Issue 57
Jan-Mar 2012

THE EDMONTON CYSTIC FIBROSIS CONNECTION

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

Contents

Upcoming Events

⇒ **Great Strides Walk**
(May 27, 2012)
- Edmonton
- Fort McMurray
- Leduc
- Whitecourt
- Grande Prairie (June)
- Lloydminster (June)

⇒ **CF Hockey Draft of Hope (April)**

⇒ **Ride for the Breath of Life (June 23)**

⇒ **Original Joe's Run for the Lung (August 26)**

⇒ **Volunteer Appreciation BBQ (September)**

⇒ **CF Spectacular/ Mayfield Dinner Theatre (October 13)**

⇒ **French Fling/Wine Tasting (October 26)**

51st AGM an Informative Afternoon

This year's AGM was the 51st meeting of our Chapter. The afternoon featured informative and entertaining talks from Dr. Brown and Dr. Zuberbuhler as they reflected on their experience over the past decades with cystic fibrosis. They reminded us all of the huge strides that have been made in the treatment of cystic fibrosis, and gave us all hope for the future.

After the doctors spoke, Chapter certificates and awards were bestowed on active members of our community (see next page for a list of recipients). This year we also handed out the Ron Moore Award, which is a very special occasion. The Ron Moore award is not handed out every year; instead, it is only awarded when it is felt the recipients merit it. Ron Moore was an active member of our chapter who embodied a spirit of determination and lived his life to the fullest. His own battle against CF was in inspiration to those who knew him. Drs. Brown and Zuberbuhler were both recipients of this award. Caroline Warren presented the award to Dr. Zuberbuhler and James Tapankov presented Dr. Brown's award. Both Caroline and James were eloquent in the difference the doctors have made in their lives and the lives of their families. Thank you Dr. Zuberbuhler & Dr. Brown!

The AGM portion of the afternoon reviewed the past year's finances and fundraising activities. Our chapter had a banner year for fundraising, especially the Great Strides Walk. Committees and volunteers worked tirelessly to raise funds to support research and clinic care.

Pat Magnan wrapped up her term as President and handed the reigns over to the new board. On March 6th, Scott Hanna was elected President of the current board (see pg. 2 for an updated board list). The chapter is very appreciative of Pat's hard work over the past 2 years. She worked tirelessly to ensure that the chapter was running smoothly and her attention to detail and conscientious work helped our chapter soar to new heights.

Thank you to all of our board members, chapter members and volunteers who give of their time and resources. Your efforts are making a difference in the fight against cystic fibrosis!

Issue 57
Jan-Mar 2012

THE EDMONTON CYSTIC FIBROSIS CONNECTION

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 57 was released March 9, 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	Scott Hanna
Past President	Pat Magnan
VP Fundraising	Stacy Hipkin
VP Pub & Promo	Deanna Morrison
Secretary	Emily Westwood
Treasurer	Andrea Richard
CF Adult Liaison	Sherri Selby
Director at Large	Peter Hackett
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
Fundraising Manager	Kathy Irvine
Chapter Coordinator	Katherine Lauzon

Chapter Award Recipients

We are happy to recognize the following individuals for their contributions to our chapter:

Level 1 Certificates:

James Tymofichuk (Crown & Anchor fundraiser), **Paul Filipow** (Hockey Draft website), **Esther Cantafio** (Carstar), **Graydon Chretien** (Raffle Chairperson), **Glenora School** (Mary Ivany memorial fundraiser), **Nelson Pacheco** (IT Support), **Michelle Childs** (French Fling)

Level 2 Certificates:

Scott Hanna (Chapter Publicity)
Gerry Boehm (Kin Liaison, Chapter volunteer)
Jordan & Megan Parker (Hockey Draft)

Ron Moore Award:

Dr. Brown
Dr. Zuberbuhler

Getting Nosy about CF with Oli & Nush!

Check out this informative and fun video! This is a short film made for the Cystic Fibrosis Trust (based in the UK) to help children with CF understand their condition and explain to other children what CF is.

Search "Oli & Nush" on youtube .com

Give the Gift Of Life

by Gerry Boehm

In August 2009 my spouse Doug and I headed down the highway to Roblin, Manitoba for a much needed break. We were to spend time with my family and stay at our favorite Edelweiss Cottage. What we did not realize was that our lives would change forever.

We had been to a church picnic on Sunday afternoon and then we were off to supper at my daughter's. When the phone rang and my sister Joyce was on the other end I knew something terrible had happened. She advised me that her sister-in-law Joan had been rushed to hospital and things did not look good. Arrangements were being made to transfer her to the Winnipeg hospital as soon as possible. The air ambulance was to arrive, but after several hours it had not, so she was taken by ground ambulance.

Joan had suffered a major brain aneurysm. She was always a very special lady and this day was no different for her. You see, Joan was a donor. In order to donate organs, you must die in hospital while attached to a ventilator. This ensures your organs are suitable for transplantation. After waiting 24 hours with no change in Joan's condition, the transplant team flew in from Toronto and families were contacted to receive the most incredibl gift: "The gift of life."

There are thousands of Canadians who are waiting for a transplant to save or improve their lives. Unfortunately many die because there are not enough organs donated. By signing a donation card, you could help save someone's life. **Sign your card and tell your family your wishes**. By sharing your decision, they can act on your behalf following death.

Our family felt that this donation helped us ease some of the grief; we know that something positive has resulted from our loss. We received thank-you letters from some of the people who received the organs. I would like to share with you the letter from the person who received the liver:

To my Donor Family

I have written this letter a thousands times in my head. I cannot believe that it has been a year since I received my new Liver. I was as scared as you must have been when you made the decision to give this amazing gift. I mourned with you at the loss of your loved one. I need to let you know that I take very good care of my gift and treat it with great respect. I do not take it for granted. My life was coming to a end and the suddenly I was given a 2nd chance. It was very over whelming at times for me to think about what your family gave to me.

At all of my family celebrations we toast your family and always remember this gift. We have encouraged all our family members and friends to sign their donor cards.

I hope your family is well, and words can not express the gratitude that I have for this gift and give thanks everyday. Is there any greater gift you can give than the Gift of Life?

Ode to Lucia

Twenty years have come and gone
Yet it seems like yesteryear
How we've missed you all along
Memories (of you) we've held very dear
However, our hope has kept us moving on
That "ACUR4CF" will soon become reality!

Donations for Cystic Fibrosis Research will be gratefully be accepted in memory of Lucia Tavano's 20th Anniversary

Please call 780-466-2265
or
Mail your memorial donations to
7814—83 Street
Edmonton, AB T6C 2Y8

Check out our chapter promotional products

Look online at our website and click on the link to see what we have available!

- Fleecies
- Hoodies
- Car magnets
- Key chains
- and more!

Watch for the NEW

Skelly Skunk, Jr.

Coming soon. . .