

October — December 2009 Issue 46

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Outstanding Volunteer Honoured

The first ever CF Spectacular event, on Saturday, October 24, was an evening of fine food and entertaining theatre held at the Mayfield Dinner Theatre.

Chaired by Julie Mitchell, the event committee organized a silent auction and a raffle to be fundraising components of the evening. With the auction, the raffle, and the sold-out crowd, the event was both a financial and a social success.

The intermission featured the presentation of the Celine Dion award to Julie Hornig, the chair of "Evening at the Citadel," another theatre-based

fundraiser. Julie has been involved with the Citadel event since its inception in 1998 and chaired it for several years.

Over the years, this event has raised over \$100,000. In addition, Julie has been involved with many other fundraisers and has also served on the chapter board while she also managed to juggle raising a family and working as a nurse.

The award recognizes those who make indispensable and sustained contributions at the grassroots level and who can always be counted on to get the job done. Previous winners of this award in our chapter have been Carey and Joan Losinski and Cathy Michael.



Super Strider Extraordinaire



The highest fundraising individual in this year's Canada-wide Great Strides Walk in May was Edmonton's own little Super Strider, Sydni, pictured left with Jocelyn Gillis, Director at Large on the chapter board, and member of the Great Strides committee. Congratulations to Sydni, to all her family and friends for their amazing work, and to all the other walkers who gave them such stiff competition!

Casino Results

The Chapter is grateful to the crew of volunteers who manned our 2009 casino on June 8 & 9. This casino raised \$75,716.88 for us.

H1N1 (SWINE FLU)

- 1) People with CF who have specific concerns about H1N1 and their personal health should contact their clinic for advice.
- 2) With respect to general advice regarding H1N1, the Foundation is consulting Canadian clinical experts to consider whether there may be any additional suggestions that might be added to the normal list of day-to-day measures pertaining to infection control.
- 3) Meanwhile, people with CF should follow the normal infection control procedures, and also consider the guidelines from Health Canada, available at:

http://www.phac-aspc.gc.ca/alert-alerte/swine-porcine/faq_rg_swine-eng.php

and at: www.fightflu.ca .

- 4) Finally until there is further advice to offer, the Cystic Fibrosis Foundation in the USA makes some useful points at this Web address:

<http://www.cff.org/LivingWithCF/StayingHealthy/Germs/SwineFlu/>.

Party Lite Candles

Are you looking for a way to help the Foundation but haven't found something yet which works for you? Maybe you are living in a small town. Maybe you are just too busy with a full time job on

top of caring for your children. This might be just the project for you.

Party Lite candles can be sold anywhere and any time to your family, friends and co-workers at a

time that is convenient for you. By selling certain sets of candles, 35% of your sales would go toward the Canadian Cystic Fibrosis Foundation. Please contact Kathy or Emily at 780-466-2265 for details

President's Corner with Alan Bartman

Another summer has passed us by again, we've watched our first snowfall come and go, and Halloween and then Christmas are just around the corner.

We are three quarters of the way through another year that has been filled with many successful fundraisers and there are a few more left to round out the year.

We have had record numbers again with both Great Strides and the Motorbike Ride and I hope the trend will continue.

As I write this, I and a few of the board members have returned from the Prairie Regional meetings in Winnipeg. Subjects discussed this year

included the 50th Anniversary Campaign (the CCF was founded in 1960 and has been working hard ever since to find a cure or control for CF), third party fundraisers, brand and logo recognition and the first ever Prairie Regional awards. I am very proud to say that several were won by the chapter and its supporters.

This past weekend, we held our first annual CF Spectacular at the Mayfield Dinner Theatre and it was an overwhelming success. I would like to extend my thanks and congratulations on a job well done to Julie Mitchell and her committee. I would also like to congratulate Julie Hornig on winning the Celine

Award. The award acknowledges a volunteer individual, couple or family who has made indispensable and sustained contributions to chapters at the "grassroots" level. It recognizes those who can always be counted on to get the job done. Julie has been volunteering with the chapter for over 15 years and recently has chaired "A Night at the Citadel" for the past several years. Next year's event is planned for April 17, 2010. With that, I would like to wish you all a great fall, and all the best for the upcoming holiday season. Once again thank you for your support of, and help with, our events.

Up Coming Events

October 24, 2009

CF Spectacular – Dinner Theatre at the Mayfield (see page 1)

November 27, 2009

Grey Cup Raffle – tickets all due in

January 23, 2010

65 Roses Sports Club: Faceoff with CF (see page 6)

February 4, 2010

French Fling – a wine-tasting experience

March–April, 2010

22nd CF Hockey Draft of Hope

April 17, 2010

An Evening at the Citadel

May 30, 2010

Great Strides Walk

Baskets Required

Should anyone have baskets of any kind which they don't want, we would love to have them. We use a lot of baskets when preparing packages for silent auctions, and our supply is almost totally depleted.

Grey Cup Score Raffle Tickets

Looking for your Grey cup raffle tickets? Look no further! Buy your raffle tickets from us now, cash prizes for regular and reverse score. Total cash payout on a single series is \$1200. Just call our office to make arrangements for your purchase.



French Fling: A Wine Tasting Experience

Come out to the Chateau Louis on Wednesday, February 4, 2010 and enjoy our second annual wine tasting evening! We are featuring 90+ French wines to sample along with some appetizers. We will have our live & silent auction during the evening, so watch for all the details that will be posted on our website very soon! This was a very successful evening last year, and we aim to make it even better this year!

Evening at the Citadel

A romantic comedy ahead of its time, Shakespeare's As You Like It features delightful characters, mischievous encounters and deliciously witty repartee April 17.

Cystic Fibrosis
Hockey Draft of Hope.

Watch for The CF Hockey Draft of Hope entry forms this year in your local Boston Pizza lounges, and the Edmonton SUN. You can also have entry forms mailed to you by request, or we encourage you to enter online, visit

www.cfhockeydraft.ca. Start looking for your entry form sometime in March!



This will be our 6th annual walk to be held at Snow Valley/Whitemud Park on Sunday, May 30, 2010. Because of the huge growth of this walk, we will be launching a satellite walk that will be held at the same time in Leduc (**with a stroller friendly walking path**). We chose this location because the local Kinette Club will host the event, and we already have several participants from the Leduc, Beaumont & Wetaskiwin area coming to the walk in Edmonton. This will give our Edmonton walk room to grow again! To register yourself or your team, visit cysticfibrosis.ca or call our Edmonton office.

Highlights of the NACFC 2008 Part 3, No. 1: The Cystic Fibrosis Pipeline: A Story of Progress, Hope and Challenge

by Preston W. Campbell, 3, M. D., Executive Vice President for Medical Affairs, Cystic Fibrosis Foundation.

Information was also obtained from the Cystic Fibrosis Foundation (CFF) that was updated as of June 1, 2009 (<http://www.cff.org/treatments/Pipeline/>), various company websites regarding their products, and B. P. O'Sullivan and S. D. Freedman (2009) "Cystic fibrosis." *Lancet* 373(9678): 891-904 and references cited within. A webcast "CF Research: Progress, Hope and Challenges Today" can also be viewed at (http://www.cff.org/LivingWithCF/Webcasts/ArchivedWebcasts/#CF_Research).

Please note that in no way is this review advocating specific treatments. It is intended as a general discussion of the research in progress. If you have any questions, please see your health care provider.

There are 6 stages of drug development: 1) Research 2) Pre-clinical trials 3) Phase 1 trials - to determine if the drug is safe for humans 4) Phase 2 trials - to establish further safety, testing for efficacy and what dosage is effective 5) Phase 3 trials - the definitive trial - to show benefit relative to untreated controls 6) Available to patients provided that steps 1) - 5) are successful and the drug passes Food and Drug Agency (FDA) or Health Canada approval, it can then be distributed to patients.

Research takes five to seven years, clinical trials, five or six years and it can take about a

year for drug approval. Generally, from the research phase, only 20% of the drugs developed go on to phase 1 testing; of that stage only 50% of the drugs developed go on to Phase 2, while 80% that have reached Phase 2 go on to Phase 3. Figure 1 shows the clinical trial status of the drugs in development for treatment of CF. These drugs are divided into 8 categories and range from the research/early patient trial phase/pre-clinical (e. g. anti-inflammatory HE3286), to where the drug is available for patients (e. g. Pulmozyme).

Gene therapy, CFTR modulation, ion transport restoration, and mucus regulation are reviewed here. Anti-inflammatory agents, anti-infectives, transplantation and nutrition will be presented in the next newsletter.

Gene therapy

CF could be treated with the insertion of one copy of normally functioning DNA into the affected cells regardless of the class of mutation the recipient had before gene therapy. In practice, however, gene therapy has proven to be quite difficult.

A phase 1 trial of compacted DNA (PLASmin™; Copernicus Therapeutics) demonstrated chloride current changes in the nasal passages of CF patients, but no evidence of gene expression. The UK Cystic Fibrosis Gene Therapy Consortium utilizes non-viral vectors for gene transfer administered by aerosol to nose and lung. In 2010, a multi-

dose study on 200 CF patients will be conducted. For now, however, gene therapy remains a hope more than a reality.

CFTR modulation or protein rescue

Vertex is developing orally bioavailable drugs with 2 targets in mind: potentiators, which increase the opening of the CFTR channels, and correctors, which will increase the number and function of the CFTR channels at the cell surface.

VX-770 targets the G551D mutation (10-15% of CF population), and appears safe and improves CFTR function. Phase 3 studies were scheduled to begin in Spring 2009.

VX-809, a corrector, targets the delta F508 mutation and is in early phase 2 trials. A Phase 2 trial of Ataluran (formerly PTC124) in CF patients that corrects shortened forms of the CFTR demonstrated safety and encouraging biological results. A Phase 3 trial is scheduled to begin Summer 2009.

A nutritional supplement derived from tumeric, curcumin, generated a great deal of interest when it was first proposed as a corrector of CFTR misfolding. Unfortunately, other investigators have not been able to replicate these initial findings.

Ion transport restoration to restore normal airway liquid/airway hydration

In cystic fibrosis, changes in salt transport within cells dehydrate mucus, causing it to become thick and

sticky. This approach targets proteins other than CFTR to improve the movement of salt in and out of cells, allowing mucus to be more hydrated and, therefore, cleared more easily. Lancovotide or Moli1901 (Lantibio) administered as an aerosol, activates an alternative chloride channel that is present in CF nasal and airway epithelia and is in phase 2 trials in Europe. In June 2008, Inspire Pharmaceuticals announced top-line results from TIGER-1 (Transport of Ions to Generate Epithelial Rehydration-1) its first Phase 3 trial with denufosal, a drug which targets reduction of sodium reabsorption through epithelial sodium channels. Inspire is cur-

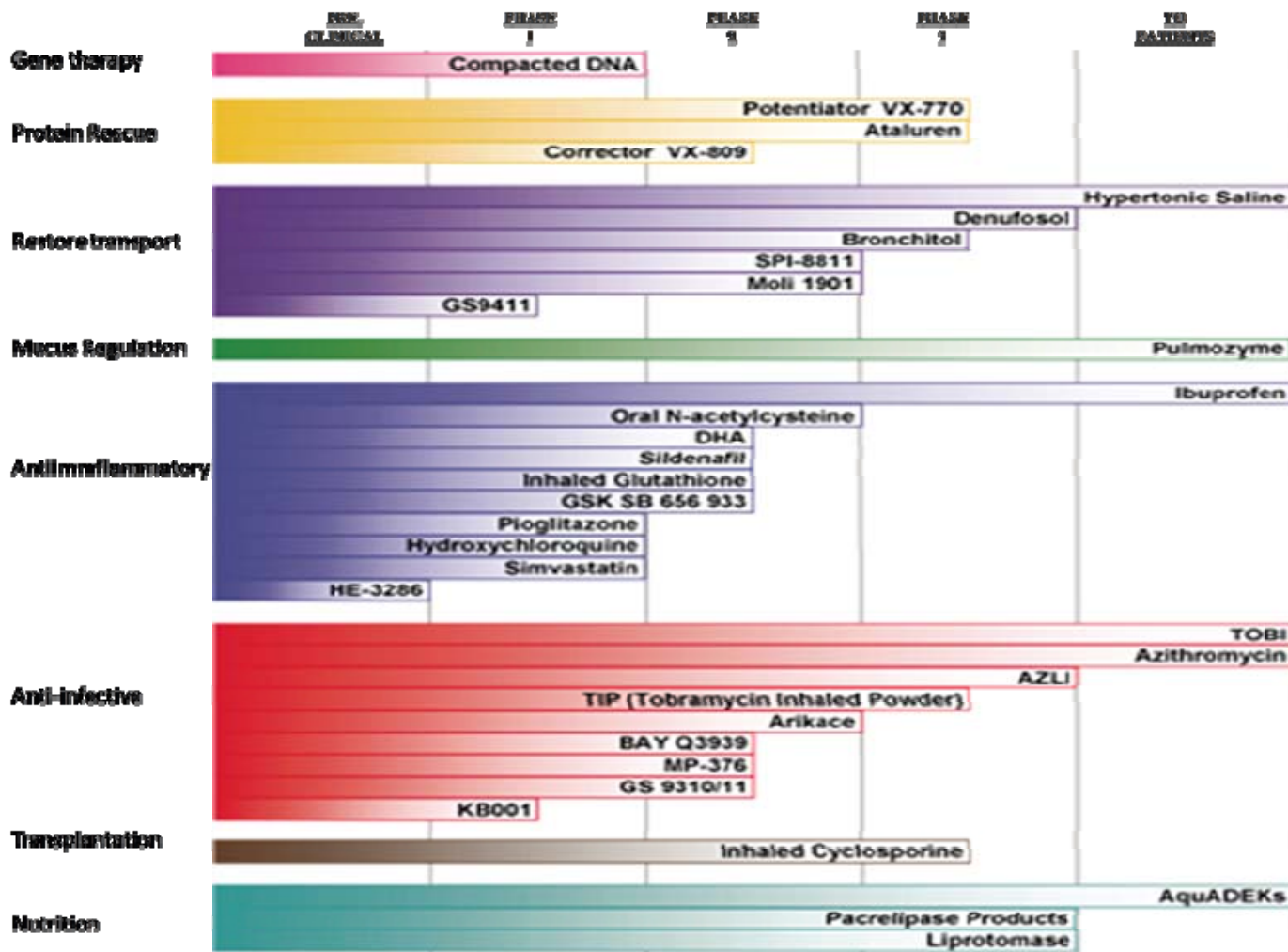
rently enrolling patients in TIGER-2, the second pivotal Phase 3 trial with denufosal. Bronchitol (Pharmaxis): A Phase 3 trial of Bronchitol (an inhaled dry powder mannitol) has begun in the United States and in Canada. Theoretically, mannitol should help rehydrate CF secretions, improving airway clearance. Trials in Australia and Europe support this hypothesis. SPI-8811: Sucampo Pharmaceuticals have produced an oral agent believed to bypass transport defect of chloride ions and it is in Phase 2 trial. Gilead GS9411: Parion Sciences has entered a Phase 1 CF clinical trial.

It acts by blocking sodium absorption.

Mucus regulation

These studies are evaluating drugs for their effectiveness in preventing, thinning and clearing thick mucus from the airways.

Pulmozyme® (Genentech): The drug was approved in 1993 and is currently being used widely. Hypertonic Saline: A Phase 3 trial in Australia had beneficial effects on pulmonary health in CF patients. Follow-up studies are determining if younger patients would benefit from this inhaled therapy.



Chapter office:

St. James Catholic Elementary
School

7814 - 83 Street
Edmonton, AB T6C 2Y8

Phone: (780) 466-2265

Fax: (780) 437-7655

Emily Westwood
Chapter Manager
ecfs@telus.net

Kathy Irvine
Fundraising Co-ordinator
ecfs.fundraising@telus.net

Websites: www.cfedmonton.ca
www.ccff.ca

Clinic: University Hospital
(780) 407-6745



Edmonton and Northern
Alberta Chapter

Meeting Calendar

Nov. 2009 – Mar. 2010

Nov. 3 - Chapter Board
Meeting

Dec. 1 - Chapter Board
Meeting

Dec. 25 - CF Office closed
until Jan. 4

Jan. 5 - Chapter Board
Meeting

Jan. 23 - Faceoff with CF

Feb. 2 - Chapter Board
Meeting

Feb. 28 - Chapter Annual
General Meeting

Mar. 2 - Chapter Board
Meeting

Matching Grant for Chair

Graydon Chretien, one of the members of our chapter, works for an employer who pays a matching grant for charitable donations he raises. This fall, Graydon is chairing the Grey Cup Raffle. Between Graydon's work, BHP Billiton's matching grant, and all the efforts of our army of raffle ticket sellers, we are looking forward to an

amazing success for this fundraiser.

Graydon reminds all raffle ticket sellers that all tickets, both sold and unsold, must be returned to the CF office by the end of November. If you will not be selling your tickets, please return them as soon as possible, because other people may be able to sell them if they get them in time.

Face off with CF

We are very excited to have Ethan Moreau return as our honorary chair in the Faceoff With CF dinner! This year the dinner will be held at the Jubilee on Saturday, January 23.

The format will be the same as last year, although the packages have changed slightly based on last year's feedback. Package prices range from \$125 - \$900, depending on the size of your party, and the memorabilia that you would like. The evening will be

fun filled with everything from a wonderful dinner to a silent auction to our "Ask the Players" segment (which was a huge hit last year!). This is a great Christmas gift for any hockey fan, a great gift for a corporate Christmas Party and a great way to spoil yourself!

Call the CF office (466-2265) for details and to get your tickets! Only 140 seats will be sold and last year, we were very close to a sell out – so get your tickets early!

Community Spirit Program Grant

All financial donations made by Albertans to our chapter during 2008 have had their donations doubled thanks to the Community Spirit Program Grant. The Program is funded by the government of Alberta through the Alberta Lottery Fund, and the goal of the program is to increase individual charitable giving to help support Alberta's non-profit and charitable organizations. In applying for the grant, we were able to include all donations

given by individuals, whether as a pledge supporting a rider in the Ride for the Breath of Life or a walker in the Great Strides Walk or a donation mailed in for the mail campaign as well as several other options people use to send us their donations. So we thank every one of you who personally makes such donations, and we also thank the Alberta Lottery Fund. Needless to say, we shall be applying for this grant again this year!

Pizza Sales at Eskimo Games

Would you like to help sell pizza at the Esks games, and raise much needed funds for cystic fibrosis research at the same time? We are looking for volunteers to man a booth as cashiers and runners, but also need volunteers to pack pizza into boxes, and to pour soft drinks and beer into glasses. We are

looking for some volunteers not only for the 2009 season, but if there is enough interest, we will partner with the Fort Saskatchewan Kinettes to do this regularly during the 2010 Esks season.

Please phone 780-466-2265 if we may add your name to the list of volunteers for pizza sales at Eskimo games.