

July — September 2009 Issue 45

INSIDE THIS ISSUE:

<i>H1n1 (Swine Flu)</i>	2
<i>President's Corner</i>	2
<i>Great Strides</i>	3
<i>NACFC highlights</i>	4
<i>Hockey Draft of Hope</i>	5
<i>Riders with Heart</i>	6
<i>Calendar</i>	6

TWO NEW EVENTS THIS FALL

Our chapter is organizing two new events this fall which we hope will become annual fundraisers. The first one, **CFar: Cystic Fibrosis amazing race**, has been in the planning process for over a year due to many challenges, promises to provide a wonderful day for families and teams with children. Please look for full information elsewhere in this newsletter, and register now by phoning

**CFar – Cystic Fibrosis Amazing Race
Postponed till SUNDAY, JUNE 27, 2010**

our office at 780-466-2265 or e-mailing Kathy at ecfs.fundraising@telus.net. The second event is **CF Spectacular**, an evening of dinner theatre and a silent auction, which will be held at the famous Mayfield Dinner Theatre. Tickets are on sale now. Usually ticket prices vary depending on where you sit in the theatre but for our event all seats are the same so buy your tickets ASAP to get the best seating choice. Please see the poster for more information.

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VOLUNTEERS: WE CAN'T THANK YOU ENOUGH

Although June was crazy, we not only survived, we thrived thanks to our wonderful volunteers. Other articles in this newsletter list the names of some volunteers, but there were many others as well. We want you to know how much you are appreciated, even if we don't list every single name. In recent months, volunteers have stepped forward to help with all of the following projects and events:

Hockey draft, Mail campaign, Great Strides walk, Alberta Cycle customer appreciation days, Advoc golf tournament, Leduc Kinsmen golf tournament, Casino, Aerobathon, and the Ride for the Breath of Life. In addition to these, several people

organized third party fundraisers and donated the funds to CF.

We extend special thanks to Cathy Michael who makes most of the phone calls required to recruit volunteers for events.



Chapter president Allan Bartman with Youth Award winners Brent Van Dorp and Erica Van Dorp.

Two of our young volunteers who have contributed in many ways over many years were acknowledged with the national Youth Award at the Great Strides Walk. Congratulations, Brent Van Dorp and Erica Van Dorp on being recipients of this award, and thank

you for all that you do and have done for CF. Great Strides was a suitable occasion for presentation of this award, since Erica is part of one of the event's top fundraising teams, Team Hyperflex, but this event is just one of many that both Brent and Erica have supported over the years.

H1N1 (SWINE FLU)

- 1) People with CF who have specific concerns about H1N1 and their personal health should contact their clinic for advice.
- 2) With respect to general advice regarding H1N1, the Foundation is consulting Canadian clinical experts to consider whether there may be any additional suggestions that might be added to the normal list of day-to-day measures pertaining to infection control.
- 3) Meanwhile, people with CF should follow the normal infection control procedures, and also consider the guidelines from Health Canada, available at:

http://www.phac-aspc.gc.ca/alert-alerte/swine-porcine/faq_rg_swine-eng.php

and at: www.fightflu.ca .

- 4) Finally until there is further advice to offer, the Cystic Fibrosis Foundation in the USA makes some useful points at this Web address:

<http://www.cff.org/LivingWithCF/StayingHealthy/Germs/SwineFlu/>.

GIFTS FROM THE NEWLYWEDS

On June 20, 2009, Amanda McKay and Christopher Connelly were married in Wetaskiwin. Amanda and her mother, Holly, have been generous supporters for ten years of the Wetaskiwin Kinetite CF Craft

Auction and Amanda was Emily Orchard's Brownie & Guide leader. So this summer when Amanda and Christopher got married, they decided that the proceeds from their wedding 's toonie bar would be

donated to the Canadian Cystic Fibrosis Foundation. They raised and donated \$940.00! Thank you to this young married couple who want to make a difference in finding a cure for Cystic Fibrosis.

PRESIDENT'S CORNER WITH ALAN BARTMAN

Summer is finally here and so are the Thunderstorms. It's nice to watch them but they can sure do a heap of damage at times. We have just wrapped up a few very busy months and have celebrated some huge successes. Our Great Strides Walk was another record breaker – we made in the neighbourhood of \$150,000. I would like to congratulate and thank all of the committee, the volunteers, and the walkers. We also had another very successful Motorbike ride which looks to be our best yet. A few others to mention include CF Gobi which was Blain Davis' run in the Gobi desert to raise money for CF research, and another

successful golf tournament was held by the Leduc Kinsmen in support of CF. Throughout the remainder of the summer there are several more fundraisers planned and I would like to encourage you to attend and support them in any way that you can – one of the best ways being just to announce them to your friends, relatives, co-workers, neighbours and frankly, anybody you pass by on the street. The more that we can spread the word about CF and our events the sooner we will find a cure or control for CF – and we will find that cure or control, its just a matter of time and we are getting closer every year. As mentioned previously, we have two new exciting events coming up this fall.

The first is CFar (Cystic Fibrosis amazing race) which will be a scavenger hunt held at Fort Edmonton park on Sunday September 13. There will also be activities after the race and a BBQ – this is a team (or family) event and all ages are welcome and encouraged to participate. The second is the CF Spectacular (Night at the Mayfield Dinner Theatre). We have the entire Mayfield Dinner Theatre booked for this one, so get your tickets early to get the best seats. With that I would like to wish you all a great summer and thank you for your support of and help with our events.

GREAT STRIDES MOST SUCCESSFUL YEAR EVER



Great Strides 2009 was a resounding success, whether we consider the number of people walking, the amount of money raised, or the enjoyment experienced during the event. This year we had well over 500 participants. We raised over \$150,000, which made it our most successful year ever. Two of the top fundraising teams in the nation were from our chapter, Team Saltsticks and Team Hyperflex. On the day of the walk, Cowboy Carter's Team and Team Cael were also among the top 10! We were pleased to be joined by local teams connected with our national team partners from Siemens (SWAT team) and Kin Canada (Kinette Club of Edmonton). Some of the other teams were Carter's Crew, Team Solvay, Smudgy, Rory's Runners, Team Charlene, Team Teresa, Team Teresa #2, Condo Crew, Tylar's Team, Team Teegin, and Brittney's Bunch. The Walk was held in Edmonton's



The warm up before the Great Strides Walk was led by volunteers from the World Health Club.



People gathered in front of the Snow Valley Lodge before the start of the Great Strides Walk on May 31.



Team Saltsticks members walked the trail in Whitemud Park along with close to 500 other people!

river valley at Whitemud Park, with the Snow Valley Ski Lodge providing the gathering place.

Prior to the walk, teams gathered for photos with the chapter mascot Skelly the Skunk and for a warm-up led by two volunteers from the World Health Club. Thank you to World Health Club, as they were gracious enough to provide us with the pre-walk warm up and two fantastic raffle items!

Following the walk, children got up close and personal with an armadillo, a snake, and a skunk, and enjoyed other attractions and activities provided by the Valley Zoo, the Balloon Princess, and a number of volunteers. Activities included face-painting, bubbles, bean bag toss, three-legged races, candy jar guessing, and a sales table.

Three sponsors helped provide entertainment, so we would like to thank Hahn & Houle, and Stitchery & More for making it possible to have the Edmonton Valley Zoo and the Balloon Princess out for the children to enjoy. Maria from Snow Valley is absolutely the best, and she has an incredible crew working for her. They made our lunch run smoothly and donated hot coffee for us at the very last minute. Sport Chek, Save On Foods, Northlands, McDonalds, Tim Hortons, Royal Alberta Museum, and the Andrew Bodga Professional Corporation also contributed to our success.

Stacy Hipkin

Jocelyn Gillis

Joe Gillis

Kelly McCley

Courtney Allen

Heidi Bidwell

Ronda Lisowski

Sydney Vandermeer

Clint Kuntz

Nancy Gillis

Elizabeth Montague, a.k.a. Skelly

Bob Hahn

Ryan Wardell

Madeleine Bosnyak

Lauren Johnston

Ashley Dechant

Annette Vandermeer

Chelsea Blatner

Every single walker and team

Michelle Irvine

Allie Malonie-Peters

Jane Halford

Deanna Hipkin

Bev Rennie

Megan Steven

Kathy Irvine

Amy McCormack

Patti Magnan

Highlights of the NACFC Part 2: Preventing Lung Disease, presented by Jeffrey J. Wine, Cystic Fibrosis Research Laboratory, Stanford University.

Cystic fibrosis was first described by Dorothy Andersen in 1938. Since that time considerable information about the disease has been amassed.

Dr. Wine outlines 5 important assertions with respect to how to tackle CF associated lung disease. These assertions are: 1. Basic research can suggest therapeutic strategies. 2. Lung function decline is caused by infections. 3. Infection can be prevented with available treatments. 4. It is essential to give prevention of infection the highest priority. 5. New treatments will make prevention easier and might approximate a cure.

Cystic fibrosis involves complex interactions between a defect in the CFTR gene which produces the chloride ion channel that is present in lungs, pancreatic duct, sweat glands etc. This defect results in altered secretion (producing thick mucus or salty sweat) so that ducts are blocked. When ducts are blocked, there is reduced mucosal defence and decreased pancreatic enzyme secretion. Decreased pancreatic enzyme secretion results in vitamin deficiencies and fat malabsorption, weight loss and subsequent susceptibility to infection followed by tissue damage. In the lung, abnormal chloride ion permeability alters ion transport, reducing water in the airway surface liquid, abnormal mucus composition, bronchial obstruction and bacterial infection, inflammation and bronchiectasis and lung insufficiency.

To study CF, mouse models have been developed. The CF mice, however, do not develop complications in their airways as seen in human, therefore are poor models for that avenue of investigation. Ferret and pig models of CF are currently being developed and characterized to determine their suitability for studying the effect of CF on lung

function.

In order to prevent CF lung disease, we must understand how airway innate defences keep lungs healthy in normal individuals and how normal airways prevent and resolve bacterial infections. In a large part, mucus clearance is the main defence against lung infection. Normal airways secrete chloride ions and allow for the correct composition of antimicrobial mucus that traps and inhibits bacteria which are then removed by mucociliary transport (little hairs lining the airway surface brush the mucus upward where it is coughed out). In CF, the structure of the mucus is altered because chloride ions are not secreted, salts and water that are normally found in mucus are reduced or absent, and this results in the formation of thick gluey mucus that is difficult to clear.

CF is life threatening because of the loss of the CFTR reduces chloride and bicarbonate mediated fluid secretion, and increase sodium mediated fluid absorption, affecting many aspects of airway innate defence. Fortunately, this picture of CF airways is extreme. Calcium activated chloride channels can also mediate secretion and prevents CF from being an early lethal disease. These channels can be a target for drugs (like denufosal, a drug in development) to compensate for the defect in CF.

It is hypothesized that CF lungs are destroyed primarily by bacterial infections rather than by intrinsic or "built-in" damage. Therefore if infections are prevented, CF lungs are preserved. While obstruction and destruction of pancreas and sperm duct occur in CF without infection, CF sweat glands have abnormal ion transport but normal structure. What about destruction of the lungs? Is it intrinsic or caused by infection induced inflammation? How can we know? We can learn by comparing intermittently and chronically infected patients.

CF is two diseases. CF-A or CF-acute

involves acute infections with little decline in lung function (or at least a slow in damage/decline with time), weight and strength. Prevention of infection and eradication of breakthrough infections appear effective in this type of CF. CF-C or CF-chronic involves chronic infection, with decline in lung function of variable rate. Treatment involves maintenance antibiotic and treatment of exacerbations. CT scans, lung function tests and exercise testing appear to support that lungs are preserved in CF-A patients with intensive prophylaxis and eradication techniques (like physiotherapy) when infection occurs.

Seven key features of CF airway infections: People with CF die from airway infections. Infections tend to involve bacteria not viruses. Bacteria are found in the mucus that coats the airway surface but not the airway surface itself. Bacterial infections are heterogeneous. Infections start high (upper airways), move low (lower lobes). Pseudomonas rapidly evolves if not eradicated from lung. After years of infection, conversion to mucoid pseudomonas occurs. The airways remodel as a consequence of inflammation. This phenomenon marks the transition from CF-A to CF-C.

What happens to chronically infected airways? Williams-Campbell Syndrome: Congenital bronchial cartilage deficiency leading to thin walled bronchiectasis with associated airway dilation on inspiration and collapse with expiration. Consequently, cough, wheezing, recurrent pulmonary infections.

What can be done to prevent this transition? Scientists try to correct the defect with drugs so that mucus is normal/infection clearance is more like normal non-CF airway clearance. Otherwise, early infections are aggressively targeted with multiple antibiotics (multiple antibiotics reduce development of resistance). Thus inhaling antibiotics and increasing mucus clearance is for a person with CF analogous to taking pancreatic enzymes; it is replacement therapy. With this strategy, it will make the transition from CF-A to CF-C all the more difficult to achieve.

GOBI MARCH: BLAIN SAYS “BEEN THERE, DONE THAT”

The Gobi March is named by Time magazine as one of the top 10 endurance competitions in the world. In June, Edmonton's Blain Davis ran this Gobi Desert ultramarathon to raise money for CF. The stony Gobi Desert is north of the Himalayas which block most of the rain –

carrying clouds. In addition to coping with desert conditions, runners also faced the challenges of elevation gain and loss on the course, the highest point reaching an altitude of about 3,000 meters (9,800 feet). Not only did Blain complete the course, he

finished in 19th place in a field that began with 130 competitors. His friend Carson Dueck finished 63rd. Between them, they raised almost \$10,000. Well done, Blain and Carson. Talk about running the extra mile for CF!

ORIGINAL JOE'S RUN FOR THE LUNG

The next Run for the Lung is planned for 2010. This event previously was held in 2005, 2007 and 2008, and raised over

\$32,000 over those three years. We look forward to meeting all runners on a sunny (or rainy) Sunday

in July or August next year at the Terwillegar Original Joe's at 2323 Rabbit Hill Rd.

GREY CUP RAFFLE VOLUNTEERS NEEDED

In 2008, the Grey Cup Raffle raised \$10,000!

This year volunteers in Edmonton and many communities throughout Northern Alberta will once again be selling these \$2 raffle tickets to their family and



friends. Each ticket has a pre-printed score for the West or the East. Prizes are given to holders of the tickets with the correct scores at the end of each quarter of the Grey Cup game, and also to those with the reverse score.

Cash prizes range from \$50 to \$400. If you would like to buy or sell tickets, or you would be able to seal tickets in individual envelopes, make phone calls, or prepare the tickets for mailing out, please phone the office at 466-2265.

HOCKEY DRAFT OF HOPE

The Hockey Draft of Hope continued this event's tradition of success, this time under the direction of new chairman Jordan Parker. With assistance from another very generous volunteer, Paul Filipow, the hockey draft

provided participants with the option of purchasing their tickets either the traditional ways of mail and fax, or by going online to the website Paul has created for this event. With the online option, the demands for volunteer

time have changed, but this event still requires lots of volunteer work. Thanks to Jordan, Paul and the volunteers listed below, this event has netted about \$19,000 for CF.

Heidi Bidwell

Marcel Fontaine

James Gibeault

Kyle Peake

Marcia Milne

Lori Hanna

Bob Rennie

Joe & Eugenia Nimchuk

Darren & Stacy Hipkin

Sue Burnham

Doris Gordon

Pam Plourde

Ken & Betty Orchard

Jacque Fontaine

Deanna Hipkin

Terra Demers

Jane Filipow

Tracy Muzika

Kim Laframboise

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

Clinic: University Hospital
(780) 407-6745



Edmonton and Northern Alberta Chapter

Calendar

April 2009 – July 2009

- July 29 - Akita Golf tournament for CF
- Sept. - Grey Cup raffle mailouts to ticket sellers
- Sept. 8 - Chapter Board Meeting
- Sept. 13 - CFar: Cystic Fibrosis amazing race
- Oct. 3-4 - Prairie Regional meetings in Winnipeg
- Oct. 6 - Chapter Board Meeting
- Oct. 24 - CF Spectacular: Dinner Theatre
- Nov. 3 - Chapter Board Meeting
- Nov. 22 - Grey Cup raffle ends
- Dec. 1 - Chapter Board Meeting

RIDERS WITH HEART

With generous hearts hidden behind their gruff exteriors, 78 bikers made the 4th Ride for the Breath of Life a tremendous success again this year. J'Lyn Nye of Joe FM, honorary chair and ride leader, led the 150km ride from the Acheson Husky along the scenic west side of Pigeon Lake to our final destination at Falun Hall.



Motorcyclists participating in the Ride for the Breath of Life gathered to listen to announcements and directions before leaving the ride's registration location at the Acheson Husky.

Once again, Joan Losinski and her crew prepared a fantastic BBQ lunch for all to enjoy. More importantly, over \$63,000 was raised in the fight against CF – a 26% increase over last year!! We thank all our riders for participating in this year's ride with special thanks going out to the following: Our volunteers gave up their time to run the registration booth, sell 50/50 tickets, assist the riders and help make the day run so smoothly. J'Lyn Nye – for being our honorary chair and ride leader. Show & Shine judge Bob Gillies and his crew.

Babes on Bikes - for receiving the Carey Losinski trophy for having the most bikers from one group – seven. An Honourable mention goes to the Sierra Thunder for raising over \$13,800 with only five riders.

Jerry Gordon - who raised \$3,000 and won \$500 in gift cards from TIG Insurance.

Jeff Andrews - our second highest fund raiser with \$5,106 in pledges. He will enjoy a Travel America vacation package for two from NorthStar Hyundai.

Abe Van Dorp – this year's highest fund raiser at \$8,405 and taking home two tickets anywhere WestJet flies.

This year's organizing committee - Darlene Bouclin, Shannon Gaucher, Monica Hoppe, Kathy Irvine, Charlene Keller, Joan Losinski, David & Bliss Robinson, Abe Van Dorp, and Emily Westwood. Our major sponsors and their generous donations that make this ride possible – Alberta Cycle, WestJet, NorthStar Hyundai, TIG Insurance, Northwest Rentals, AirGas, Ft. Edmonton Kin Club, Acheson Husky, Falun Community League, Western Dispatch, Image Auto, Petrin Mechanical. Please consider patronizing their businesses as they obviously care and contribute to our community.

We are in the process of compiling a book of this year's Ride, which will be available soon. Pictures of the Ride may be viewed at <http://www.loneeyephography.ca>. Next year is the 5th anniversary of the Ride for the Breath of Life tentatively scheduled for June 19, 2010. We hope to see you and many of your friends out for a great day next year!! In the meantime, keep the rubber down and the chrome up.



For the Ride for the Breath of Life, riders could register as individuals or teams. Photo includes L-R: J'Lyn Nye, Mark Mullaly, Ron Haukenfrers, Mike Hughes and his daughter Holly Hughes, Kellie Harrison, and Abe Van Dorp.