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## Upcoming Events

- ⇒ **Great Strides Walk**  
(May 26, 2013)
  - Edmonton
  - Fort McMurray
  - Leduc
  - Whitecourt
  - Grande Prairie (June 1, 2012)
  - Lloydminster (June)
- ⇒ **Gift Card Orders, November 21 and December 10**
- ⇒ **Trip Raffle Draw (December 4, 2012)**
- ⇒ **Volunteer Opportunities!**
- ⇒ **Grey Cup is on November 25th. Pool tickets need to be in by November 19**
- ⇒ **Wetaskiwin Kinetite Craft Auction (November 2, 2012)**

## Gift Card orders Nov. 21 & Dec 10



Great CHRISTMAS gifts for those "hard to buy for" friends and family on your list!

Support our chapter by purchasing gift cards. We receive a percentage of each gift card purchased. These are great to give as gifts, or just to use in places you know you will shop. We accept cheques, cash or debit only for this fundraiser.



Some of the most popular cards include:

- HBC (The Bay, Zellers, Home Outfitters)
- Chapters/Indigo/Coles
- Starbucks
- Many Restaurants
- Cineplex Odeon
- Loblaws (Extra foods, Superstore, etc.)
- Safeway

## Great Strides Walk

Get ready for **online registration** to be ready in January this year! That means you will be able to start collecting donations earlier too!

The Great Strides Walk committee is planning a workshop this year for team captains. Our plan is to have the workshop in conjunction with our Annual General Meeting in March, so stay tuned! Let us know what YOU would like to learn at the workshop, just let our Chapter

office know!

We will also continue to distribute our monthly Great Strides™ walk newsletter starting in January by email, so if you would like to be on that list, email Kathy at [kirvine@cysticfibrosis.ca](mailto:kirvine@cysticfibrosis.ca).



## Trip Raffle Tickets

Just imaging...\$5000 to go towards a dream vacation for you and your family! Tickets are only \$10 each! If you are interested in purchasing a ticket or if you could help sell tickets, please give our CF office a call at 780-466-2265.

The draw will be held on December 4th at our Board Meeting; just in time to escape the cold Edmonton weather!! For full details and rules on this raffle visit our website at [www.cfedmonton.ca](http://www.cfedmonton.ca).





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

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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.

|                         |                  |
|-------------------------|------------------|
| President               | Scott Hanna      |
| Past President          | Pat Magnan       |
| VP Fundraising          | Stacy Hipkin     |
| VP Pub & Promo          | Deanna Morrison  |
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| 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     |

# Volunteers Needed!!

## We need volunteers for:

- Casino on Feb 5 & 6, 2013**

Our Chapter receives a Casino once every two years, so we are currently looking for volunteers to help with our February 5 & 6th dates. If you are interested or would like to help, please let us know as soon as possible at the CF office.

- Selling raffle tickets at Strathcona Market on Nov 24, 2012**

We have a table donated to us at the very busy Strathcona Market to help sell some of our trip raffle tickets on Saturday, November 24th. We need two volunteers for each shift 8:30 - 11:30 and 11:30-3:00pm. If this is something you would be able to help with, please contact the CF Office.

## REMINDER Grey Cup

Just a reminder to all of our Grey Cup ticket volunteers to please have your tickets turned into the CF Office by November 19th. If anyone has tickets they are unable to sell, try to get them back us right away! We have a few sellers on our waiting list that would be able to sell the tickets for us. :-)



to

Thank you very much to all of our volunteers for making this such a successful year with Grey Cup ticket sales! It is looking really good for a sell out of 3 sets of tickets.

**Note:** *If you are selling Grey cup & trip raffle tickets, please write one cheque for each raffle. These are two different raffles with their own accounts.*

Condolences to the family and friends of

**Greg Tymofichuk**

He will be remembered for his amazing art, joy of life and love of music.

Rest easy Greg

**-Joan Tabak on behalf of the Edmonton CF Clinic**

## Wetaskiwin Kinette Craft Auction

In Support of Cystic Fibrosis Canada  
**FRIDAY, NOVEMBER 2, 2012**

At

Wetaskiwin Seniors Centre  
5216—54 Street

Live Auction...Silent Auction

Enter Raffle to win a  
Diamond Pendant!

Doors open at 6:00pm

Admission \$15.00

Call 780-361-8595 for details

## President's Message:

Thank you to all of you who helped in the recent plea for the approval of Kalydeco, the first therapy that targets the underlying cause of Cystic Fibrosis. KALDYDECO (Ivacaftor) is currently under priority review by Health Canada. Cystic Fibrosis Canada made a submission this month to the Canadian Agency for Drugs and Technologies in Health (CADTH). This submission contains valuable patient feedback on the benefits of the drug KALYDECO. Members of the Edmonton and Northern Alberta Chapter provided crucial input both in testimonials and recruitment for those testimonials. All of your efforts are extremely valuable and will contribute to better lives for people living with Cystic Fibrosis.

This drug helps improve the function of the defective protein - leading to better lung function, weight gain and lower sweat chloride levels. For a cystic fibrosis patient with the specific G551D mutation, access to KALYDECO could lead to a healthier, fuller, longer life.

Of the 4,000 Canadians living with this devastating disease, about 100 CF patients in Canada have the specific G551D mutation of the *CFTR* gene that can be treated by KALYDECO. There are more drugs in the pipeline that will help more people. Each new drug of this kind will be specific to the genetics of the patient.

There is so much hope today for a cure or control for all people with Cystic Fibrosis. We are getting close to the day when we see every person with CF living a long, full, healthy life. That is our dream and I believe it will happen within my daughter's lifetime.

You, the members of this chapter, are the ones that give me the most hope. You are accomplishing so much with each and every contribution you make. Thank you for all the volunteering and fundraising you continue to do. Know that every effort you make, no matter how small it seems to you, is bringing us that much closer to realizing our dream. Together we can make it happen!



## Original Joe's Run for the Lung

It was a beautiful day with over 50 participants ready to run 5km's, with special mention going to a very exceptional lady who had cystic fibrosis. She is on the lung transplant list and finished the 5km walk alongside her oxygen tank as everyone cheered for her! It was a great moment and reminder to everyone as to why we were there! With that said, the event brought in over \$10,000 thanks to our participants raising pledges and of course our sponsors! Thank you to The Running Room, Sokil Transport, to Original Joe's (Rabbit Hill Road location), Vines and Infinite Fitness for your continued support in our fight against cystic fibrosis!



This run was started for Jessie McQuitty, who lost her battle with cystic fibrosis at the tender age of 24. It continues in her memory. Jessie's mom with friends and family are in this picture.



My daughters, Heather and Marie, and I had the privilege of attending the U of A Shinerama kick-off event in September. It was a pancake breakfast put on by second year medical students. To my amazement, about 200 students showed up at 8:00 am on a Saturday morning. The energy and enthusiasm of these students was fantastic to see.

Shinerama is Canada's largest post-secondary fundraiser involving students at almost 60 university and college campuses across Canada, raising money for cystic fibrosis research.

Shinerama was developed in 1961 as a way for students to get involved and give back to their community. Since 1964 it has been partnered with Cystic Fibrosis Canada (then known as the Canadian Cystic Fibrosis Foundation) in sole support of Cystic Fibrosis.

This year, the U of A student volunteers went around doing "acts of kindness" to raise funds and awareness for Cystic Fibrosis. These energetic young people did a sensational and inspirational job!

At the breakfast, I gave a short talk about cystic fibrosis then handed the floor over to Heather, my 11-year-old daughter. Heather's twin sister, Marie helped hand out straws to the students while Heather began her "straw speech". The students attempted to breathe through the narrow-bored drinking straws while Heather delivered her talk about what it's like to live with CF. Heather made a big impression and I could see the compassion in the audience while she talked. There was real understanding when they finally got to remove the straw and breathe normally again. A huge communal sigh of relief could be heard. In the end Heather was thrilled to shake the hand of Edmonton Mayor, Steven Mandel. ~Submitted by Scott Hanna

### CF Spectacular

Thank you to everyone who was able to make it out to the CF Spectacular fundraising event this year and thank you to Deanna Hipkin for chairing this event. With the great silent auction items found by Deanna, Kim and Lori, the event turned out to be a success even though selling seats this year turned out to be a struggle. We had some great support with selling our trip raffle tickets here too selling over \$1000 worth of tickets! The play featured "The Beatles", this was part TWO from last year and it was a really good story with some great Beatles music!



### French Fling

The French Fling - a wine-tasting experience was held on October 19. The committee worked hard at making some great changes with a patio area for sitting and inviting Nespresso out to serve specialty coffees. It was a very nice evening with some incredible silent auction items. Thank you to Marie, Sandy, Jane and everyone else who was able to help make the event special with the incredible items you brought. Thank you to Seann & Michelle Childs for chairing this event again this year.