



THE EDMONTON & NORTHERN ALBERTA CONNECTION

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Calendar

Sept.-Nov. 2010

Sept. 7

Chapter Board Meeting

Sept. 7

Draw for Trip Voucher raffle at board meeting

Sept. 8

Raffle begins for Grey Cup game tickets Nov. 28 in Edmonton

Oct. 5

Chapter Board Meeting

Oct. 23 CF Spectacular Dinner Theatre

Oct. 23-24

Prairie Regional meetings hosted in Edmonton at Mayfield Inn

Nov. 2

Chapter Board Meeting

Fore! Akita Drilling Drives for a Cure



On an almost perfect day for golfing weather, Akita Drilling held its annual golf tournament in support of the fight against CF. And what a successful tournament it was, raising just pennies shy of \$28,000. Organized as always by Lorne Thompson along with Traci and Amber, also from Akita, the tournament provided both great golf and lots of laughs and fun. Some of this year's fun extras



One team with volunteer Joan

were rolling the fuzzy dice to choose whose drive shot got counted, playing Minute to Win It, and dressing in goofy outfits for team photos. Many of the same golfers come back year after year, many of the same businesses send golfers and sponsor holes, and even our volunteers ask us if they can volunteer again.

With Ron Clarke as program emcee, the program and auction at the supper continued the spirit of fun. But along with the fun, the golfers never lose sight of the reason for the tournament. This year they welcomed our beloved nurse Joan Tabak as their special speaker. ●

An Event Everyone Wants to Go To

"Through the efforts of the volunteers, through the support of our major sponsor, AKITA Drilling, and the support of all of our numerous other sponsors we've been able to make this an event that everyone wants to attend (nearly demand it) and know that they are contributing to a very *real* effort," says Lorne Thompson, Engineering Manager at Akita Drilling.



MC Ron Clarke, organizer Lorne Thompson, & CF Fundraising Manager Kathy Irvine

Local CF Research

Dr. Jonathan Dennis of the University of Alberta is excited about the potential for phage therapy to improve the quality of life of people with cystic fibrosis.

For many years, his research team has been exploring the use of bacteriophages – viruses that kill specific bacteria – to treat chronic and life-threatening bacterial infections. This treatment strategy, originally discovered by a Canadian scientist early in the 20th century, offers a viable alternative to antibiotic resistance.

Dr. Dennis' research team is currently studying a phage called 'DC1', and its enzyme product, that target the bacteria *Burkholderia cepacia* complex. This enzyme product can penetrate the outer layer of the complex, as well as *B. cepacia* complex biofilms – dense communities of bacteria. Penetration of the bacterial defences causes the complex to become more vulnerable and easier to eliminate.

The DC1 phage or enzyme could be used together with other phages or antibiotics to eliminate the *B. cepacia* complex more effectively.

"*B. cepacia* infection is very difficult to treat and poses a major health risk for people with CF," said Dr. Dennis.

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Dr. Jonathan Dennis (second from the left) with his research team at the University of Alberta.



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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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CF Clinic News

On the move

The CF Team has been split into Adult and Pediatric. For Yvonne and Joan who are part of the Pediatric Team, this means a change of office location to the main building of the hospital. The CF Team would like to welcome Diane Dzoze who has joined them as the Adult Clinic secretary and who will be working out of the old CF offices. Please help her out when you call by saying your complete name and number. ●

Pediatric CF Clinic
5H2-30 Walter
Mackenzie Centre
U of A Hospital
8440 - 112 Street
Edmonton, Alberta
T6B 2B7
Phone 780-407-6563
Fax number TBA

Adult CF Clinic
(numbers & address remain the same)
CSB 7-109 CSB University of
Alberta Hospital
8440 - 112 Street
Edmonton, Alberta
T6G 2B7
Phone 780-407-6745
Fax 780-407-3112

In memoriam

Thoughts and prayers go out to the friends and family of Dallas Auger. He will be remembered for his spunk and love of Spiderman. Breathe easy Friend. ●

Breathing New Life into our Organization

Building on our overall corporate image and tagline, *Breathing life into the future*®, the Canadian Cystic Fibrosis Foundation and Quebec Cystic Fibrosis Association will be making some changes to enhance recognition of our organization. Effective February 2011, we will be adopting a new logo, and changing our names to Cystic Fibrosis Canada and Cystic Fibrosis Quebec.

Plans for the launch of the new names and logo are being developed through discussions with individuals from chapters all across Canada. We expect that the launch plan will be ready and distributed to all chapters during September. Please stay tuned for more details. We should be able to give you a sneak peek at the new logo and name in the next issue of this newsletter. ●

Upcoming Event: CF Spectacular

Our second CF Spectacular, a dinner theatre event at the Mayfield Inn, is coming on October 23, so get your tickets soon. As usual the evening features a top-notch theatre event, an amazing extravagant buffet, and a silent auction to delight any shopper's heart. This year's play is "Nashville Icons: Dark Star, life and times of Roy Orbison."

To purchase tickets, call the Mayfield box office at 1-877-529-7829 or log on to their website www.mayfieldtheater.ca. All tickets are \$90 +GST, so the early

purchasers get the best choice of seats.

In the audience this year will be at least two people from each of the other chapters from the prairie provinces as well as some staff from our national office. Prairie Regional Meetings of chapter delegates are being held in Edmonton over the same weekend as the CF Spectacular and delegates will join our local fundraiser for the evening. Please join us by giving them a warm northern Alberta welcome when you meet them in the buffet line or at the auction tables. ●

President's Corner

By President Patti Magnan

As we change the type of theatre event we host from an "Evening at the Citadel" to the "CF Spectacular" at the Mayfield Dinner Theatre, we are calling on all of you to help us. We need you to support

this event, by attending and bringing your friends and family. The musical is sure to be entertaining, and the food is always delicious. Together we can make this a huge success! ●



Employment and CF

What do you want to do when you grow up? When I was little, I wanted to be a veterinarian then a doctor and eventually I worked toward doing medical research and teaching. I can definitely say that CF influenced my decisions but other factors also played a role. For example, I moved to Edmonton more than 20 years ago because my husband found a job here.

Unfortunately, at the time, it was one of those Alberta “bust times” so finding a job for me was tough. I finally found work as a technician in a couple of university labs; I then took on graduate studies at one of the labs on the advice of my supervisor and learned about heart disease.

I have since worked in other labs, and am slowly working on an education degree – I have done some teaching which was a lot of fun but can be physically demanding especially when teaching young children! I am currently unemployed so this topic has become somewhat relevant to me and I am considering my prospects.

“Cystic Fibrosis Education – Employment/Career,” (<http://www.cfeducation.ca/en/employment.aspx#top>) offers some tips to consider when thinking about what to look for when planning a career, some of which is included below (refer to the website for more detail).

Besides asking yourself what are you interested in doing, and what experience and schooling you'll need to do the job, you will need to do an honest assessment of the state of your health, and whether it will limit your choices.

Key issues to consider before picking a job or occupation

Can you work full time? How physically demanding is the job? How flexible is the job? For example, would your employer give you needed time off for hospitalization or home IV treatments?

Also, check if there is potential for reducing your hours if your health demanded it. What benefits does the employer offer? Keep in mind that having CF means that you will need coverage for your medication and sick days. Would the severity of your cough affect your job? This could be a problem in the food industry, or if you have a job talking on the telephone all day.

Will you need to travel or relocate to another city or town? If you have to move, will you be able to maintain a safety net or your support group or have the same resources for health care?

Environmental issues

It is well known that certain environments can be harmful to the lungs, especially if you have an underlying condition like asthma or CF. Will you be exposed to smoke fumes, vapors, mists or sprays? These can be found in many different occupations, like welding or bartending.

Is there dust? This could come from many sources. It could be mineral dust from rock sources such as those in mining or sand-blasting. Dust could also come from living material like plants, animals, and microorganisms. This type of dust, (which includes spores, fungi and other tiny organisms) may be inhaled in occupations dealing with plants, trees, animals, and crops. Is there a workplace standard in the occupation? For example, those doing auto body work with fiberglass must take precautions to avoid inhalation of fiberglass, because the fibers can become deposited

in the lungs. Are special masks and filters available for occupations where inhalation of harmful particles is known?

What are your chances of contacting a cold or flu in the work setting? Daycares and schools, for instance, are known for spreading germs. Likewise, different kinds of bacteria are often found in hospital settings. You will also need to think of the germs and bacteria you may be carrying, and whether you may be a danger to people with low immunity such as candidates for transplants. By the same token, you will also have to consider whether some infected people are a danger to you.

Evaluating your job choice

Evaluating your job choices in terms of your own health limitations and the work setting can be overwhelming. It's important that you discuss your choices with your physician and CF team. Above all, try to be realistic without getting discouraged. It may take some time, but with a little research and an honest assessment of your strengths and weaknesses, you could find yourself doing a job you love with co-workers who support you.

Some resources for finding work in Alberta

From “The Guide: Resources for the CF community 2009” (http://www.cysticfibrosis.ca/assets/files/pdf/TheGuide_Resources_CF_2009_E.pdf) and “Government of Alberta Jobs– Information for Persons with Disabilities” (<https://www.jobs.alberta.ca/disabilities.html>)

Alberta Learning Information Service (ALIS) (<http://alis.alberta.ca/>) provides information for career planning, post-secondary education and training, educational funding, job search, labour market trends, and workplace issues.

WORKink™ (<http://workink.com/>) is an online career development and employment portal for Canadians with disabilities. It provides job search tools, career guidance and resources pertaining to education and employment.

EmployAbilities (<http://www.employabilities.ab.ca/#>) is charitable non-profit organization, located in Edmonton dedicated to promoting and enhancing employment and learning opportunities for persons with disabilities. This is accomplished by a variety of different programs providing training on computers, assistance with resume and cover letter creation and modification, as well as on the job support if needed.

Alberta Works (<http://www.employment.alberta.ca/FCH/3171.html>) focuses on training people for employment. The goals of Alberta Works are to help unemployed people find and keep jobs, help employers meet their need for skilled workers, and help Albertans with low incomes cover their basic costs of living. Alberta Works achieves these goals through its four program areas: Employment and Training Services, Income Support, Health Benefits and Child Support Services.

Disability Related Employment Supports (<http://employment.alberta.ca/CES/3159.html>) provides assistance to Albertans in overcoming the barriers to employment created by their disability. You must meet certain criteria outlined on the website and they offer workplace, job search and educational supports. ●



Fall Raffles

'Tis the season for CF raffles, especially of the Grey Cup variety. September 7 marked the conclusion of the Destination Anywhere/ Trip Voucher raffle. (This article is being written before the draw date, so we don't have the name of the winner yet.)

After that we have two types of Grey Cup tickets to sell:

1. Grey Cup pool tickets: this is the same raffle we have been running for many years. Tickets printed with game scores (East vs. West) are packaged into sealed envelopes and sold for \$2 each. Holders of tickets with game scores from the end of each quarter as well as for the final score win cash prizes. If you are not already a seller of these tickets, but would like to be, please contact the CF office.

2. Grey Cup game tickets: With the 2010 Grey Cup game happening in Edmonton, we are offering a raffle in which the prizes are tickets for seats to attend the game. These tickets are selling at \$5.00 each.

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

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

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"Phage therapy offers a safe and effective treatment option and a possible solution to the threat of antibiotic resistance."

Members of the Dennis lab are also testing phage delivery into the lungs. Dr. Dennis has had success with delivering phages into an artificial lung using nebulizers (devices used by persons with CF to deliver drugs to their lungs.) He has also successfully used phage therapy as a treatment in a caterpillar infection model, further demonstrating the promise this therapy holds for people with CF.

The CCFF awarded Dr. Dennis a \$75,000 grant for 2010-2011 to study phage enzymes. Through a partnership with the Canadian Institute of Health Research - Institute of Infection and Immunity, the CCFF is also contributing \$125,000 over five years to investigate phages that specifically target the B. cepacia complex, as well as phage delivery methods. ●

Curtain Closes on An Evening at the Citadel

After 13 years holding "An Evening at the Citadel," our chapter board has made the decision to discontinue this event. Chaired by Julie Hornig, "An Evening at the Citadel" has always provided a lovely night out for all guests. The experience has become increasingly challenging for the planning committee and volunteers. With members of the current committee stepping down, and no one stepping up to take their place, we have discontinued the event.

However, we are delighted that members

of the Citadel committee have offered to transfer their efforts into supporting the fall CF Spectacular event at the Mayfield Dinner Theatre. Over the years, the Citadel committee has raised over \$147,240 for the fight against CF – definitely worth a standing ovation and loud bravos!

If you would be interested in organizing a new theatre event, please let us know. We are interested in exploring something similar to "An Evening at the Citadel," but with one of the less expensive theatre companies in the city. ●

Run! Run! Run!

During August, three Runs were held in support of the fight against CF.

"Fight CF! Fight CF! Fight CF!" cheered the enthusiastic group of walkers and runners at the starting line for the NAIT Shinerama Run. This Run is one of several events planned by NAIT students to raise funds, and this is the first year they have organized a Run. It was really well done, especially considering it was their first!

The Canadian Derby, organized by Intact Insurance, included several running events as well as a fashion show and family-friendly activities over a two-day period, August 22-23. The Canadian Cystic Fibrosis Foundation was one of the charity options open to Derby participants. We will receive a full report later, but at this point we know that one runner has already raised over \$600.

Original Joe's Terwillegar location hosted the fourth run for the Lung on August 29. First organized in 2006 in honor of Jessie McQuitty, this event continues in her memory, thanks to the leadership of Ally Stone and Rob Sokil. ●

Community Spirit Grant



Alberta Lottery Fund

Thank you, Donors! Your individual donations qualified our chapter to receive a \$25,000 grant from the Community Spirit Program again this year. This is a Government of Alberta program funded through the Alberta Lottery Fund.

The program aim, encouraging individual donations to non-profit organizations and registered charities, is clearly reflected in the application process. Funds raised through events, donations from businesses or corporations, other government funding, and grants from other agencies are among the categories of revenue which are ineligible for counting on

the application.

However, all individual donations are eligible and we were able to tally a sufficient amount to qualify for this grant. Our thanks go to all our individual supporters as well as to the Government of Alberta for their encouragement with this grant.

With the program grant ceiling of \$50,000 in each 3-year period, we are ineligible to apply again this year. However, when we apply next year, our application will be based on 2010 donations, so all individual donations this year are definitely welcome. ●

