Issue 55
Sept-Oct 2011

THE EDMONTON CYSTIC FIBROSIS CONNECTION

Cystic Fibrosis Canada
Breathing life into the future®
EDMONTON & NORTHERN ALBERTA CHAPTER

Contents

Calendar

September

24– CF Spectacular @ Mayfield Dinner Theatre

October

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

November

1– Chapter Board Meeting
24– Gift Card orders due (last order of 2011)
27—Grey Cup

December

24– Chapter Board Meeting

Fab Four Invade the Stage at CF Spectacular

Get ready for the four lads who shook the world! This year's CF Spectacular on September 24 promises to be an entertaining tale of how this phenomenally successful group began. In July 1957, a young man played a gig in a church garden party and another young lad showed up to watch...and thus began the most prolific and successful musical event in history: The Beatles. The world had never seen anything like them and in all likelihood, never will again. Part One tells the story of their early beginnings in 1957 thru to their last performance in America in 1966; from the cavern club in Liverpool to the seedy clubs in the red light district of Hamburg, and then on to America.

Everywhere they went...pandemonium - perhaps better described by the new word of the day, Beatlemania! The Beatles re-invented the music industry both as an art form and a business. This musical revue visits the triumphs and challenges that they encountered upon their meteoric rise to fame and fortune, set to the infectious music of four lads who shook the world . **This show sold out last year, so get your tickets soon!**

Check out
www.mayfieldtheatre.ca
for ticket details

(synopsis courtesy www.mayfieldtheatre.ca)

Record Breaking Year for 10th Akita Golf Tournament

In 2001, Akita employee Mike found out his new nephew Jake had CF. Wanting to help make a difference in Jake's life, Mike teamed up with Akita to organize a charity golf tournament to benefit CF. Although Mike has since left Akita, Engineering Manager Lorne Thompson and his assistant Traci Windsor took up the cause and have kept the tournament running.

In its first year, the tournament raised nearly $18 000. This year, Akita raised $44 000 through the hard work of Lorne and Traci and the generosity of Akita employees and colleagues! Jake and his mom Taryn addressed the crowd and expressed their thanks for the hard work and dedication shown by Akita. We are fortunate to have such a partner in the fight against CF.

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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.

Issue 55 was released September 15, 2011.

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	Pat Magnan
Past President	Allan Bartman
VP Fundraising	Julie Mitchell
VP Pub & Promo	Scott Hanna
Secretary	Stacy Hipkin
Treasurer	Carolyn Grono
CF Adult Director	Megan Parker
CF Clinic Liaison	Joan Tabak
Director at Large*	Peter Hackett
Director at Large	Deanna Morrison
Director at Large	Andrea Richard
Director at Large	Sherri Selby
CF Kin Liaison	Gerry Boehm
Fundraising Manager	Kathy Irvine
Chapter Coordinator	Katherine Lauzon

*Peter Hackett was appointed as a board member following the resignation of Lisa Taylor. Thank you to Lisa for her service to the board!

President's Message

For the past six years the Cystic Fibrosis Canada office here in Edmonton has been very fortunate to have Emily Westwood as an exceptional employee and office manager. Emily brought her many skills as a former teacher and principal to the job. She was very organized, and very knowledgeable. She provided

sound advice to many different board members throughout the years. Emily was the friendly voice on the phone, and the smiling face that greeted volunteers. Her special dedication came from a love for her niece and nephew who have cystic fibrosis, and she always went that extra mile because of them. She also cares very much about the many families that she knows in our chapter. We will miss Emily very much as our office manager, but we look forward to seeing her as she continues on as a volunteer for our chapter. Emily, we wish you a very well deserved and happy retirement.

Kathy Irvine Honoured

Kin Canada honoured Kathy Irvine by presenting her with their highest honour, a Life

Membership, at a special surprise supper held at the Leduc Kin Hall on June 28th. Kathy is a member of the Leduc Kinettes and also has been active for many years at club, zone & district levels, including serving as a District Governor. Warm thanks for her contributions to the Kin organization and congratulations on being awarded this honour were shared during the evening's program.

Kathy is also the Fundraising Manager for Cystic Fibrosis Canada, Edmonton & Northern Alberta Chapter. Our chapter adds our own thanks and congratulations. Through Kathy's Kin connections and Kin Canada's support for cystic fibrosis, we have been able to communicate more effectively with our own members in Edmonton and Northern Alberta.

Run for the Lung Finishes First

On August 28, the Terwilliger Original Joe's once again hosted the Run for the Lung. The run, held in memory of Jessie McQuitty, attracted over 75 participants this year. Runners gathered on the beautiful morning, took part in a group warm up and set off on their way. Amongst those who came out were Katie Jirsch, Jessie's childhood friend and the original run organizer, and Joan McQuitty, Jessie's mom. Joan traveled from outside the province to run in the event and address the participants at the post-run lunch. Original Joe's not only hosted the event, but provided a delicious lunch afterwards and put in many hours of their own time to ensure that the event was a success. Rob Sokil, our volunteer run organizer, also put in a great deal of time organizing the day and provided many of the prizes for the runners. With the combined efforts of so many dedicated individuals, the run raised nearly $10 000 for research. We look forward to another great year in 2012 and hope you can join us. Start your training now!

Katie Jirsh & Joan McQuitty


Runners Set Off

See the website for race-day results.

Upcoming Events

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!

Get your tickets @
http://frenchfling.eventbrite.com/

Grey Cup Raffle Tickets & Trip Raffle 2011:

Now on sale! Call the office for details

Featured Sponsor: Terwilliger Original Joe's

The Terwilliger Original Joe's has always valued being a part of the community it resides in. Managing partner Ally Stone feels that this involvement is a "natural response to the wonderful relationships" that the restaurant cultivates with its guests and the neighbourhood. So it was only natural when employee Katie first suggested a run in support of her friend Jessie, who suffered from CF, that Original Joe's got on board. Although Stone knew little about CF when the run began, she has greatly increased her knowledge of the disease. Not only has she increased her personal awareness; she also strives to educate the guests who come into the establishment about CF, why it is an important cause and tries to get them involved and motivated. She firmly believes that "no one should have to suffer" the way that many affected by CF do, and this increases her motivation and desire to help find a cure. She is inspired by the great progress made in research in the past 20 years, and looks forward to a future without CF.

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Get Connected

With the rise of social media, getting connected is easier than ever. If you are on facebook, try searching the following groups to connect:

- **Alberta Parents of Cystic Fibrosis Kids**
- **Parents of Children with Cystic Fibrosis**
- **CF Mamas (a US group)**
- **Moms (and dads) with Cystic Fibrosis (a resource for parents with CF)**

Kin Connection

The Edmonton Kinsmen club presented our chapter with a cheque for $20 000 raised at this year's Corporate Cup.

At Kin Canada's national convention, Cystic Fibrosis Canada was presented with a cheque for $917 939.00 raised this year for CF!

Thank you Kin!

Cystic fibrosis and going to school

By Sherri Selby

It's that time of year again! School days, school daze?! Here are some tips for getting your child ready for school:

Five Things Teachers Need to Know

1. A child with cystic fibrosis may cough frequently and at times violently. The cough is related to the cystic fibrosis and is not infectious. (In my experience, teachers have learned to pace the classroom instruction such that I did not miss what was said because I couldn't hear very well while I was coughing – it also helped them to slow down so everybody could understand!)
2. Due to digestive problems related to cystic fibrosis, a child with cystic fibrosis has to take enzymes when he eats, and may have stomach pains or a sudden need to use the restroom. (Usually students were curious about the enzymes and teachers were good to "catch you up to speed" if you had to absent yourself)
3. Let the teacher know that it's okay to let classmates know about her condition as long as it is done in an appropriate way; be willing to help prepare a program.
4. A child with cystic fibrosis has a serious health condition, but she or he is still a child with ordinary interests and hope and dreams. Please help keep his life as normal as possible (AMEN!).
5. Please keep the lines of communication open between the home and the school. A child with cystic fibrosis needs all the adults in their life working together.

For **post-secondary education**, there are issues to consider for individuals with cystic fibrosis. The healthcare team can help with options and strategies to keep students well during their academic career, as well as help with the application process. Accommodations that may be requested include:

1. Changing the required number of class hours per semester.
2. Providing a specific residence room (like a private room, or a room with a private bathroom), on-campus housing or parking.
3. Changing class attendance rules such as providing other options such as internet or video; and allowing late entry to class due to treatments.
4. Changing project or exam due dates because of illness or hospitalization.
5. Providing class notes during absences or recording/videotaping the lecture.
6. Providing the opportunity to finish coursework after the course has ended.
7. Accommodating dietary needs.

Most colleges and universities have an Office for Students with Disabilities that can help students with required accommodations.

Teacher's guides to cystic fibrosis are available at
http://www.cysticfibrosis.ca/assets/files/pdf/Teachers_Guide_to_cystic_fibrosisE.pdf

(Sourced from: http://specialchildren.about.com/od/cysticfibrosis/a/CFschool.htm)