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Upcoming Events

- ⇒ **Great Strides Walk**
(May 27, 2012)
 - Edmonton
 - Fort McMurray
 - Leduc
 - Whitecourt
 - Grande Prairie (June)
 - Lloydminster (June)
- ⇒ **Ride for the Breath of Life (June 23)**
- ⇒ **Original Joe's Run for the Lung (August 26)**
- ⇒ **Volunteer/Sponsor Appreciation Dinner (September)**
- ⇒ **CF Spectacular/ Mayfield Dinner Theatre (October 13)**
- ⇒ **French Fling/ Wine Tasting (October 26)**

Hockey Draft Scores Again!

This year's Hockey Draft of Hope has closed again, with nearly 1000 entrants. Our online entry system is more popular than ever, which has helped reduced the amount of volunteer time needed to run this fundraiser. Jordan and Megan Parker once again donated many hours to organizing and running the draft, and continue to update the website and monitor the hockey playoffs. Stay tuned to our website for the winners!

www.CFHockeydraft.ca



Great Strides Newsletters answer your questions

This year we started publishing monthly Great Strides Walk Newsletters to give our teams and walkers more details leading up to the big day on **May 27**. Each newsletter highlights specific details and offers tips for fundraising.



Other features are:

- Current team fundraisers
- Fundraising incentives
- Partner spotlights
- Requests for volunteers
- Parking details
- Safety tips

Gift Card orders due June 15



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
- Sobeys (IGA, etc.)



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.

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Issue 58 was released May 10, 2012.

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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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

Volunteers Needed!!

We need volunteers for Edmonton Great Strides Walk!!

6 volunteers needed: to help with parking control at Snow Valley. You'll get to wear a bright vest and maybe even carry a radio! Your help is needed to ensure that only those authorized to park at Snow Valley do so.

2 volunteers needed: to help with bus transportation. You will be helping shuttle walkers to and from the walk.



Call our office at
(780)466-2265

Adult CF Clinic Celebrates 35 Years!

This year the Adult CF Clinic will celebrate 35 years of providing care to adult Cystic Fibrosis patients in Edmonton & Northern Alberta. While the exact info is hard to pin down, we know that this clinic was one of the earliest in Canada and likely in

North America. It has been our good fortune to have Dr. Brown and the many excellent staff that have worked at the clinic over the past 35 years. There will be a celebration of the clinic in the fall, so keep your eyes open for more details to come!



Chapter Recognized for Excellence in Fundraising

This year's National AGM took place in Vancouver from April 26-28. It was an excellent opportunity for Chapter members to come together and network, as well as a chance to hear about the many exciting developments in research and care for CF patients. Some of the highlights were:

M/SAC (Medical Scientific Advisory Committee): The committee reviewed 95 research and award applications, 41 clinic incentive grants, 5 transplant centre incentive grants, and 1 clinical fellowship application. This year the committee saw several entirely new research applications, which is very exciting; this shows that there is interest amongst researchers in getting involved in CF research.

Governance: The new Canada Not-for-Profit Corporations Act came into effect in October of last year and it allows 3 years for charities to comply. Cystic Fibrosis Canada is moving to quickly adopt this and bring our Organization into line with this new Act.

Campaign Overview: Our Organization is conscious that we need to ensure we seek out new donors so that we don't fatigue our current donors. National is working on "The New FACE of Cystic Fibrosis" campaign, which is designed to attract a new type of donor. The campaign is moving away from presenting CF as only a childhood disease and focusing on the personal stories of people living with CF and the challenges they now face as they age. National has asked our Chapter to help by identifying any individuals or companies that we think could be approached as potential donors. If you think you have ideas, please contact our Chapter office.

Medical/Scientific Panel: Several doctors spoke and gave updates on different areas of CF research. Dr. Peter Pare spoke about Personalized Medicine and how this is trying to make treatments more specific to a patient in order to achieve the best results. Dr. Peter Durie spoke about several different medications and treatments. One of the most exciting is VX770, which is effective at improving gate defect (as in G551D). The FDA in the US has approved this. It is quite costly, and there is work happening to advocate to the government to potentially cover the costs of this drug. Dr. Durham Wong reported that in a unique move, Canadian private drug plan companies will now pool costs of high priced drugs, lessening the risk of patients losing employer sponsored coverage.

Chapter Awards: Each year, Chapters across Canada are recognized for various achievements. We are proud to report that our Chapter won the **Excellence in Fundraising Award for 2011-2012!** We had a fantastic year in 2011-2012, with a record-breaking amount of funds raised. Many thanks to our dedicated volunteers who made this possible!



Kinsmen Club of Edmonton Wins Julia Award

The Kinsmen Club of Edmonton was also recognized at the National AGM with the presentation of the Julia Award. The Julia



Award is named in memory of Julia Herbert, CF poster child from 1987-1989. The award is intended to acknowledge groups or individuals who have made significant, ongoing (at least 5 years) contributions to Cystic Fibrosis Canada through a local Chapter. The Kinsmen of Edmonton have run the Kin Corporate Cup for years in support of CF. They run the entire event themselves, which requires a great deal of time and commitment from their members. Other areas they have helped include providing their building as a venue for many events, partnering with us in the creation of our old Skelly Skunks and our new Skelly Skunk, Jr. mascots. They also allow us to promote events on their advertising sign and participate in our events as

supporters. Thank you Kinsmen Club of Edmonton!



servus credit union **Donation of Sky Suite a Sweet Deal!**

Servus Credit Union is a member-owned financial institution serving nearly 390,000 members from more than 100 locations in 62 communities. Our vision of building a better world—one member at a time—inspires a commitment to provide sound, advice-based financial products and services; help members achieve personal satisfaction, enjoy financial stability and a good quality of life; and improve the communities where its members live and work.



At Servus, we are committed to building lives not just bank accounts. Servus is dedicated to being a good corporate citizen and giving back to our communities. Our goal is to contribute financially and in-kind through the volunteer and giving nature of our staff.

We were delighted to donate the use of our sky suite to Cystic Fibrosis Canada Edmonton & Northern Alberta Chapter for a silent auction item for the French Fling and hope the participants enjoyed their experience.



Congratulations to the Pediatric CF Clinic!

They are now part of the Stollery Children's Hospital!

Melissa, our pediatric dietician, has taken a year long temporary assignment elsewhere. Joan Poon will be covering in her absence. Thank you Joan!

Congratulations to Dr. Winnie Leung (adult clinic) and her husband. She delivered a beautiful baby boy on January 6th.

The adult clinic welcomes Dr. Roland Nador to our team. He is an experienced doctor who some of you may know through the transplant team. He will continue to work in both areas.

Skelly, Jr. is Here!



**Available at the Great Strides
Walk and in our Office!**

\$10/each