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Calendar

April - June 2011

April 4
Chapter Board Meeting

April
Hockey Draft

May 3
Chapter Board Meeting

May 29
Great Strides Walks:
Edmonton, Leduc, St. Paul, NWT (Ekati), Grande Prairie, Fort McMurray

June 5
Great Strides Walk:
Lloydminster

June 7
Chapter Board Meeting;
Raffle draw

June 13
Leduc Kinsmen golf tournament

June 18
Ride for Cystic Fibrosis motorcycle ride

June 25
Chapter Anniversary

Rosenau Transport: Time Flies

When Carl Rosenau, president of Rosenau Transport, first got involved through the Kinsmen as Cystic Fibrosis Director in 1984, he says there was much further to go.

"The life span was short. The pills were many. The 'beatings' were often. All this has come a long way in 27 years, but there is still more road to cover to finally find a cure," says Rosenau.

"In my business I get a lot of requests for donations. This chapter is one of the hardest working volunteer organizations I have ever seen," he continues.

Rosenau Transport Ltd. was incorporated in 1957, and has grown into one of the largest regional carriers in Western Canada. The company provides general freight service between Alberta, Saskatchewan, Northern British Columbia and Manitoba terminals. It also has a network of commodity services across the prairies with connections to Eastern Canada and the United States.

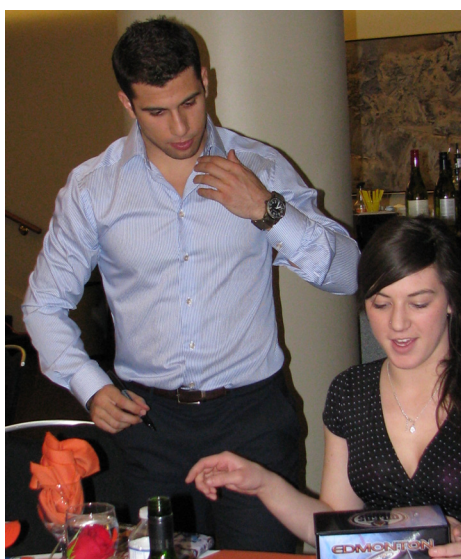
"When I started, to me, it was a very worthwhile project and has stuck with me

since then," says Rosenau.

"We publicize the chapter in our pamphlet, when appropriate, that we support CF and explain the strides it has made over time. At all of our awards banquets it is always announced as being one of our corporate philanthropic projects. At our AGMs, when we discuss what or who we are going to support for the coming year, there has never ever been a question about our continued support for CF," he says. ●



Faceoff with CF sponsor Carl Rosenau and guests enjoyed a fantastic meal catered by Elegant Affairs



Faceoff with CF honorary chair Andrew Cogliano autographs memorabilia for guest Michelle Irvine

Hockey Hero Salutes True Heroes at Faceoff Dinner

Edmonton Oiler Andrew Cogliano came to the podium after an inspiring presentation by Faceoff with CF committee chair, Chris Husch.

"I know that people look to hockey players as inspirations, but I want you to know that your family is an inspiration to me," said Cogliano.

The dinner took place on February 20 at the Jubilee Auditorium and included a fundraising photograph session with Cogliano, a chance to have memorabilia autographed and a silent auction. Dan Tencer of 630 CHED emceed the dinner.

The committee wishes to thank Cogliano, Tencer, guest Joey Moss, and all of the sponsors for an enjoyable evening.

The Edmonton and 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 St., Edmonton.

Issue 53 was issued Apr. 10, 2011. It was edited by Patrick Lépine with contributions by Pat Magnan, Emily Westwood, Sherri Selby, Megan Parker, Kathy Irvine & Stacy Hipkin and Patrick Lépine.

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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VP Pub & Promo	Scott Hanna
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Chapter Assistant	Katherine Lauzon
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Sherri's Corner: Medical News at AGM

Joan Tabak presented highlights of the 24th annual North American Cystic Fibrosis Conference (NACFC) 2010 at the Annual General Meeting March 13, 2011. She gave us an update of the most recent drugs in development for the treatment of cystic fibrosis, specifically, the airway surface liquid restorers and anti-infectives. Information was obtained from (and more detail is available at) <http://www.cff.org/treatments/Pipeline/> updated as of February 23, 2011. Please note that in no way is this review advocating for specific treatments. It is intended as a general discussion of the research in progress. If you have any questions, please see your health care provider.

Agents that restore airway surface liquid

Liquid bathes the surface of the lung airways and keeps them moist. However, in cystic fibrosis, changes in salt transport within cells dehydrate mucus, causing it to become thick and sticky. Agents that restore airway surface liquid

correct the defect in cystic fibrosis by targeting proteins other than CFTR to improve the movement of salt in and out of cells. This allows mucus to be more hydrated and, therefore, makes it easier to clear. One of these potential drugs, Denufisol, was under development by the company Inspire Pharmaceuticals. In June 2008, denufisol showed promising results from TIGER-1, its first Phase 3 trial (the trial showed improved lung function compared to those who received placebo).

However, TIGER-2, the second pivotal Phase 3 trial with denufisol showed no clinical benefit. The company is currently reviewing all the data before making a decision about whether to do additional studies.

Hypertonic saline is another way to make the airway liquid more liquid for cystic fibrosis but it only seems to do so while it is nebulized. Once the nebulization is stopped, it is rapidly re-absorbed and the airway surface liquid is the same as before.

Continued on page 3 as Medical News

President's Corner By President Patti Magnan

Have you ever wondered how much money our chapter could raise for cystic fibrosis research if every one of us entered the Great Strides Walk? Last year teams and individual entrants representing just 38 people with CF attended the walk at the Edmonton Snow Valley/Whitemud Park site but they collected \$120,000 in pledges.

There are 115 pediatric patients and 153 adults registered at the CF clinics here in Edmonton. Just imagine how much more money could be raised if every parent, grandparent, aunt, uncle, brother, sister, cousin, and friend of each person with CF sponsored someone

in our Great Strides Walk.

Many of these people would be happy to help if we just take the time to ask them. Even small pledges would make a real difference when combined with those of other walkers all across the country.

I challenge you to enter a team in the Great Strides Walk this year. Please consider this as a way of rallying your friends and family in a strong show of support for your loved one who struggles with Cystic Fibrosis. They will be very happy to know that you are working toward curing this disease, and you will feel great knowing that you are making a difference. ●

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Medical News

It is used selectively (~1% of our adult population). It tends to not be well tolerated. The clinic monitors a patient's first dose, by comparing their before- and after- treatment pulmonary function tests. The treatment is continued if it is well tolerated and of benefit. However, it costs \$65/20 vials and is not covered by Alberta Health; taken once or twice a day, long term use may not be practical given the expense.

Anti-infectives (anti-biotics)

Because chronic lung infections are a problem for those with cystic fibrosis, antibiotics are a vital part of CF care. Antibiotics help fight infections by attacking the bacteria that cause them.

Cayston® (aztreonam) was developed in collaboration with Gilead Sciences, Inc., and is the first CF drug to advance — from beginning to end — through the Cystic Fibrosis Canada's drug development pipeline. Cayston provides a much-needed antibiotic alternative for cystic fibrosis patients with *Pseudomonas aeruginosa*, who often develop resistance to existing antibiotics. It also shortens treatment time for CF patients.

A typical treatment regimen of airway clearance, inhaled medications and pancreatic enzymes may take patients up to several hours per day to complete however; Cayston is administered with a new device that allows patients to take the medicine in less than five minutes. This is up to four times faster than other nebulized antibiotics. It received FDA approval on February 22, 2010 and became available to patients in March 2010 (U.S.).

Health Canada has issued a Notice of Compliance with Conditions (NOC/c) for Cayston (October 2009). Products authorized under Health Canada's NOC/c policy have demonstrated promising benefit, are of high quality and possess an acceptable safety profile based on a benefit/risk assessment. An additional longer-term confirmatory Phase 3 study is underway.

Novartis Pharmaceuticals is developing TOBI as a powder - TIP (TOBI Inhaled Powder) - to enable a faster, more convenient dosing regimen. Dosing of TIP will take a fraction of the time of liquid TOBI. A Phase 3 trial has completed enrollment.

Arikace™ (Insmed, Inc. See <http://www.insmed.com/arikace.php>) Arikace is a special formulation of the antibiotic amikacin. Insmed is working to develop this drug as an inhaled antibiotic treatment which could result in: (1) improved efficacy resulting from sustained deposition of drug in the lung and ability to penetrate *P. aeruginosa* biofilm penetration and drug release; (2) decreased side effects and improved tolerability; (3) reduced dosing frequency; and (4) decreased time for administration. Insmed has approval to begin a phase 3 trial by the US Food and Drug Administration. ●



Come Celebrate!

On Saturday, June 25, our chapter will be celebrating! Celebrating 50 years of hard-working volunteers. Celebrating great strides in improved treatment and care for people with cystic fibrosis. Celebrating the increase of median age of survival from 5 to 46.6! And remembering the loved ones we have lost.

Invitations to the Anniversary Celebration have been mailed out to past and present volunteers and staff of the Edmonton & Northern Alberta Chapter - if we had addresses for them. But if you did not receive an invitation, or you know of someone who should have received one but didn't, please extend the invitation to them on our behalf. ●

Schanks for Cystic Fibrosis

by Megan Parker

I was fortunate enough to speak at and attend "Shoot, score, and so much more", an event put on by the Kinette Club of Edmonton on February 25 at Schanks. The evening was filled with games, prizes, snacks, and a silent auction with fabulous items to bid on. The turn-out was incredible! A special thank you to the organizers of this successful event and to all of those that attended. The Kinettes estimate that the event raised \$5,000 for cystic fibrosis ●



Casino

By Pat Magnan

Every second year our chapter has the opportunity to raise funds by supplying volunteers to work at a casino for two days. On March 28-29, thirty six of our volunteers assisted at Century Casino on Fort Road in Edmonton. They were the general managers, bankers, cashiers, count room supervisors, count room workers and chip runners.

The volunteers were fantastic! They arrived on time, worked hard and kept on smiling even though some of the shifts ended as late as 3am. Several volunteers commented that they enjoy working casinos because they have a great time talking to old friends and meeting new people.

If you are one of the people who volunteered at the casino: Thank you, thank you, thank you!! Thank you also to the Century Casino and its staff.

The chapter expects to receive approximately \$70,000 from the casino and the money raised will go directly toward cystic fibrosis research taking place in Alberta.



Century Casino floor

Carstars Soap It Up for CF

All Edmonton Carstar locations will be holding their annual carwashes on Saturday June 11 to raise money for CF. They will also be trying to achieve a world record for the most cars washed in one day. More information will be available. Keep checking back on our website for more information.

Volunteers -we love you!

April 10-16th is National Volunteer Week, the perfect reminder for us to tell you how much we appreciate you. To quote Cheryl in our national office, "I am constantly amazed at your passion, your ability to turn it into action that results in impact. Thank you, you are all super-heroes."



Gift Card Sales

In 2011 you will have the opportunity to purchase gift cards three times if you wish. The first order should be submitted with payment by April 22. The order form to use is attached. Please do not use earlier forms because the selection of cards changes periodically. Please use cheque or cash for payment (our profit margin is small) and also please plan to pick up the cards after the order is ready (May 10) to avoid postage costs. Send or bring your order to our office in St. James School, 7814-83 St., Edmonton.

The schedule for the year is as follows:

Orders in by April 22, pickup after May 10

Orders in by July 22, pickup after August 10

Orders in by November 24, pickup after December 12

Another Giant Step Into Our Communities

In 2005, our Chapter joined in the new national Great Strides Walk campaign to help raise funds towards cystic fibrosis research in hopes to find a cure or control for this terrible genetic disease. In 5 short years, this one fundraiser alone has brought in close to \$500,000.00 through our Chapter. Way to go!!!

From 2005 - 2009 we had one walk location in Edmonton, and in 2010 we started to expand the walk into some of our northern towns and cities. The Grande Prairie Kin club & Leduc Kinette club started walks in their communities, an aunt to two children with CF started a walk in St. Paul, and a dad with a daughter who has CF started a walk (with matched giving) at his work site at the Ekati Diamond mines.

Well we are very excited to say that these locations will all be hosting their second annual Great Strides Walk this year and we have another TWO NEW locations for 2011: Fort McMurray and Lloydminster, AB, where both locations are being organized by parents of children with CF.

If you are near any of the seven locations, we encourage you to support your local walk. Not only is this a great way to get involved with our Edmonton & Northern Alberta Chapter fundraising initiatives, it's also a great way to network with other families who face the same challenges as you. The Red Deer and Calgary Chapter are hosting walks in Red Deer, Calgary and Lethbridge this year.

Here is a little bit about what's happening at the different locations.

Edmonton is excited about hosting the GSW at Snow Valley Lodge/Whitemud Park again on Sunday, May 29. Registration will be at 9:00 am with warm up and introductions by our emcee, Ryan Jespersen, host of Breakfast Television on CityTV at 10:00 am. Our beautiful walk through Whitemud Park will start at 10:30. New this year, following the walk, will be a BBQ lunch followed by Airbrush Tattoos and entertainment by "Mugsy" the Clown. We are very excited about two new awards that we will be presenting to the Top Fundraising Individual and Top Fundraising Team. All registered participants who raise \$200 verified on-line by April 29 will be entered into a draw to win an 8GB iPod Touch. For more information on how you and your family can participate please contact Stacy Hipkin at dshipkin@shaw.ca or 780-467-5954.

Grande Prairie will be hosting their second annual walk this year on Sunday, May 29. Registration will take place by the Muskoseepi Park Pavillion at 10:00am with the walk starting at 11:00am. After the walk stick around for some lunch, water, snacks & activities. There will be face painting for the younger crowd, and the Grande Prairie Kin club is working on getting a clown for entertainment! For the bigger kids in the crowd, there will be a few items up for grabs



Taking Steps to Cure Cystic Fibrosis

in a silent auction and we will be selling items with the CF logo on them too. If you, or someone you know is able to help out by donating silent auction items, or sponsoring the walk, please contact Edith Gillett at edithgillett@hotmail.com or call the Edmonton & Northern Alberta Chapter at 780-466-2265.

St. Paul will be hosting their second annual walk on Sunday, May 29. Registration will take place at the Co-op starting at 9:00am, with the walk starting at 10:00am. After the walk there will be face painting and Skelly the Skunk, our Chapter Mascot, will be on site. Stick around for the BBQ lunch that will be provided for a small fee. Team Dragonfly is selling items as a part of their fundraising efforts, so if you have questions regarding the walk, or want to buy some bird suet, homemade dragonfly bookmarks, or fish hooks, email Helen at walkforcf@live.com or call the Edmonton & Northern Alberta Chapter at 780-466-2265.

Leduc Kinette club is hosting their second annual walk on Sunday, May 29, 2011. There is pre-registration set up for this location on Saturday, so take advantage of this if you are participating in Leduc! Registration on Sunday will start at 10:30am, with the walk beginning at 11:30am. We would like to welcome our first Corporate Team from the Executive Royal Inn!

There are a lot of fun activities planned for after the walk. The Valley Zoo will bring some animals for the kids to check out. There will be face painting, Buzz & Dizzy from Caring Clowns will be joining us again, and we have another special guest lined up to do some magic. His name is Sam, and from what I understand, he is only around 12 years old and a great entertainer! Our local M & M's store owner Arlene and her volunteers will be providing BBQ burgers for lunch again this year! For any additional information, please contact Penny Karen at 780-986-8879 or the CF office at 780-466-2265.

Fort McMurray is a new location and Gillian & her crew are very excited about having a walk right

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Continued from page 5

Giant Step

at home! Registration will be held in the Casman Centre starting at 9:30am with the walk beginning around 10:00am at the track located at Father Mercredi High School. There is a lot of planning in the works with this being a new location, but the committee is working on some fun activities for the kids, possibly an auction or raffle...you will have to check the Chapter website & Facebook page for updates! So far, the committee is planning cookie and/or cupcake decorating for the little girls, and a hockey shoot out game for the boys! For additional information, you can contact Gillian at 780-713-0780 or the CF office at 780-466-2265.

Lloydminster is another new location for this year, and Jennifer and her committee are also very excited about having a walk right at home! They will have registration at 9:00am with the walk starting around 10:00am at Bud Miller Park on Sunday, June 5! The Lloydminster Kinsmen and Kinette clubs will be getting involved by helping with a BBQ for the participants, and volunteering their time on the day of the event! For additional information, you can contact Jennifer at 780-871-4317 or the CF office at 780-466-2265.

Corporate Teams are a great opportunity to make a difference in your community, not to mention promoting physical fitness, unity & team building within your company. Your staff will have a chance to meet families who deal with cystic fibrosis on a daily basis, and some walk locations will have a speaker that will touch on some of the challenges that cystic fibrosis throws into family life. If you are interested in registering a corporate team, please call 780-466-2265 or email ecfs.fundraising@telus.net. ●

Chapter AGM

"There's always a debate as to which form of physiotherapy is best. There is no definitive answer. No matter what you do, just DO IT," says Joan Tabak.

The annual Cystic Fibrosis Information Day and Chapter AGM, recently held on Sunday, March 13, provided a very full agenda for the 40 people in attendance. Paediatric Clinic Nurse Coordinator Joan Tabak, Melissa Sheehan, dietician, and Josette Salgado, Adult Clinic Nurse Coordinator, presented the most recent information gleaned from a cystic fibrosis conference they attended. (See the article by Sherri Selby about their reports on page 2.)

Following a break with refreshments provided by Gerry Boehm and the Kin Club of Fort Edmonton, we launched into the business for the day. This included reports about the past year, plans for the upcoming year, and the election of board members. The three newly elected board members are Deanna Morrison, Andrea Richard, and Megan Parker. Eight people previously elected to the board are continuing to serve.

The highlight of the AGM was the presentation of awards, making the meeting a celebration as much as a business meeting. President Pat Magnan presented Certificates of Appreciation to these greatly appreciated volunteers:

Helen Chapdelaine: Helen is a very active volunteer in St. Paul, where she organizes a variety of events both large and small and promotes awareness of cystic fibrosis in the local media. It is thanks to Helen that St. Paul hosted a Great Strides Walk in 2010. Helen brought two of her St. Paul team with her, Tom Matthews and Chantal Michaud. Tom was one of the team captains for the St. Paul Great Strides Walk, and the sixth highest

By Emily Westwood

individual fundraiser in Canada.

Patrick Lépine: Patrick has been our chapter's newsletter editor for about 3 years and he also serves on the planning committee for the Ride for Cystic Fibrosis motorcycle ride.

Kinette Club of Edmonton: This club has supported our chapter over many years (co-sponsored Skelly Skunk, attended most 65 Roses events). They continue to do so through their annual event at Schanks (Shoot, Score, and so Much More), and by hosting our wine-tasting event, French Fling.

Kin Club of Fort Edmonton: This Kin Club is another long-time supporter of 65 Roses events, is currently a big supporter of the Faceoff with CF dinner and of other chapter events.

In addition, Pat presented the Volunteer Leadership Award to **Stacy Hipkin** and the Grassroots Leadership Award to **Abe Van Dorp**. These two individuals chair our two largest fundraising events. Stacy chairs the Edmonton Great Strides Walk and serves on the chapter board. Abe chairs the Ride for Cystic Fibrosis motorcycle ride, raising over \$18,000 himself in pledged donations in the last 2 years, and has also organized a slow-pitch softball fundraiser for the past 15 years.



Stacy Hipkin received the Volunteer Leadership award from President Pat Magnan at the chapter AGM. With Stacy at the head table are the following board members L to R: Scott Hanna, Julie Mitchell, Carolyn Grono, Stacy, and Patti Magnan.



Abe Van Dorp received the Grassroots Leadership award at the chapter AGM from chapter president Pat Magnan