Issue 51

Dec. 2010 – Jan. 2011

Canadian Cystic Fibrosis Foundation

# THE EDMONTON & NORTHERN ALBERTA CONNECTION

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## Calendar

**Dec. 2010 – Mar. 2011**

Dec. 7
Chapter Board Meeting

Jan. 4
Chapter Board Meeting

Feb. 1
Chapter Board Meeting

Feb. 20
Faceoff for CF

Mar. 1
Chapter Board Meeting

Mar. 6
Annual General Meeting (Kinsmen River Valley Place)

Mar. 28-29
Casino for CF Volunteers needed

## February 2011 Marks New Name and Look for Organization

As of February, 2011, the Canadian Cystic Fibrosis Foundation will be known as Cystic Fibrosis Canada. Of course, we will continue to be the same well-respected organization, with the same mission, vision and values and with 50 years of history and service to Canadians. Our commitment to finding a cure or control for cystic fibrosis is stronger than ever. We fund the best CF research aimed at achieving this goal.

With the new name and logo, we expect to be able to better communicate all across Canada what we do and who we help. The new graphics will appear more current and contemporary and therefore we hope also more professional and credible. At the same time, the change is an opportunity to communicate what we have already achieved.

A leaflet is enclosed to give you a sneak peak at the new look. Work is continuing in preparation for this change which will coincide with the beginning of a new fiscal year and will mark the end of the organization's first 50 years. ●

## A Weekend to Remember in Edmonton

Delegates from all chapters of the Canadian Cystic Fibrosis Foundation in Alberta, Saskatchewan and Manitoba gathered in Edmonton for the Prairie Regionals meetings on the weekend of Oct. 22- 24.

The discussions and presentations left everyone feeling better connected with each other and better prepared to work on the challenges we face. The weekend had many highlights.

Dr. Jonathan Dennis, Professor in the Department of Biological Sciences at the University of Alberta, presented "Superbugs Need Superdrugs." The work of Dr. Dennis and his research work with his research team was featured in the September issue of our chapter newsletter, Connections. Hearing him speak about his work brought that brief report to life and opened our eyes to a whole new possibility for treating bacteria in the future.

Our organization is fortunate to have four partners who work with us both at the national level and at the chapter level. Those four partners are Kin Canada, Advocis, Carstar, and BioGuard.
At the local level, some of those partnerships are more successful than others. Through the presentation and the discussions, delegates learned how we can strengthen each of those partnerships.

Greg Duhaime (right), Pres. of the Edmonton Kinsmen Club, accepts the Praire Regional Support Group Award from MB Director Darcy Hodgins.

David Robinson, of the Ride for the Breath of Life committee, receives Prairie Regional Adult with CF award from AB Regional Director Joanne Meulenbelt.

Caroline Warren receives Volunteer Leadership Award from MB Regional Director Darcy Hodgins.

Every prairie chapter organizes a motorcycle ride each year as one of its fundraisers. Through a sharing time, we learned about how each ride is organized and we looked to each other for ideas to improve success. Part of the discussion included the pros and cons of making this a national event similar to the Great Strides Walk.

Every chapter, and therefore the whole organization, benefits from the incredible dedication and generosity of its volunteers. Their inspiring stories were told during the presentation of awards. With the event being held in Edmonton, we were able to invite our award recipients to receive their awards in person. Our award winners were: for the Support Group Award, Edmonton Kinsmen; for the Volunteer Leadership Award, Caroline Warren, and for the Adult with CF Award, David Robinson.

The Edmonton & Northern Alberta Chapter would especially like to thank the Edmonton Kinsmen Club for hosting the Hospitality Suite for delegates as they arrived Friday evening, Andrea Pratt for facilitating all sessions, and Rene Coutu for representing the national perspective. Your contributions made the weekend a positive, constructive and worthwhile experience.

Issue 51
December 2010 - October 2011

THE EDMONTON & NORTHERN ALBERTA CONNECTION

CF Connection is a free newsletter for members published bimonthly by the CCFF Edmonton & Northern Alberta executive committe with offices in Rm 205 of St. James Elementary Catholic School at 7814-83 St., Edmonton.

Issue 51 was issued Dec. 7, 2010. It was edited by Patrick Lépine with contributions by Pat Magnan, Emily Westwood, Sherri Selby and Patrick Lépine.

**Mission**

The Canadian Cystic Fibrosis Foundation (CCFF) helps people with cystic fibrosis. The Foundation 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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| | |
|---|---|
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| Fundraising Manager | Kathy Irvine |
| Newsletter Editor | Patrick Lépine |

# CF Clinic News

**By Sherri Selby**

Both the paediatric and adult CF clinic offices will be closed over the Christmas period from Dec 24, 2010 to Jan 4, 2011. Please make sure you have enough of all the medications you need to cover you or your child for that time.●

Paediatric CF Clinic
5H2-30 Walter Mackenzie Centre
U of A Hospital
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Edmonton, Alberta
T6B 2B7
Phone 780-407-6563
Fax 780-407-6274

Adult CF Clinic
CSB 7-109 CSB University of Alberta Hospital
8440 - 112 Street
Edmonton, Alberta
T6G 2B7
Phone 780-407-6745
Fax 780-407-3112

## Office closed for holidays

The CF Foundation office will close at noon, December 24 and reopen on Monday, January 3, 2011.

# Thank You Sponsors

In 2009- 2010, our chapter worked on developing a new fundraiser, CFar: cystic fibrosis amazing race. During the development work, five sponsors stepped forward to contribute financially to the success of this event. Even though it was cancelled, all five sponsors offered to leave their sponsorship gift as a general donation. We sincerely wish to thank the following businesses for their generosity: Agrium, Insight Medical, Badger Engraving, Davey Textiles, Grandin Agencies.

Agrium Advanced Technologies
Smarter Ways To Grow™

Insight Medical Imaging

Davey Textile Solutions

Grandin Agencies

# President's Corner

**By President Patti Magnan**

This year, 2010, marks the 50th Anniversary of the Canadian Cystic Fibrosis Foundation. I was able to attend the anniversary celebration in Ottawa as part of our National Annual General Meeting last April. This was especially meaningful to me because my family experienced the lack of medical treatment for cystic fibrosis long ago, and has also benefited from the huge improvements in medical treatment in recent years. I grew up hearing stories about my mother's two very young siblings who had passed away. The doctors did not know how to help them, and they both died very suddenly: Raymond from a bowel obstruction, and Barbara from pneumonia. This was absolutely devastating to my grandparents. Today, thanks to the medical research funded by the Canadian Cystic Fibrosis Foundation, our seventeen-year-old son, who has CF, is doing very well. In honour of our foundation's 50th anniversary, I am asking you to consider giving a special donation of $50, $500 or even $5000, so that the foundation can continue their work toward finding a cure.●

THE EDMONTON & NORTHERN ALBERTA CONNECTION

# Employment and CF

**By Sherri Selby**

As part of the Annual Day for Adults with CF that took place May 1, 2010 during the Foundation's Annual Meeting and Conference, one of the topics included "Breathing Life into Your Career" by Career Coach Alan Kearns. I cover only some of the ideas he expressed. The videos from this session are available on the Foundation's Web site (http://www.cysticfibrosis.ca/en/aboutUs/EducationDay.php) for more information.

Alan Kearns is a Workopolis career expert, author of "Get the Right Job Right Now!" founder of CareerJoy™ (a career coaching company) and a regular contributor to Canadian media on the latest trends in careers and career development in Canada (http://www.careerjoy.com/faq). Since having CF is part of our identity, rather than use it as an excuse not to try or to see it as a weakness, he instead suggests it be used as a catalyst: that is, to consider the attributes that you develop because of this disease and how it may help with respect to being the right person for the job. Possible benefits or strengths you develop might include flexibility, organization, management, empathy, discipline, mental toughness – all important soft skills that employers look for when recruiting.

Mr. Kearns suggests that we further get to know your strengths: what are your talents/your values? What are you passionate about? He suggests the most successful people career-wise have built on these aspects. He also stressed the importance of community: 70 per cent of employment opportunities arise from getting involved in a community such as the CF community and employers often look on how we helped raise the profile of that community. He also suggests to be prepared to change and adapt given how rapidly the world and technology are changing. Don't be afraid to seek help e. g. get coaching on interview skills, using the technology to the fullest to market yourself.

In sum, take risks but be aware of your limitations, and above all, trust yourself and listen to your gut. ●

# A Spectacular Night

**By Emily Westwood**

No one was *Cryin'* at the second annual CF Spectacular held Saturday, October 23 at the Mayfield Dinner Theatre. The sell out crowd enjoyed a top-notch performance of Dark Star: The Life & Times of Roy Orbison which told Roy's life story while also featuring such hits as *Oh Pretty Woman*, *Blue Bayou*, and *Running Scared.*

Of course the evening included the fabulous buffet for which the dinner theatre is well-known as well as an appealing assortment of items in the silent auction. The Mayfield Inn generously donated a room for two along with tickets to one performance at the Theatre as a door prize. The lucky winner was Daryl Pratt.

After Roy sang *It's Over*, we tallied the revenue and expenses to find we had made over $15,000. We are making this an annual event , so watch for details about next year's show.

# CSU 52 keeps the Chapter Office Working

**By Patrick Lépine**

The Civic Service Union 52 Benevolent Society has supported the chapter's operations for many years.

Each year, the chapter applies for a grant under their programs for "Community Organization Application for Funding".

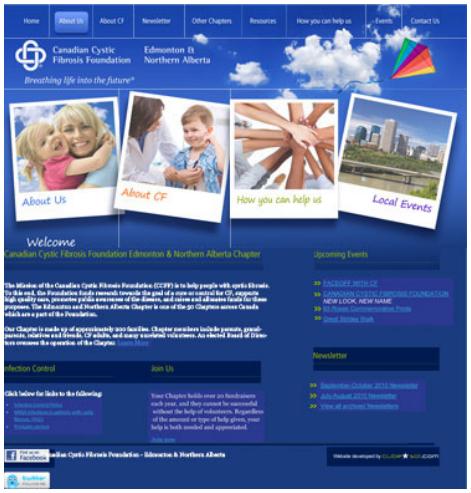
Their grants have contributed greatly to our general operations over the past five years.

- 2006 - $4,500 for our Skelly Skunk mascot
- 2007- $2,000 for Photoshop software and UPS units for CF office computers
- 2008 - $2,000 for website software for preparing and posting info on our chapter website
- 2009- $2,000 for hiring a website designer to redesign www.cfedmonton.ca
- 2010- $2,000 for purchasing new server equipment for the office network

The union represents employees of the City of Edmonton, City of Edmonton, the Edmonton Public Library, TELUS World of Science - Edmonton, EPCOR (Edmonton & Calgary), and Capital Power Corporation.

We would like to thank Marion Leskiw, the recently retired President of Civic Service Union 52 and Zonia Wuschenny, Chair of the Civic Service Union 52 Benevolent Society, Members & Community Support Committe.

The Skelly Skunk mascot costume is just one of many items the CSU 52 Benevolent Society has funded over the years.




CSU 52 funds paid for the redesign of the chapter website and software to keep it updated.

# Fall Raffle Winners

'Tis the season for CF raffles, especially of the Grey Cup variety.

With the 2010 Grey Cup game happening in Edmonton, we offered a raffle in which the prizes were tickets for seats to attend the game. Those tickets sold for $5 each.

First prize was 2 seats to the Grey Cup game (Section N, Row 7, Seats 9 & 10) and an autographed Eskimo football

Second prize was 2 seats to the Grey Cup game (Section EE, Row 38, Seats 13 & 14) and a Grey Cup jacket.

Winners of Grey Cup seats raffle. Jim Bischoff won first prize while Conrad and Cathy Michael won the second prize tickets.

# Destination Anywhere

*Trip Raffle*

Where would you go if you won a travel voucher worth up to $4000? Disneyland? Mexico? Maui? Las Vegas? Buy a ticket for $10 on our Destination Anywhere Raffle.

The winner was Barbara Beaudoin. She will consult with a travel expert at Argyll Travel to explore her options and plan a trip to the destination of her choice. ●

# Casino Volunteers Needed

Our next casino is scheduled for March 28-29, 2011. We always need more volunteers for this event. If you are willing or interested in volunteering, please let us know as soon as possible by phoning the CF office. We need to submit names for the key positions in January. This is one of our largest fundraisers, so every volunteer is much appreciated.

# Locals Join National Adult CF Committee

At the October 15 meeting of the Adult CF Committee, **Megan Parker** was elected as the Western Vice-Regional Representative. A volunteer with both the Central Alberta and the Edmonton & Northern Alberta Chapters for many years, Megan has been especially appreciated as a speaker about CF at fundraisers.

Megan has also been the CF Adult Director on the board of the Edmonton & Northern Alberta Chapter since March 2010.

In this role, Megan follows **Sherri Selby**, acting as the liaison between the local chapter board and the national Adult CF committee. Fortunately, Sherri Selby has continued to serve on our chapter board as a Director at Large and is a valuable contributor to our chapter newsletter with her very informative articles about living with CF.

With her first meeting in 2009, Edmonton CF Clinic Nurse Coordinator **Joan Tabak** began serving with the Adult CF committee as the Professional Advisor.

The Adult CF Committee is a standing committee of our organization. Members include adults with cystic fibrosis who represent different regions across the country, a representative from the Medical/Scientific Advisory Committee, **Dr. Rabin** of Calgary, and Joan as professional advisor.

The committee provides perspective and advice on CF-related issues, and advocates for public policies and programs to help people with cystic fibrosis. ●

# Support for CF parents

Several parents have been talking about organizing in some way to provide connection, encouragement, strength, and suggestions for each other in facing the challenges of caring for children with CF.

A small group is planning to hold a lunch or coffee event at a restaurant to assess general interest and possible direction for such a group. If you would like to be provided with the details about the restaurant meeting, please call Pat at 780-466-6044. ●

# Faceoff with CF Announces Guest of Honour for February Dinner

Mark February 20, 2011 on your calendar to join Edmonton Oiler Andrew Cogliano, our guest of honour, at this year's Faceoff with CF. The evening's format will be very similar to recent years with the dinner, auction and program happening in the Jubilee Auditorium banquet hall.

Last year's Faceoff with CF was completely sold out. Watch for more details on registration prices and packages in our next newsletter, on our website www.cfedmonton.ca , or call the CF office to have your name added to the list of those who receive information packages by mail. ●

Edmonton Oiler Andrew Cogliano will be the guest of honour at this year's Faceoff with CF dinner.

"Destiny is not necessarily what we get out of life, but rather, what we give." --Cary Grant


December 5, 2010 is International Volunteer Day. The spirit of volunteerism is recognized in many individuals. An integral part of celebrating volunteers is putting a face on Canadian volunteerism by publicizing volunteers who are currently doing inspirational things in their provincial and local communities. They are agents of social change who strive to improve the lives of others. The Edmonton & Northern Alberta Chapter of the Canadian Cystic Fibrosis Foundation is privileged to have many outstanding volunteers. Helen Chapdelaine is one such extraordinary volunteer.

Helen is the great-aunt to Madison and Haley, who are three and two years respectively. Madison and Haley both suffer from Cystic Fibrosis. Cystic Fibrosis is the most common, fatal genetic disease affecting Canadian children and young adults. It is a multi-organ disorder that affects primarily the lungs and the digestive system. A build up of thick mucus in the lungs causes severe respiratory problems. In the digestive tract, Cystic Fibrosis makes it extremely difficult to digest food and absorb adequate vitamins and nutrients. Ultimately, most Cystic Fibrosis deaths are due to lung disease.

Since September 2009, Helen has worked tirelessly to raise awareness and funds for Cystic Fibrosis with the help of her hometown, St. Paul, Alberta. With her crew of volunteers that she has pulled together over the last 14 months she has achieved amazing success. On March 10th, 2010, Helen decided to take on the responsibility of organizing a Cystic Fibrosis "Great Strides Walk" for St. Paul. This required coordinating volunteers, recruiting walking teams, numerous meetings with chapter staff and the committee she founded, finding a staging area and creating the Walks' route, as well as securing local sponsorship. These were just a few of details that Helen spent numerous man-hours on. In addition she spearheaded a number of fundraisers for the St. Paul "Great Strides Walk" including: a bake/handmade fish hook sale, a silent auction, a BBQ and a raffle. In only its first year, the St. Paul walk made very close to $36,000 . "Team Dragon Fly" from her walk in St Paul raised the 7th highest amount of all teams across Canada. Helen was also responsible for the sale of 2,116 Grey Cup Pool tickets. Helen is an inspiration not only to her community of St. Paul, but also our province of Alberta. Constantly she takes on new volunteer challenges, attempting to promote awareness of Cystic Fibrosis and to raise money for further medical research.

The Edmonton & Northern Alberta Chapter of the Canadian Cystic Fibrosis Foundation would like to take this opportunity to thank Helen and all of its volunteers in its fight to find a cure for Cystic Fibrosis. With the help of our outstanding volunteers, we have great hope that the cure is right around the corner.

# Help Andrew Cogliano win the Faceoff with CF!

## Faceoff with CF

***A dinner and auction in support of the fight against Cystic Fibrosis***

**February 20th, 2011 at 5:30 PM**

**Jubilee Auditorium Banquet Room**

**Honorary Chairperson:**
**Andrew Cogliano**
**Edmonton Oilers**

**With a limited number of each package available, call (780)466-2265 now to help drop the puck on CF!**

### $900 Power-Play Package

- 4 tickets to the dinner
- 4 Edmonton Oilers hats
- 4 tickets to an Edmonton Oil Kings game
- 1 framed picture from event, signed at the event
- 1 Edmonton Oilers jersey or print

### $150 Hat-Trick Package

- 2 tickets to the dinner
- 1 Edmonton Oilers hat

### Additional Tickets

- Adult: **$70**
- Child (12 and under) **$50**

Please note, additional tickets are only available along with the purchase of one of the packages listed above and are limited to a maximum of 4 extra tickets per package.

EDMONTON OILERS COMMUNITY FOUNDATION

Canadian Cystic Fibrosis Foundation

65 ROSES SPORTS CLUB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