

January — February 2010 Issue 47

INSIDE THIS ISSUE:

Promising News	2
President's Corner	2
Upcoming Events	3
NACFC highlights	4
Shoot, Score & So Much More	6
Calendar	6

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History worth Celebrating

May of 2010 marks 50 years since the formation of the Canadian Cystic Fibrosis Foundation. Did you know that 2007 was the first year that there were more CF adults than children in Canada? That is due to improved life expectancy achieved through improved medications and treatment developed through research. The



50th anniversary reminds us of the many people who have worked so hard to make the progress we have, such as the 2007 marker. Needless to say, we also still have much work to do.

One of the many volunteers who made a difference over the years here in Edmonton is Irene Serink. In 2003, chapter president Darlene Bouclin presented her with the Celine Dion

award, a national award given for sustained, dependable volunteer contributions at the grassroots (non-executive) level. Irene's volunteer efforts span almost 50 years, and a short list of what she has done includes holding garage sales, working bingos and casinos, and selling tickets at numerous events. About two years ago, she worked her last casino, but she still finds small ways to help. Wow!

Five fabulous volunteers with the Edmonton & Northern Alberta Chapter have received the Celine Dion award over the years. Those five award winners are:

2003	Irene Serink
2005	Chris Small
2006	Joan & Carey Losinski
2007	Cathy Michael
2009	Julie Hornig

Auction for "An Evening at the Citadel"

Auctions are important to the success of many of our fundraisers. For the "Evening at the Citadel," the organizing committee has approached many of the same potential donors many times, and would really appreciate your support with locating items as well.

Some possibilities for items are: gift certificates to restaurants, spas, and specialty stores of all kinds; electronic gadgets such as MP3s, GPSs, or

iPhones; certificates for unique experiences like paintballing for a group, a whitewater rafting excursion, six months of flowers from a florist, ski lift passes; themed baskets like romantic, toolkit, fishing package, or a gardening package.

But this is far from an exhaustive list, so just use your imagination and consider the contacts you have to locate items. If you contact the CF office, we'll get the items to the Citadel committee.

Promising News by Cathleen Morrison, CCFF CEO

We have received some very encouraging news from Health Canada respecting the regulation of pancreatic enzymes. Health Canada expects to put forward, in the very near future, a recommendation that pancreatic enzymes, when used to treat pancreatic exocrine insufficiency, should be placed on *Schedule F* (prescription-requiring drugs) to the *Food and Drug Regulations*.

We have been informed that the required regulatory process that culminates with the Governor in

Council making a regulation to change to *Schedule F* may take up to a year, or more. Thus, during this period, Health Canada will allow certain pancreatic enzyme products to continue to use labels bearing a DIN. This will avoid the situation of manufacturers having to bring their DIN labelling into compliance with the *Natural Health Product Regulations* in January 2010, only to have to change labelling again when the Schedule F amendment should come into force. We are extremely pleased with

this development, and are very appreciative of Health Canada's responsiveness and action to the concerns raised by the CF community. We thank you for your personal support, and in particular wish to acknowledge and thank Drs. Mark Chilvers and Peter Durie for their leadership in developing our submission to Health Canada.

We will continue to communicate with Health Canada, and as information comes to us, we will keep you up-to-date.

Golf in January

No, we're not actually golfing this month, but we do not want to miss thanking our good friends who hold golf tournament fundraisers for CF. Thank you, kind friends.



In 2009, the local **Advocis** group held their third golf tournament fundraiser and donated \$10,000.



Akita Drilling held their 8th tournament and in the eight years, they have raised over \$200,000!



Waiward Steel held their 20th tournament for us in 2009.

President's Corner with Alan Bartman

Last year, 2009, was another very successful year for both our chapter and the foundation itself. Fundraising was once again very successful and advances have been made in CF research.

The Edmonton and Northern Alberta chapter has continued to meet or exceed its fundraising goals and these goals themselves have steadily been rising. It is through the efforts of the chapter members, committees and board

members that these results have been possible, and for that I would like to thank each and every one of you.

The chapter Annual General Meeting will be held on Sunday March 14 at the Kinsmen Clubhouse, and once again we will hold a Cystic Fibrosis information session following the meeting. Dr Brown from the Edmonton CF clinic will be doing a presentation for those in attendance. Please try to

make it out for the afternoon if you are able.

In closing, there are several events happening in the near future that are sure to be a good time and successful in raising funds for CF research. Some of these are the Oilers dinner (Jan 23), the French Fling wine tasting (Feb. 4) and the Edmonton Kinettes CF night at Schanks (Feb. 20).

Have a great month everyone.

Up Coming Events

January 23, 2010

Faceoff with CF
(sold out)

February 4, 2010

French Fling - a wine-
tasting experience

March-April, 2010

22nd CF Hockey Draft of
Hope

March 14, 2010

Annual General Meeting
and CF Information Day

April 17, 2010

An Evening at the
Citadel

May 30, 2010

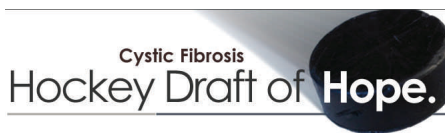
Great Strides Walk



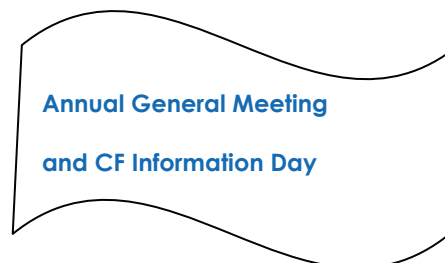
French Fling —

A Wine Tasting Experience

Come out to the Chateau Louis on Wednesday, February 4, 2010 and enjoy our 2nd annual wine tasting evening featuring 90+ French wines to sample along with some appetizers. We will have our live & silent auction and the evening will be emceed by Seanna Collins. This was a very successful evening last year, and we aim to make it even better this year!



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!



Sunday, March 14, 2 pm
Kinsmen River Valley Place



An Evening at the Citadel

Join us for a *complete* evening theatre package at the world-class **Citadel Theatre**. Tickets include:
6:00 p.m. Wine & Cheese Reception, Silent Auction
7:30 p.m. “As You Like It”
10:00 Dessert Reception
Tickets are \$75 per person. Please call the CF office soon since this event usually sells out.



1. **Main Walk:** Sunday May 30 with registration at 9 a.m. at Snow Valley, Edmonton.
2. **Leduc:** Sunday, May 30 with 10:30 a.m. registration at Telford Place. Hosted by the Leduc Kinettes, this location features a stroller-friendly path.
3. **Grande Prairie:** Date to be confirmed (possibly June 6.)
4. **Ekati Mine:** Sunday, May 30th at the Accommodations Bldg at the mine site, NWT.

To register yourself or your team for any of the locations, visit www.cfedmonton.ca or call Kathy at the CF office.

Highlights of the NACFC 2008 Part 3, No. 2: 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.

This article is a continuation of the review on drugs in development for the treatment of CF. *Please note that in no way is this review advocating for 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.*

Anti-inflammatory

The drugs in this category are being studied for their ability to reduce inflammation in CF lungs in order to help decrease chronic damage to lung tissue. **Ibuprofen:** A four-year high dose ibuprofen trial completed in 1990 demonstrated less lung function decline in the treatment group than the control group. This effect was greatest in 5-13 year-olds.

Oral N-acetylcysteine (BioAdvantex): An antioxidant, oral N-acetylcysteine replenishes glutathione levels in neutrophils. Placebo-controlled 12-week study at Stanford University demonstrated decreases in inflammatory cells in lung and positive indications of changes in pulmonary function.

DHA (a beneficial fatty acid): At the University of Massachusetts, a pilot study to examine effect of infant formula fortified with DHA on pathogenesis of CF in 120 newly diagnosed patients at 16 centers began in 2003. **Pioglitazone, Hydroxychloroquine:** These approved therapies (approved for non-CF indica-

tions) are being evaluated in exploratory Phase 1 trials in CF to determine if they are tolerated and if anti-inflammatory effects are seen.

Simvastatin (Zocor™): A HMG-CoA reductase inhibitor (also a common cholesterol lowering drug) that increases nitric oxide (NO) production in cultured CF epithelial cells. Investigators are evaluating whether simvastatin increases exhaled NO production in CF patients, synthesis of pro-inflammatory cytokines and whether measures of inflammation in the upper respiratory tract correlate with those from the lower respiratory tract.

Inhaled Glutathione: A Phase 1 trial of inhaled glutathione has been completed in Germany and a Phase 2 trial is now in progress. **HE-3286:** (Hollis-Eden Pharmaceuticals) An oral immune-regulating hormone which has replaced HE2000.

Sildenafil (Pfizer, Viagra™): Based upon prior work by researchers at the University of New Mexico, clinicians there are examining whether sildenafil can lower markers of airway inflammation and measures of airway infection in CF patients, as well as alter the patient's perception of their own well being.

Anti-infectives

The compounds in this category are being evaluated for their effectiveness in fighting acute and chronic lung infections by destroying infection-causing bacteria that enter into the airways and colo-

nize.

TOBI® (Novartis Pharmaceuticals): Used widely for Pseudomonas (P.) infection.

Azithromycin (Pfizer): A large-scale trial was completed in 2002. In patients with chronic P. aeruginosa, this oral antibiotic improved lung function and weight gain, and decreased hospitalization rate. Two follow up studies are in progress.

AZLI (Gilead Sciences): Multiple Phase 3 trials of the aerosolized form of aztreonam, a widely used I.V. antibiotic in CF, have been completed.

TIP (TOBI Inhaled Powder): Novartis Pharmaceuticals is developing TOBI as a powder to enable a faster, more convenient dosing regimen. Dosing of TIP will take a fraction of the time of liquid TOBI. A Phase 3 trial has completed enrollment.

Arikace™ (Transave): A liposomal formulation of the antibiotic amikacin. Animal model studies have shown it to decrease the P. aeruginosa burden in the lung. Positive results from a Phase 2 trial on CF patients were recently announced.

MP-376: MP-376 or Aeroquin is a new formulation of levofloxacin being developed by Mpex Pharmaceuticals for aerosol administration to CF patients for management of chronic pulmonary infections due to P. aeruginosa and other bacteria. Phase 2 Trial results showed that nebulized Aeroquin met the primary endpoint of reducing bacterial counts of P. aeruginosa in sputum after 28 days of dosing versus placebo.

BAY Q3939: Bayer Schering Pharma is developing an inhaled version of their antibiotic ciprofloxacin for

treatment of airway infections. A Phase 2 study in Germany and USA is underway.

KB001: Kalobios Pharmaceuticals has initiated a Phase 1 clinical trial to test the safety of their antibody approach for treatment of *P. aeruginosa* lung infections.

GS 9310/11: Gilead Sciences inhaled combination antibiotic (fosfomycin and tobramycin) has completed Phase 1 testing in Australia. A U.S multicenter Phase 2 trial is currently enrolling patients.

Transplantation

Lung transplantation is the final therapeutic option for patients with end stage lung disease. Inhaled cyclosporine (APT Pharmaceuticals) is being evaluated for its ability to reduce the chance of organ rejection, which is common after transplantation. A randomized placebo controlled trial at the University of Pittsburgh was recently performed.

The group treated with inhaled cyclosporine showed a significant

decrease in number of deaths and the development of chronic rejection.

An additional clinical trial has been requested by the FDA before this drug is approved for clinical use.

Nutrition

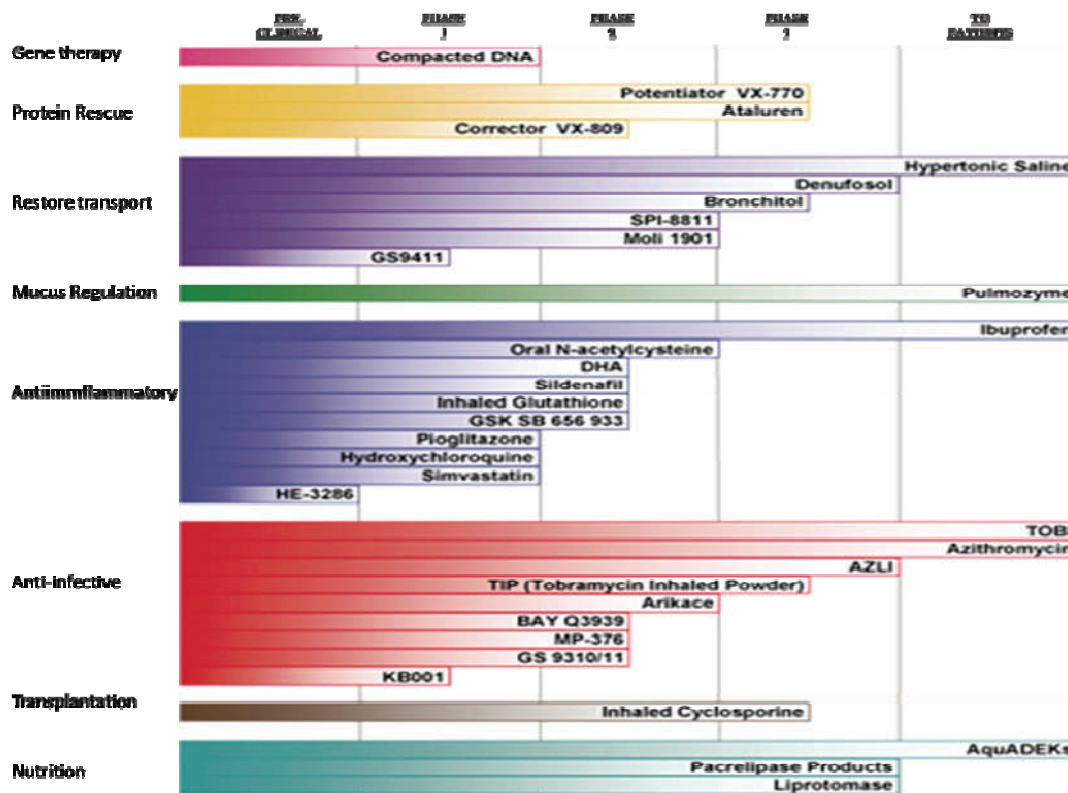
The benefits of maintaining good nutrition for long-term survival and lung health cannot be overstated. Specially formulated supplements in this category include vitamins, as well as enzymes that increase both fat and vitamin absorption, allowing better nutrition for people with CF, who can become malnourished as a result of thick mucus clogging the pancreas.

AquaDEKs: Yasoo Health created an oral antioxidant vitamin formulation specifically for CF patients. A Phase 1 trial has been completed. A clinical trial to assess the safety and ability of this formulation to increase blood levels of antioxidants, normalize plasma levels of

fat-soluble vitamins, improve pulmonary function and improve growth parameters began in 2007.

Pancrelipase Enzyme Products: In the USA, the FDA has required pancreatic enzyme products to be reformulated and undergo clinical testing in order to receive FDA approval. Companies completing this process include: Axcan Scandipharm (Ultrase), DCI (PANCRECARB), Eurand (Zentase), McNeil (Pancrease MT) and Solvay (Creon).

Liprotomase (formerly Trizytek, Altus Pharmaceuticals): Non-porcine pancreatic enzyme replacement. Phase 1 studies have not identified safety concerns. A Phase 2 trial has been completed, demonstrating safety and efficacy and a Phase 3 trial also has ended. Work to complete requirements for FDA submission is ongoing.



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Edmonton and Northern
Alberta Chapter

Meeting Calendar
Jan. 2010 – Feb. 2010

Jan. 5 - Chapter Board
Meeting
Jan. 23 - Faceoff with CF

Feb. 2 - Chapter Board
Meeting

Mar. 2 - Chapter Board
Meeting
Mar. 14- Chapter Annual
General Meeting



Help us give the
breath of life for
someone with
Cystic Fibrosis

THE KINETTE CLUB OF EDMONTON PRESENTS

SHOOT, SCORE & SO MUCH MORE

February 20, 2010 at 7 pm
An evening of games, fun and a silent auction

CALL SUSAN 780.983.0305 OR CAROL 780.984.2085 FOR TICKETS

Tickets \$15
(include snacks & an opportunity
to bid on great items)

Location
Schanks
9927-178 Street



All proceeds go to Cystic Fibrosis