time with your families. With that I will end this note as I am off with the kids to the Yukon in about 12 hours.

Allan

Parent Support Group Disbanded

In recent months, the chapter board debated the future of the parent support group. The concern was due to its small attendance. At the May board meeting, the decision was made to disband the group, at least for now. At the same time, the board recognized the value of having support, especially when families first receive a CF diagnosis and therefore suggests two support alternatives: Parents might be interested in signing up on the Facebook site "Cystic Fibrosis Support Group for Edmonton/Northern Alberta" which has about 9 members right now. Another alternative is to contact Lisa Grono at grono@shaw.ca. Lisa has kindly agreed to be available either through Facebook or by e-mail to discuss issues around cf.

The board is grateful to Lisa and Shawn Grono and to Jennifer Ellis for their facilitation of the parent support group for over a year.

Ride For The Breath of Life

A generous, hard-working bunch of motorcycle riders came out for the 3rd annual Ride for the Breath of Life Motorcycle Ride.

More than one hundred bikes assembled at the Acheson Husky site for registration and over $46,000 in pledges was submitted. With Abe Van Dorp as the lead rider and J'lyn Nye, honorary chair and program emcee right behind, the group travelled (loudly!) a scenic country route west of the city to reach the destination point of Falun Community Hall.

At the hall, Joan Losinski and her crew of volunteers joined by Deanna and Shawn Thorn provided a delicious BBQ meal for all riders. As always, J'lyn hosted the program with heart and fun and flare.

The highest fundraiser for the second year in a row was John Luchyk from Drayton Valley. He raised $6725 this year! The second and third highest fundraisers were also from Drayton Valley: Marty Gibson with $4050, and Amy Newberry with $3135. The fourth and fifth highest fundraisers, Jerry Gordon and Abe Van Dorp, raised over $3000 each. The efforts of these riders as well as all the others will make a difference for CF. It is because of people like them and the pledges they raised that we were able to exceed our goal this year. Their donations will be used to help finance the continuing fight against CF, both by funding clinics and lung transplant centres for CF patients, and by funding scientific and medical research.

David Robinson, chair of the 2008 ride, and his wife Bliss along with J'lyn Nye, honorary chair and program emcee, stand with members of Carey Losinski's family. This year the Carey Losinski trophy went to the Canadian Motorcycle Cruisers for most members of a group in the Ride.

The front bumper of David Robinson's bike wears the names of people with CF who friends and family honored by participating in the 2008 ride.