



Breathing life into the future®
EDMONTON & NORTHERN ALBERTA CHAPTER

Contents

- 1- Chapter AGM highlights
- 2- Kick-Off Fundraiser & Presidents message
- 3- Casino
- 4- Live Webinar
- 5- Carstar Collision & Ride for the Breath of Life
- 6- Great Strides™ walk & Leduc Kinsmen Golf

Upcoming Events

Kick-Off Party— May 4

Great Strides walk —May 26

EDMONTON

LEDUC

GRANDE PRAIRIE —June 1

WHITECOURT

FORT MCMURRAY

LLOYDMINSTER

Leduc Kinsmen Golf— June 7

Carstar “Soap’s it Up”

carwash— June 8

Ride for the Breath of Life—

June 22

Additional Information for our Chapter events can be found on our website or call 780-466-2265 for details.

Chapter AGM

Just prior to the start of our annual cystic fibrosis (CF) information day and chapter AGM we held our first ever Great Strides™ workshop for team captains with great success! It was a time for sharing ideas on different ways to raise funds for teams; and chat about the walk which in turn developed some new ideas that we would like to incorporate into the walk. We had some really positive feedback on the session and will plan to do this again for next year!

For the CF information portion of the day Dr. Zuberbuhler & Joan Tabak presented highlights from the 2012 NACF conference held in Florida as well as a discussion of current issues in CF care. Adult clinic director Dr. Winnie Leung, pediatric physiotherapist Suzanne, adult physiotherapist Joyce, and nurse Josette also added some comments during the presentations.

Awards presentations followed the CF information session with Past President Patti Magnan presenting the following awards to our greatly appreciated volunteers.

Certificates of Appreciation

Heather Hanna with the help of her parents, was able to start our Chapter’s very first School Great Strides™ walk in 2011; through the walk, she also had an opportunity to talk to her peers about cystic fibrosis and there was public awareness gained through local newspapers. 2013 will be the 3rd year for Heather’s walk at her local school and her twin sister is holding a first time walk at her new school! Heather has been very active with the Chapter in many ways over the last few years helping with everything from stuffing envelopes to speaking out about cystic fibrosis through many media opportunities.

The **Husch family** was recognized for their chapter support through Chris chairing our

Faceoff with CF event and Michelle sitting on the Great Strides™ walk committee. The whole family worked very hard with the Stollery last year bringing awareness to cystic fibrosis through Drew being the Stollery child. Sydney is our Edmonton 2013 Super strider which will bring additional awareness to Cystic Fibrosis Canada through media opportunities; and Taryn helps out by raising funds with a school bake sale every year!

Gillian Holloway’s daughter has cystic fibrosis and she was looking for a way to help her daughter. Gillian chose to do so through a community Great Strides™ walk in Fort McMurray. In two short years this walk has brought in \$50,000 that will help fund research and ensure high quality care in our CF clinics. She also managed to pick up some media opportunities through this event to help create awareness of cystic fibrosis in her community.

The **Leduc Kinette club** has been a longtime supporter of Cystic Fibrosis Canada, but exceeded all expectations of donations to our organization by using the Great Strides™ walk as a vehicle to not only raise needed funds but awareness within the community. They have raised \$60,000 through the walk over the last 3 years.

The **Wetaskiwin Kinette Club** and longtime supporters of Cystic Fibrosis Canada have hosted their Kinette Craft Auction for 14 years! The project includes a huge live auction, a 50/50 draw, a silent auction and this past year they raffled off a Diamond necklace! Every year the ladies make sure that there is a speaking opportunity for someone from our Chapter to educate the Wetaskiwin community about cystic fibrosis. Since 1993, the Wetaskiwin Kinette club has raised close to \$90,000 in support of Cystic FibrosisCanada.

Continued on page 3



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

Office Phone: 780-466-2265

Website: www.cfedmonton.ca

Email: info_edmonton@cysticfibrosis.ca

Issue 62 was released on March 28, 2013

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.

President	Scott Hanna
Past President	Pat Magnan
VP Fundraising	Stacy Hipkin
VP Pub & Promo	Deanna Morrison
VP Fund Dev.	Peter Hackett
Secretary	Emily Westwood
Treasurer	Andrea Richard
CF Adult Liaison	Maureen Jamieson
Director at Large	Shawn Thorn
Director at Large	Allan Bartman
CF Adult Clinic Liaison	Joan Tabak
CF Peds Clinic Liaison	Angela MacDonald
CF Kin Liaison	Gerry Boehm
Chapter Manager	Kathy Irvine
Event Coordinator	Vacant

Kick-Off Fundraiser

The Ride for the Breath of Life motorcycle ride committee is working on a FUN filled evening that will kick-off Cystic Fibrosis Awareness month! This will be a night out for everyone, who is of age, to join us at the Canadian Brewhouse (9538 Ellerslie Road) for just \$10/ticket and this includes one free drink and entry into a door prize draw! We will be holding a silent auction with some fantastic items including an autographed Ryan Nugent-Hopkins jersey and there will be a 50/50 draw! Come out and join us on Saturday, May 7th and get your tickets early



Presidents Message

This is a very exciting time in the CF community. I feel fortunate that my daughter was born during this time and not earlier. We are getting so close to a cure/control for CF. The quality and length of a CF patient's life is truly improving due to the development of substantially better treatments.

It was announced on March 26th that the Canadian Drug Expert Committee (CDEC) has recommended that the drug KALYDECO™ (ivacaftor) be added to the formulary listing of publicly funded drug plans for the treatment of cystic fibrosis in patients age six years and older who have the G551D mutation in the CFRT gene. This is the first approved drug to address the basic cellular defect in CF and not to treat the resulting side effects of the defect.

This is only the first drug directed at the defect, more are coming out of the pipeline. The credit for the progress in CF is due to you! You have stepped up and raised funds for CF research. Without you the cure would be out of reach!

Help us keep up the momentum by getting involved or volunteering at our upcoming fundraisers. We have the **Kick-Off Party** on May 4th; five **Great Strides™ walks** (different locations), most happening on May 26; **Ride for the Breath of Life** on June 22nd; and our ongoing fundraiser **Cents Makes Sense**. Check out our web site for all the details or call the office to get involved.

Another way you can make a big difference is by joining our Chapter's Board of Directors. Having no experience, I found the idea of joining the Board very intimidating five years ago. It's really not as scary as you might think. Give the office a call if you are interested.

Thank you for all the support you give our Chapter and cause. I feel very honored to be associated with such a wonderful group of people.

Chapter AGM cont.

The **Grono family** was presented the **Grassroots, level two award**. Lisa & Shawn have been a part of the Great Strides™ walk for as long as we have records for (2008), possibly longer! In 2009 the Grono family put on a team fundraiser at the King and I pub that was a huge success and ended up with a record breaking year in fundraising with just about \$27,500.00 for a team total! Last year was their second best, coming in at \$26,025.00. Their team is the first to break an accumulative total of \$100,000.00!! Lisa and Shawn's children, Sidney and Logan have both appeared on television to help raise awareness of cystic fibrosis and Lisa has always kept her phone line open for newly diagnosed families to reach out to her.

Scott Hanna, our Chapter President, presented **Patti Magnan** with the Volunteer Leadership, level two award. She has been involved with the chapter for many years and even traveled from St. Paul when she lived there to help out the office on occasion. After moving to Edmonton her involvement grew. She has sat on the board since 2006, joining as a director and moving through the ranks quickly; she currently is the Chapter's Past President. She has been a great leader, possessing some of the greatest listening skills possible and pays attention to the smallest of details. She is always attentive to our chapter member needs and works really well with all of our volunteers. Patti has been a key volunteer with the Casino and Grey Cup raffle over the last few years and has just joined a newly formed National Great Strides™ walk committee.

Akita Drilling has held a golf tournament comprised of business associates since 2002 in support of Cystic Fibrosis Canada. This tournament was started through an employee who had just shared the news about his nephew being diagnosed with cystic fibrosis back then. In 2011 they celebrated their 10 year Anniversary and partnership with Cystic Fibrosis Canada and raised a record breaking \$44,000.00! In 2012, they broke another record by raising

an astounding \$52,500.00! The cumulative total that Akita Drilling has raised is just over \$325,000.00. The Chapter has recognized Akita Drilling with awards in the past, even with our National Julia Award; but felt we should recognize their recent incredible achievements with a special recognition certificate that we will present to them at their 2013 tournament.

The Edmonton & Northern Alberta Chapter had two **Regional Award** winners back in October. **Abe Van Dorp** was unable to be at that meeting, so we presented his Grassroots Volunteer award at the Chapter AGM. He has been involved with the chapter for 17 years in many ways; raising funds through his softball tournament, working casinos, and helping raise awareness through the media just to name a few. His largest involvement is through the Ride for the Breath of Life motorcycle ride since 2007. He went from being a rider, to chairing the event, helping to raise \$142,225.00 over the last four years.

Stacy Hipkin was presented her Volunteer Leadership award at the Regional meetings in October. She joined our chapter and jumped in with both feet by chairing the Edmonton Great Strides™ walk in 2009. Stacy has been the chair ever since organizing and planning the majority of the walk. Last year she helped to form some additional leadership roles for the walk because of the size and amount of work needed to pull off this massive event. Along with chairing the event, she is the team captain on her team and in 2012 they were the highest fundraising team in Edmonton. To help get her to this level, Carter's school had their own Great Strides™ walk and his 4H club helped raise funds and awareness through collecting coins in Leduc. Stacy currently sits on the Edmonton & Northern Alberta Chapter board as the VP Fundraising for her second year in this position but has been on the board since March 2009.

Casino

We would like to thank all of our wonderful volunteers who came out to work the February 6 & 7th Casino. Many of you took a day off work or went to work very tired after working a late shift. We greatly appreciate your significant contributions to pull off this two day event! A special thank you goes out to Graydon Chretien as the chairperson for our Casino; and to Patti Magnan as our past chairperson who assisted Graydon with his first Casino.



DONATE NOW

The Edmonton & Northern Alberta Chapter is thrilled to announce the launch of our very own "Donate Now" button! This just makes it a little bit easier and convenient for our local donors to make general, memorial or tribute gifts. An extra added bonus of using the online donation service is that we now provide an electronic tax receipt as soon as the payment has been processed.



Carstar Collisions Soaps it Up National Car Wash

Carstar is the largest and fastest growing automotive repair franchise network. It has more than 400 locations in North America. Founded in Hamilton, Ontario in 1995, CARSTAR Automotive Canada Inc. now has more than 140 locations in ten provinces. CARSTAR selected Cystic Fibrosis Canada as its charity of choice in 1997. It has raised 2 million through an annual golf tournament, casino gala and its 'Soaps it Up' national car wash.

Locally, we there are five Carstar Collision locations that participate in this huge event! They pre-sell carwash tickets that can be picked up from one of the locations and then you can stop by on June 8th to have your car washed! There will be a couple of Carstar Collision reps joining us at the Edmonton GreatStrides™ walk on Sunday, May 26th, and they will have the car wash tickets available to purchase on site as well.

~World Record from Saturday, June 11, 2011 for "World's Largest Car Wash - Multiple Venues." There were over 140 events throughout Canada and the U.S. supporting CARSTAR's Soaps It Up National Car Wash Fundraiser that washed 4918 cars, breaking the previous record of 4105!~



Ride for the Breath of Life



The 9th annual Ride for the Breath of Life motorcycle ride for the Edmonton & Northern Alberta Chapter will be held on Saturday, June 22nd this year. The committee is still working out many of the details but are very excited to announce that they will include a poker rally in the ride this year. Participants can choose to purchase a hand at the cost of \$25 each with cash prizes to be awarded. For more information and updates on the Ride for the Breath of Life, visit www.cfedmonton.ca. You will also be able to find a link for online registration here.



Circle of Friends - Linking Adults with CF

The Adult Cystic Fibrosis Advisory Committee is looking for writers interested in contributing a story to the Spring 2013 Circle of Friends publication. This is a newsletter that is produced by and for adults with cystic fibrosis in Canada. If you, or someone you know, is interested in contributing an article, special feature, news item or tribute to an individual in your/their community, please contact Joanna Valsamis by email at jvalsamis@cysticfibrosis.ca.



Great Strides™ walk



The Edmonton & Northern Alberta Chapter will be holding walks at the following satellite locations: Leduc, Grande Prairie, Fort McMurray, Lloydminster and Whitecourt along with our Edmonton location.

Full details of all these walk locations can be found at www.cfedmonton.ca, www.facebook.com/cysticfibrosisedmonton or www.cysticfibrosis.ca.

This event is not only a great way for our chapter members and CF community to help raise funds for cystic fibrosis research;

- it's an opportunity to connect with other parents dealing with the same issues, questions and concerns as you are about cystic fibrosis.
- It's a great way to get friends and family involved in making a difference in the lives of those they know with cystic fibrosis.
- It's a great way to get schools involved as well as educating the children about cystic fibrosis.
- If your child is involved in any kind of extra-curricular activities, it's an opportunity to get them involved.
- It's also an opportunity to attract corporate teams and connect them to the CF community through sharing your stories.

For more information on how to get involved with the walk, please contact the Edmonton & Northern Alberta Chapter office at 780-466-2265 or visit www.cfedmonton.ca. You can also find special edition newsletters filled with information on the Great Strides™ walk through this link.



Leduc Kinsmen Golf Tournament

The Leduc Kinsmen will be hosting their 20th Annual Kinsmen Charity golf tournament on Friday, June 7th. The Leduc Kinsmen donate a portion of the proceeds from this tournament to Cystic Fibrosis Canada; so please think about joining them for a full day of fun, food and of course golf! Entry fee is \$185/

person. For more details or to register, contact Kelly Howe at 780-983-6059 or Kelly_Howe@cargill.com.



Adult CF Clinic - Welcome!

The adult clinic would like to welcome Dr Kim Mulchey and Dr Jalad Yehya. They are working adult clinics with us as well as looking after persons admitted to hospital.

Joan Tabak
Adult Cystic Fibrosis Clinic



www.twitter.com/CF_Edmonton

www.facebook.com/cysticfibrosisedmonton



Challenges in Cystic Fibrosis



Medical Panel - Live Webinar

Friday, April 26, 2013

3:00 p.m. to 5:15 p.m. (EST)

Join an interactive session to discuss
Challenges in Cystic Fibrosis with guest
speakers:

- **Dr. Mark Montgomery** – *Early detection of CF complications*
- **Dr. Anne Stephenson** – *National perspective on evaluation and follow-up of CF patients*
- **Dr. Harvey Rabin** – *Patient engagement: An adult perspective*

Visit our website soon for registration information
www.cysticfibrosis.ca