



Breathing life into the future®

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Calendar

July

- 22– Gift Card orders due
- 27– Akita Golf Tournament
- 28– Chapter Board Meeting

August

- 9– Movie Night @ Millwoods Town Centre
- 16– Movie Night @ Millwoods Town Centre
- 21– Intact Insurance Canadian Derby (marathons)
- 28– Original Joe's Run for the Lung

September

- 6– Chapter Board Meeting
- 10– Shinerama, NAIT
- 17– Shinerama, U of A
- 24– CF Spectacular @ Mayfield Dinner Theatre

October

- 4– Chapter Board Meeting
- 28– French Fling Wine Tasting
- 28– Travel Raffle Draw

November

- 24– Gift Card orders due (last order of 2011)

Great Strides Towards a Record Breaking Year

Well, it has been an exciting couple of years with the Great Strides Walk and our Edmonton & Northern Alberta Chapter grew again with two new locations!

The first is the **Fort McMurray walk** that was chaired by Gillian Holloway along with a small committee and was supported by six teams who brought in just over \$20,000.00! The kids were able to put their name in for a special draw each time they did a lap around the track. After the walk the kids enjoyed cupcake decorating, bubble blowing, face painting & just having fun running around during a beautiful day! Thank you to Tony & Janette Kaminski from the Fort McMurray

Kinsmen and Kinette clubs for coming out to help with registration!

Our other new location was **Lloydminster, Alberta** chaired by Jennifer Symon. The walk was on June 5th and the weather started out on a shaky note, but again we ended up with a gorgeous day...just in time for the walk to begin. The Lloydminster Kinette club came out to work the registration table

& the Kinsmen flipped burgers on their new BBQ for everyone! Thank you for your continued support!! Jennifer had help from a couple of friends and her family with the planning, and they had lots of fun things planned for the kids after the walk. There was a kite-making station, nail decorating, face painting and so much more to do! The total to date brought in is at just over \$36,000.00!!



Superstrider Heather Hanna cuts the ribbon to begin the walk in Edmonton

The **Grande Prairie** Kin Club hosted their 2nd annual Great Strides Walk and brought in an amazing \$15,400.00 with 4 Teams!! Thank you for continuing the walk in your community!

The **Leduc** Kinette Club also hosted their 2nd annual Great Strides Walk bringing in almost \$18,000.00 with some sponsorship money still to come. Caring Clowns Buzz & Dizzy came out to entertain the kids for the day, the Valley Zoo came out with some small animals and there was face painting, bubbles and more! M & M Meats sponsored our BBQ again, not only bringing food for everyone, but their own volunteers too!



The Edmonton & Northern Alberta Connection is a free newsletter for members published bimonthly by the CFC Edmonton & Northern Alberta executive committee with offices in Room 205 of St. James Elementary Catholic School at 7814-83 Street.

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Mission

Cystic Fibrosis Canada helps people with cystic fibrosis. It 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.

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The **St. Paul** walk also celebrated its 2nd year, raising just over \$30,000.00! Helen Chapdelaine chaired the walk again, and did an incredible job with media and preparing for the walk day. The weather was great with a few things to do for the kids including a visit



St Paul— Skelly Skunk led the walk on the whole route and was a big hit with the children.

from Skelly the Skunk and there was a BBQ that followed the walk for all to enjoy with a small donation in return.

The Great Strides Walk **Edmonton** held on Sunday May 29th was a huge



Edmonton— On the trail with Carter's Crew, one of the top 3 fundraising teams at this walk.

success! The weather was spectacular and the planning committee couldn't have been happier with a beautiful, sunny morning and over 550 enthusiastic CF supporters in

attendance. Our emcee, Ryan Jespersen, host of Breakfast Television



Edmonton— Emcee Ryan Jespersen and Chairperson Stacy Hipkin introduce the two star members of the Saltsticks team.

on Citytv, welcomed everyone. The crew from World Health Club warmed up our walk participants and Edmonton's own National Superstrider, Heather Hanna, cut the ribbon to start the walk. Following the beautiful 5 km walk through the trails of Whitemud Park, everyone returned to a



Leduc - Walkers of all ages, all sizes, all abilities (even the dog!) enjoyed the pastoral Leduc trail.

wonderful barbecue lunch. Everyone enjoyed a picnic atmosphere along with a children's entertainer, airbrush Tattoo artist and slurpees courtesy of the MAC's Froster Machine. Congratulations to our Top Team Fundraisers: Team Teegin (\$23,989.00), The Saltsticks (\$22,260.84) and Carter's Crew (\$18,508.00), and our Top Individual Fundraisers: Teegin Mortenson (\$14,111.00), Sydni & Logan Grono (\$12,866.00) and Carter



Fort McMurray— Teams assembled on the track at Fr. Mercredi School, which was fortunately not in an area affected by the smoke of nearby fires.



Leduc— Bubble-making was one activity option for children at this walk location.

LaFramboise (\$11,023.00). The Edmonton walk total was \$172,733.00!! Awesome job!

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Thank you to all of our Great Strides Walk Chair People and Committees for your continued support with our satellite walks. We wouldn't be in your communities if it wasn't for your hard work! Thank you to all of our sponsors, because our walks just wouldn't be the same without your support. Thank you to our Kin Clubs who continue our fight against cystic fibrosis right along our sides! A huge thank you goes out to all the team captains for organizing and motivating your teams to be so successful! To each and every individual participant and volunteer, we truly appreciate your support. We were so successful in the funds and awareness raised for Cystic Fibrosis that we should all hold our heads high!! Donations are continuing to come in and at this time we can proudly report that our



Edmonton—Many activities were provided for children before and after the walk.



Lloydminster— this walk (and others) included face-painting as one of the activities for the children

Motorcycle Ride Rained Out

Saturday, June 19th proved to be just too wet for the Ride for Cystic Fibrosis. Riders coming from west of Edmonton drove in on their bikes for registration at Acheson while riders from the east came by vehicle due to the rain already in their area. On the same day the City of Edmonton closed some river valley trails due to flooding.

But all was not lost. Between the riders who had collected their pledges online as well as those who brought pledged donations to the registration site, we have collected over \$28,000. We have asked all others to bring

their pledges to the CF office, and we plan to hold a ride at some time during the summer.

The Central Alberta/Red Deer chapter joined our Ride for the first time this year. They met and registered in Red Deer and were planning to ride to join us for the BBQ and program at Falun Hall. We look forward to meeting them all *next* year. Thank You Abe Van Dorp for your chairmanship and planning for this event.

Featured Sponsor: HyperFlex Dance Studio

For Jen Mills, Artistic Director and owner of Hyperflex Dance Studio, the past seven years have been a journey of both education and inspiration. Her connection with cystic fibrosis began when she was given the opportunity to teach a new student, Erica, who has CF. After meeting Erica, Jen began to learn about the disease and the many related challenges. As the relationship continued, Jen admired Erica's talent and work ethic. She notes that Erica "has taught me so much about life and strength and is a true inspiration, not only to myself but to her dance family at the studio." Jen's experiences with the chapter have also given her opportunities to meet and become friends with various committee members who all inspire her with their "very large hearts."

Hyperflex Studio is a competitive dance studio in Edmonton that specializes in the training of

competitive dancers. They offer a variety of dance styles (jazz, ballet, lyrical, tap and hip hop) from specialized instructors. All the staff and students at Hyperflex are passionate about dance, and they have extended this passion to the search for a cure or control for CF.



Jen and the family at Hyperflex have had the opportunity to learn about and witness "some of the great strides medicine has made to help treatment and control of the disease." They have also noticed that there is a lack of knowledge about CF in the general public. They decided that they needed to inspire and educate others in order to move closer to a cure or control for

CF. As a result, Team Hyperflex was created and they have been fundraising for the Great Strides Walk for the past four years. Every year this team has approximately 40 members ranging in age from 5-17 and since they began fundraising they have collected over \$73 000. Students at the school not only spend hours fundraising but also donate their dance prize money towards CF research.

All dedicated dancers dream of being the best they can be and push themselves daily to achieve these visions. Jen also has another wish. Like all of us who know someone with CF, she wishes that she could cure Erica's CF. "If there was any way possible I could do that, I would." With the inspiring support from groups like Hyperflex Dance Studio, this dream may someday soon be a reality.

National Conference 2011 In Sherbrooke

Sherbrooke, Quebec and the Estrie Chapter of Cystic Fibrosis Canada hosted the 2011 national annual conference. Attending members of the Edmonton & Northern Alberta chapter described various experiences from moving, emotional and hopeful to informative and encouraging. Moving and emotional because of the opportunity to know that we are not alone in the fight against this disease. Informative and encouraging because of ideas shared about running chapters and events and also about progress in research. And also disappointing – due to the fact that there was no session this year for CF Adults while the organization works out a new infection control policy.

With obvious affection and high regard, the organization bid farewell to former CEO Cathleen Morrison. At the same time, we welcomed new CEO Maureen Adamson who brings new energy and direction. We celebrated the achievement of Kin Canada who raised almost \$1 million for CF this year (have Kleenex ready when our own Gerry speaks!). We connected with representatives from chapters all across Canada during various sessions but particularly during a meeting for the

Prairie region, chaired by Rita Steiner and Joanne Meulenbelt. We applauded the careful stewardship of our dollars under the direction of our treasurer Miles Nagamatsu and financial managers Connor, Clark and Lunn (even their presentations were enjoyable!).

To help all of us increase awareness about cystic fibrosis and therefore to support our fundraising efforts, our organization has a new website to use. www.drowningontheinside.ca is a great place to send people who are just learning about CF. They will see real people, hear real stories, and will learn how they can support the search for a cure or control.

Presentations from the researchers have been recorded and are still accessible on our national website www.cysticfibrosis.ca. Go through the Research section to find the link to the archived webcast "Cystic Fibrosis Bugs: the good, the bad, and the ugly".

As CEO Maureen Adamson said, "Our bottom line is not about making money but about making a difference in the lives of families affected by cystic fibrosis. Our sights are squarely set on finding a cure."

Carstar Soaps it Up for CF!

By Kim LaFramboise

On Saturday, June 11, Dave, Carter, and I, had the pleasure of volunteering at the south east Edmonton Capital CARSTAR location (7420-76 Ave.) to help them with their annual car wash which benefits Cystic Fibrosis. CARSTAR started the Soaps it Up National Car Wash 8 years ago when one of the franchise partners was affected by CF, and has now raised over \$1.9 million dollars for CF research and treatment.



It turned out to be a perfect day for a car wash! Both Dave and I were touched at many times throughout the day to see the staff and volunteers, who were mostly unaffected by CF, working so hard for families like ours. It was inspiring, and a lot of fun! Cars were washed that were already clean, while others were thickly caked in mud, and even a stretch limo stopped by to support

the fundraiser. The south east location also had set up a BBQ for people to enjoy, and silent auction to bid on as well.

In addition to raising funds for Cystic Fibrosis, CARSTAR also managed to set a new Guinness World Record for the largest car wash in history. More than 140 CARSTAR locations across Canada, and the United States washed 4918 cars in eight hours on Saturday, which broke their previous record for "World's Largest Car Wash – Multiple Venues."

Three other Edmonton Carstar locations also ran car washes. They were the Glacier (10350-72 Ave.), Borelli's (12542-133 St.) and Champagne (10980 Mayfield Rd.) locations. This year, CARSTAR will be donating over \$105,000 to Cystic Fibrosis Canada and to local fundraising groups. Thank you to CARSTAR, its employees, and volunteers, for helping to raise funds and awareness for the fight against CF!

Save the date. . .

DRIVE-IN FOR A CURE!



&



Join us August 9th & 16th at
Millwoods Town Centre for a great
Evening of old-fashioned family
entertainment!

Featuring:

Giant Movie Screens

Popcorn & Treats

50/50 Draw

\$5 Entry per car

Check our website for details

Gates open at 7 pm

Movie begins at dusk (roughly 9 pm)

Thank you to Millwoods Town Centre for
this fundraising opportunity!

Gift Card Sales

Gift card sales is one of our ongoing fundraisers. A percentage of the value of each purchased card is donated back to us. You still have two opportunities to purchase gift cards this year. The schedule is:

-Orders all in by July 22, pickup after August 10

-Orders in by November 24, pickup after December 12

The order form to use is attached. It lists all the businesses whose cards you can buy and the percentage of the card value that we receive. (DB means declining balance, so if you don't use up the whole value on your first purchase, the remaining value is still there.) Please use cheque or cash to pay for your order (our profit margin is small) and also please plan to pick up the cards after the order is ready to avoid postage costs. Send or bring your order to our office in St. James School, 7814-83 St., Edmonton.





President's Message

A celebration dinner was held to mark the 50th Anniversary of our chapter. In attendance were long-time members of our chapter including special guests Vera Clegg, Irene Serink and Ray and Mary Lou Rouault.

James Tapankov, our guest speaker and also an adult with cystic fibrosis, shared the very exciting news that he and his wife just had twins. They now have four beautiful children. He spoke about the importance of living life with hope and courage, and the importance of parents modelling this behaviour for their children who have cystic fibrosis. "Woe to those who love their traditions...more than

hope." (Bill Williams, Naked Before God).

Joan Tabak, nurse from the adult cystic fibrosis clinic, shared photos of mist tents, low fat diets and camps for children with cystic fibrosis that were popular at one time, but are no longer recommended. She spoke about medical progress such as new antibiotics, devices to provide faster delivery of inhaled medication and lung transplants.

Gerry Boehm shared the story of her sister's sister-in-law who suffered a major brain aneurism, and donated her organs to help others. 75 people received organs and tissue from this one individual's body. With several

members of our chapter currently waiting for a lung transplant, organ donation is a very important topic. Gerry asked everyone to sign their organ donor card. Organ donation cannot be made without the consent of the family so it is crucial that people wanting to do this, make their family aware of their wishes.

Guests at the anniversary celebration enjoyed a delicious dinner and the opportunity to socialize. Thank you very much to Gerry Boehm for organizing the event, to the Kin Club of Fort Edmonton for their assistance and to the Kinsmen Club of Edmonton for the use of their facility.

Cystic Fibrosis Hockey Draft of Hope.

2011 is proving to be a very successful year for the Hockey Draft of Hope. Final numbers are not confirmed, but we do know that ticket sales were up and expenses did not increase so we are looking forward to an excellent bottom line this year.

Event chairpersons Jordan and Megan Parker thank all the supporters who have helped make this year such a success, especially *Primrose IDA Pharmacy*, *Speedy Auto Service*, and *The Edmonton Sun*. Each year more and more of the ticket buyers are making their purchases online through the website www.cfhockeydraft.ca and this has reduced the number of volunteer hours needed for data entry. However, this event still requires and appreciates the volunteers who stuff envelopes to mail out entry forms and confirmation forms, Paul Filipow who runs the website, and the volunteers who enter data for tickets not purchased online.

Ticket buyers – we thank you too!

This year's biggest winners are:

- 1st Round (\$2,000) - R Refvik
- 2nd Round (\$500) - J Mason
- 3rd Round (\$500) - J Packolyk
- 4th Round, 1st place (\$10,000) – M McBain
- 4th Round, 2nd place (\$2,500) – J Packolyk
- 4th Round, 3rd place (\$1,500) – D Rewega
- 4th Round, 4th place (\$1,000) – L Stoski



Upcoming Events

CF Spectacular

Buy your tickets as soon as possible for this year's CF Spectacular, our event at the Mayfield Dinner Theatre. The date this year is September 24th, and the program will be featuring the ever popular music of the Beatles. To purchase your tickets, contact the Mayfield directly either by phone at 1-877-529-7829 or online at www.mayfieldtheatre.ca. All tickets are \$104.99 plus GST.

French Fling

Our wine-tasting event, the French Fling, will be held this year at La Cité Francophone on Friday, October 28th. The French Fling is a lovely evening of food, wine, conversation, and shopping! Information about purchasing tickets will be included in our next newsletter.

Right now, your help would be much appreciated in getting the word out to potential ticket buyers as well as to potential donors of auction items. The planning committee is seeking quality items for the event's auction – **please let us know if you have any you can donate.**



Students from the University of Alberta and from NAIT conduct fundraisers each fall in support of cystic fibrosis. Watch for NAIT students on September 10th when they will be out running their events (maybe shining shoes or shining cars, but probably doing things that have nothing to do with shining). And watch for the U of A students the following Saturday, September 17th. Both groups are currently developing their plans for their Shinerama days.

Original Joe's Run for the Lung

Calling all r-u-n-n-e-r-s (and walkers)! On Sunday, August 28th the Original Joe's in Terwillegar will again host the Run for the Lung. The run route is being updated this year, but will again begin and end at the restaurant location. The Run is posted on the Running Room website so you can direct all your sponsors to make their pledged payments there if they wish. Posted on our chapter website are printable pledge/donations forms (www.cfedmonton.ca) and the link to the Running Room site.

The first person to register for this year's Run is Joan McQuitty, mother of Jessie in whose honor this event is held. We are really looking forward to having Joan with us.



Trip Raffle 2011: Destination Anywhere



Where would you go if you won a travel voucher worth up to **\$5000**? Disneyland? Mexico? Maui? Las Vegas? Buy a ticket (or several) in our new Travel Raffle to get a chance to make this decision! If you are the first prize winner, you will consult with a travel expert at Argyll Travel to explore your options and plan a trip to the destination of your choice. If you are the second prize winner, you will receive a certificate for a Via Rail round trip for two from Edmonton to Vancouver.

Tickets are \$10 each or 3 for \$20 and tickets are available at the CF office. Call us to buy tickets or to get tickets to sell. The draw for the winners will be made at the French Fling venue on October 28th. See our website www.cfedmonton.ca for official rules.

We also need sellers for these raffle tickets, so if you can help please let us know!

Get the Word Out We've Got Gear!

We are happy to report that we now have a stock of promotional materials in the office. These items range from cosy fleecies (a staple in any weather) to car magnets to kites. Each item is logoed with the new Cystic Fibrosis Canada design in order to increase our visibility and encourage recognition. Items range in price and some are available for free. These are great to purchase for yourself or to sell at those fabulous fundraisers you host all year. See the insert for a full listing.

Wish Foundations

As a parent or relative of someone with cystic fibrosis, you may wish to nominate them for the granting of a wish. We have two organizations who have supported CF families in the past.



One is the Make-a-Wish foundation. They recently had a fundraiser at which Verity Filipow and her family were speaking about their very positive experience. "The mission of Make-a-Wish Canada is to grant the wishes of children with life-threatening medical conditions to enrich the human experience with strength, hope and joy" (www.makeawish.ca)



Another foundation, the Children's Wish Foundation of Canada is a national organization dedicated to granting the most heartfelt wishes of children diagnosed with life threatening illnesses. Founded in 1984, Children's Wish has granted over 17 000 wishes for children and their families—each being an individual adventure, carefully structured to meet the needs of that particular child. To learn more or to refer a child, visit ChildrensWish.ca.

CALLING ALL VOLUNTEERS!

Can you spare some time to help out at with any of these events? If so, please call the office (780-466-2265)

- We need raffle ticket sellers for our Trip Raffle!
- July 27 at Akita Golf Tournament. Help needed from 10 am until 6 pm.
- We need help to stuff Grey Cup Raffle ticket envelopes! Supplies can be picked up in the office and done at home. Begins in July.