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President	Caroline Van Dorp
VP Fundraising	Marcia Zroback
VP Publicity & Promotions	**Vacant**
Secretary	Salima Nurani
Treasurer	Judy Quathamier
Assistant Treasurer	Alexandra Moore
CF Adult Director	** Vacant **
CF Clinic Liaison	Joan Tabak
Director at Large	Patti Magnan
Director at Large	Julie Hornig
Director at Large	Julie Mitchell
Director at Large	Michelle Husch
CF Kin Liaison	Gerry Boehm
CF 65 Roses Liaison	**Vacant**
Chapter Co-ordinator	Emily Westwood
Fundraising Co-ordinator	Yvonne Wupori

65 ROSES OILERS DINNER

"Hi, my name is Chris Pronger, . . . , and this is my lovely wife, Mike Comrie." This introduction of himself and his wife, given by our honorary chair, Edmonton Oiler Ethan Moreau was greeted with applause and laughter at our November 22nd 65 Roses Oilers dinner. The dinner event was at-

tended by almost 70 people at The Derrick Club. Included in that number were honorary chair Ethan Moreau and his wife Ornella, Edmon-

ton Oiler Steve Staios and his wife Susannah, author and guest speaker Heather Summerhayes Cariou, and emcee Bryn Griffiths.

Bryn Griffiths co-hosts the 4-hour morning sports show on Team 1260 CFRN Radio. Thank you Bryn for emceeing the evening and helping create the relaxed and fun atmosphere. Rob Sokil, chair of the 65 Roses

Committee, served as a very efficient "Vanna" assisting Bryn.

Heather Summerhayes Cariou has recently published her book titled *Sixtyfive Roses: a Sister's Memoir*. We were very honoured to have her attend our evening and also speak to us sharing her own thoughts about

the work of the Canadian Cystic Fibrosis Foundation as well as sharing some greetings from her parents,



Rob Sokil, 65 Roses Sports Club chair, chats with Michelle Thornell

the founders of the Foundation. Sponsors and guests enjoyed an abundant buffet dinner before the program and a competitive live auction afterwards. Thought-provoking words from Bryn Griffiths, Heather Cariou, Ethan Moreau and president Caroline Warren were sprinkled with lots of moments of humour. We estimate that once all income and expenses associated with this event are finalised, the event will have raised

Thank you 65 Roses Sports Club, and thank you, Sponsors



Lorraine & Joe Herlein, Primrose IDA Pharmacy with Oilers Ethan Moreau and Steve Staios and Erica Van Dorp

Each sponsor received an autographed copy of Heather Cariou's book, *Sixtyfive Roses* and a Skelly skunk with a copper ribbon autographed by Ethan Moreau.
Boreal Machine Inc.
Cornerstone Child Development Centre
David Hrycun Professional Corporation

John Weir Professional Corporation
Keen Family
Kinette Club of Edmonton
Kinsmen Club of Edmonton
Le Papier
Lehigh Inland Cement
Marc Johnson Group
Northwest Rentals

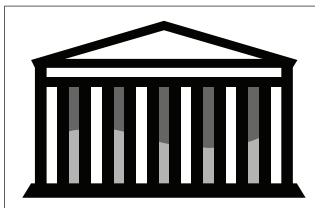
Novartis Pharma
Primrose IDA Pharmacy
Production Die-Makers & Machine
Saville Group
Sokil Express Lines
Steel-Craft Door Products Ltd.
Symitrix Solutions
The Truck Outfitters
Weatherford Canada

IN MEMORIAM

Our Chapter is saddened by the loss of one of our beloved volunteers. Carey Losinski of Wetaskiwin passed away Wednesday, January 17, 2007.

Carey and his wife Joan were the 2006 recipients of the Celine Dion award, which acknowledges a volunteer individual,

couple or family who have made an indispensable and sustained con-



tribution at the non executive level, and were featured in Issue 34 of this newsletter.

Carey and Joan have contributed in many substantial ways in Chapter and National events and in Wetaskiwin events since the birth seven years ago of their first grandchild with CF.

Volunteer Help Wanted for 2007

Your Chapter holds over 20 fundraisers each year, and they cannot be successful without the help of volunteers. Our activities vary, so to make the best use of our volunteer time, we'd like you to identify what you would be willing to help with. Regardless of the amount or type of help given, your help is both needed and appreciated.

Please check off the fundraisers which you are most interested in helping.

- ☐ Bingo
- ☐ Casino
- ☐ Citadel evening
- ☐ Collection boxes
- ☐ Craft sales (making crafts)
- ☐ Golf tournaments (Akita, Ladies, Oilers Alumni)
- ☐ Hockey Draft (data entry, stuffing envelopes, validation)
- ☐ 65 Roses (Oilers and Eskimos) dinners
- ☐ Motorcycle run
- ☐ Walks (e.g. Great Strides) and runs (e.g. Original Joe's Run for the Lung)

Please check off all roles or tasks below which we could call on you to assist.

Advising or governing

- ☐ Membership in a committee
 - ☐ 65 Roses Sports Club
 - ☐ Specific fundraising event (from list above)
 -
 - ☐ Planning
 - ☐ Setting up and/or cleaning up
 - ☐ Soliciting items for silent or public auction
 - ☐ Publicity & Promotion
- ☐ Membership on board of directors

Selling

- ☐ Product sales (we can ship items to you if you are outside of Edmonton. Check off specific item(s) you would like.)
 - ☐ Frightlites (glowsticks for Halloween)
 - ☐ CF Bracelets
 - ☐ CF Christmas cards
- ☐ Tickets for:
 - ☐ Citadel evening
 - ☐ Grey Cup Raffle
 - ☐ Hockey draft
- ☐ Booth / event sales
 - ☐ Christmas crafts

Office Help

- ☐ Stuffing envelopes
 - ☐ mail campaign
- ☐

Public Speaking

- ☐ At a fundraising event
- ☐ To media

Name of Volunteer

(Please make an additional copy for other volunteers in the family.)

Thank you so much for your help. Together we make a difference for everyone living with Cystic Fibrosis.

MEDICAL NEWS

Rockline Industries recently instituted a voluntary product withdrawal of store brand baby wipes sold between Aug. 21 and Nov. 17, 2006.

This withdrawal was the result of routine product testing that detected the presence of a micro-organism known as *Burkholderia cepacia* (*B. cepacia*). According to the Centers for Disease Control (CDC), *B. cepacia* is a bacteria that can be found in soil and water. The CDC says, "*B. cepacia* poses little medical risk to healthy people. However, people who have certain health problems like weakened immune systems or chronic lung diseases, particularly cystic fibrosis (CF), may

be more susceptible to infections with *B. cepacia*. *B. cepacia* is a known cause of infections in hospitalised patients." Information on *B. cepacia* can be found on the CDC website at: (http://www.cdc.gov/ncidod/dhqp/id_BcepaciaFS.html).

Rockline encourages anyone using store brand baby wipes to check the lot code of the wipe. A lot code is not the same as a bar code. On Rockline packages, the lot code is typically found on the back label or side panel of the package and includes the word "Lot" followed by a series of numbers.

Affected products have a single lot code within the ranges of those identified below. No other lot codes other than those spe-

cifically mentioned are affected, however like any other organic based product, wipes can spoil over time. Rockline recommends discontinuing the use of any wet wipe that has a bad odour.

Affected packages are 80-count units sold in single or multiple unit packages, such as 160, 240, 400 or 720-count pop-up style wipes. The wipes are sold under different names. The safest and most reliable way to identify the wipes is to check the lot code. Only the lot codes listed are affected. The retailer names include: Wal-Mart's Parent's Choice (240 refill or 400 club box), Loblaw's Teddy's Choice (240 refill or 560 box), Sam's Club's Member's Mark (720 box), Safeway (160 refill or 400 box), and A&P's and Metro's Simply Kids (160 refill).

80-count units sold in single or multiple unit packages (such as 160-count, 240-count, 400-count, and 720-count) pop-up style store and private brand wet wipes

LOT **06233 0220197**XXXX through LOT **06253 0220197**XXXX
(includes all sequential lot numbers between 06233 and 06253)
AND

LOT **06233 0220693**XXXX through LOT **06253 0220693**XXXX
(includes all sequential lot numbers between 06233 and 06253)

For more information or for assistance in identifying a package, please contact Rockline Industries at 866-964-3322.

PRESIDENT'S CORNER

Starting with this newsletter, I want to share with you some of the plans we have for the chapter for the next year – and the first plan is around communication. Throughout the year, we receive information from our national office about things such as the infection control policy or newborn screening for CF. We include much of it in the next newsletter – but depending on the timing of the information relative to the next newsletter, that may be anywhere from 2 weeks to 3 months away.

To help us get information to you sooner, we have been using email addresses – and that has been a great help! In addition, it has helped us reduce our costs and our volunteer hours to print, stuff and mail the newsletters. But, we need more email addresses...please share your email address with us! The July, 2007 newsletter will be the LAST newsletter that has a mass mail out – what does that mean? If you do not have email or access to a computer, you just need to call our office and we will continue to mail you a newsletter. But, if you do have email, we

want to become more reactive with the information we get and use your email to send it. So, to continue receiving the newsletter after July, we need an email address or phone call from you by August. We will NOT share your email address with anyone – including our national office – this is solely for our chapter purposes. We will have reminders in the next two newsletters – but why wait, send us your email address today and start getting information quicker!

You can call our office at 466-2265 with your email, or email it to ecfs@telus.net

AN EVENING AT THE CITADEL

The Edmonton chapter of the Canadian Cystic Fibrosis Foundation invites you to an evening of theatrical entertainment, and much more! The "Evening at the Citadel" fundraiser will take place on February 10, 2007 at the Citadel theatre. This event includes a wine and cheese reception, the performance of the play, "The Constant Wife", a Grand Marnier and dessert reception following the play, plus a silent auction.

Constance Middleton is a very rare creature — beautiful, intelligent, and utterly unconcerned with the fact that her husband is having an affair with her best friend. In this classic comedy of manners and mistresses, the delicate balance of love and marriage is upended when a shocking indiscretion is publicly revealed.

Marital misadventures among the privileged class have never been as dangerously irresistible as they are in *The Constant Wife*, penned by the legendary sharp wit W. Somerset Maugham.

"The Constant Wife", a social comedy, has been described as "deliciously witty, an antecedent to the women of *Desperate Housewives* and *Sex and the City*." The cost of this event is only \$55, an outstanding bargain. Tickets will be available at the CF office after December 1, 2006. We'd also greatly appreciate donations for the silent auction for this event. If anyone has restaurant or hotel connections these make great silent auction items! Help us in the fight against CF, and have a fun evening out!

An Evening at the Citadel

Saturday, February 10, 2007

6:45 p.m. - Private Reception -
wine, cheese, door prizes

8:00 p.m. - *The Constant Wife*

10:00 p.m. - Private Reception

- desserts, Grand Marnier

Tickets are only \$55.00 each

Limited number of tickets
available

Phone Cystic Fibrosis Office
at 466-2265

HELP SKELLY FIND A HOME



Skelly is an adorable, loveable, huggable stuffed, cuddly skunk. He is one of a kind, made specifically by Russ Berrie for the Edmonton Chapter of the Canadian Cystic Fibrosis Foundation.

A ten year old girl who spends hours each day fighting the effects of cystic fibrosis came up with the idea of building a skunk because "CF Stinks". The skunk is named for Bill Skelly, founding chairman of the 65 Roses Sports Club in Edmonton.

We are extremely grateful to the Kinsmen and Kinette Clubs of Edmonton who funded this project so that 100% of the money raised will go to research for cystic fibrosis.

Each Skelly Skunk sells for
\$15.00.

Please phone
the Edmonton CF Office at
466-2265 to make your
purchase.

An updated version of the "MRSA Infections In Patients With Cystic Fibrosis — Frequently Asked Questions" document is available through the website for the National office of the Foundation - www.cysticfibrosis.ca.

Infection Control Policy

The Foundation has updated its Infection Control Policy and the information below was forwarded to all Canadian chapters.

An *ad hoc* task force comprised of CF Clinic Directors and Infection Control Specialists, has had an opportunity to discuss issues surrounding infection control, and policies regarding contact among individuals colonised with Methicillin-resistant *Staphylococcus aureus* (MRSA). The members of this ad hoc task force agreed that the following clarification to the Foundation's infection control policy should be added.

Clarification:

- individuals with CF who are known to be colonised with MRSA, regardless of whether or not they are actively sick, shall not attend CCFF-sponsored meetings and events;
- Individuals without CF who are known to be colonised with MRSA, and are actively sick and/or are coughing/sneezing shall not attend CCFF-sponsored meetings and events; and,
- Individuals without CF who are known to be colonised with

MRSA, and are NOT actively sick and/or are not coughing/sneezing shall be permitted to attend CCFF-sponsored meetings and events, on the understanding that, like all meeting participants, they will observe diligent hand hygiene.

To help reduce the risk of transmission of MRSA, it is further recommended that at all Foundation sponsored meetings and events, individuals wash their hands thoroughly with soap and water or with an alcohol-based hand sanitizer, as they enter and leave each session or event. The Foundation is investigating the possibility of providing a modest subsidy for the purchase of alcohol-based hand sanitizer products. Further information will follow in the New Year.

As always, we ask for your co-operation in ensuring that the Foundation's policy on this subject is respected. Please remember that this policy is a "risk reduction" policy, and that there are no guarantees that CCFF meetings and events will be free of MRSA or *B. cepacia* complex. The onus is on those with MRSA and *B. cepacia* complex to govern themselves in accordance with the policy, and not on any other person to enforce the policy.

Raffle

"HUNTER & SEAL"



Original Inuit Soapstone Carving by **Mark Totan**

Value: Appraised at \$1200.00

Draw Date: February 10th, 2007

Tickets: \$5.00 each (pink) or 3 for \$10.00 (mauve)

Available from the CF Office (466-2265)

Draw will take place at the premier presentation of "The Constant Wife" at the Citadel Theatre on February 10, 2007, in support of the Canadian Cystic Fibrosis Foundation.

Winners, if not present, will be notified by telephone.

Must be 18 years of age or older to purchase.

License #243919

Quilting Fabric Needed

Norma Zdunic makes many quilts, donating some for CF craft sales and auctions. If you have any fabric laying in a drawer or cupboard somewhere, and

you are wondering what to do with it, please consider donating it for quilt-making fabric. Cottons are best, but other fabrics work too. Even gently

used men's shirts provide good fabric. If you can help, please bring your fabric donation to the CF Office, and Norma will pick it up here.

Volunteer Opportunity

In June, 2006, our Chapter held its first Motorcycle Run fundraiser. Plans are well under way for a second ride this year on Satur-

day, June 23. The Committee would appreciate having additional members to help with the planning and organizing of this

event. If you can help, please call the CF Office or note your interest on the enclosed Volunteer form.

Sixtyfive Roses: A Sister's Memoir

Heather Summerhayes Cariou was six when her four-year-old sister Pam was diagnosed with Cystic Fibrosis and given only months to live. "Sixtyfive Roses" was the way Pam pronounced the disease that altered the lives of her siblings and parents, who in turn helped alter the community's response to the disease by founding the Canadian Cystic Fibrosis Foundation. With the help of the Foundation, research, and new treatments, the fight to save Pam lasted for years, ending with her death at the age of 26. This beautifully written memoir offers an unsparing eyewitness account of the pain,

hope and valour of a family in crisis as it falls apart and pulls itself together again and again, only to



emerge stronger and more loving. At the heart of the story is the relationship between the two sisters: Pam burdened with crippling terminal illness, and Heather with the anguish of survivor guilt. As they

journey through childhood, adolescence and young adulthood, each struggles for autonomy, yet helps the other learn where to find joy and meaning in a world of pain and uncertainty.

"Rich in detail, loving, funny and profoundly moving, SIXTYFIVE ROSES is a story about fighting for your life and your dreams, in spite of obstacles. It's about loving fearlessly and the choices we make in the name of love. It's about the kind of faith, fortitude and forgiveness we tell ourselves we don't possess, but which is present in all of us."

Copies of the book are available for sale in our Chapter office for \$30.00 each. Please drop in to purchase one or phone if you would like to have one shipped to you.

Chapter office:
St. James Catholic Elementary
School
7814 - 83 Street
Edmonton, AB T6C 2Y8
Phone: (780) 466-2265
Fax: (780) 437-7655

Emily Westwood
ecfs@telus.net

Yvonne Wupori
ecfs.fundraising@telus.net

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

Clinic: University Hospital
(780) 407-6745



Edmonton and Northern
Alberta Chapter

CF Stinks

Calendar

Feb. 10	Bingo
Feb. 10	An Evening at the Citadel
Feb. 16-18	Kin Corporate Cup
Nov. 7	Kin Event for CF at Schanks Athletic Club
Mar. 4	Chapter AGM
Mar. 6	Board meeting

Christmas Craft Sale

On a bitterly cold December 2, our Chapter set up its craft sale booth at the Strathcona Farmers' Market. The booth looked very festive indeed with the display of wooden candles made by volunteer Carey Losinski. Sales were slow at the Market, but our office location in St. James School allowed items to be dis-

played and sold right up until Christmas. To Carey, Norma Zdunic, Jane Filipow, Shirley Rumsey, and Brenda Coyes – thanks for your donated items for the sale. Thanks also to the volunteers who manned the booth for the day – Doris Gordon, Melanie Bouclin, and Jane Filipow. Christmas craft sales

topped \$700.00. On October 28, another miserable day weather-wise, we sold Skelly skunks, Grey Cup raffle tickets, and Frightlites at our booth at the Market. Thanks to the volunteers that day: Esmond Warren, Shirley Warren, Brent Van Dorp, Erica Van Dorp, and Caroline Warren.

Grey Cup Raffle

The Grey Cup raffle raised \$3600 in 2006. Our Edmonton Eskimos didn't win in 2006, but thanks to volunteer ticket sellers, the Edmonton Chapter did! As usual, the money will be used for CF research projects in the Edmonton area. Participants in

the raffle won if their tickets had correct scores for first, second, third or fourth quarters as well as for the final score. A few people contacted us to ask why they didn't receive tickets to sell this year. We apologise to anyone we missed,

and we certainly don't want to do that again. The set-up and distribution of tickets occurred at the same time as staffing was in transition in the Chapter office. Please let us know if we should call on you next year to sell raffle tickets.

Generous Donors – Our Thanks

Throughout 2006, we received many donations, both large and small, both financial and gifts-in-kind. We sincerely thank every business, every family, and every individual who has contributed to the fight against cystic fibrosis with a donation. Here are just some of the many donors whose supported the Edmonton and Northern Alberta CF Chapter in 2006:

United Way of the Alberta Capital Region
United Way of Grande Prairie and Region
United Way of Calgary
Kin Cub of Fort Edmonton
Kinette Club of Wetaskiwin
Kinette Club of Edmonton
Kinsmen Club of Edmonton
Kinette Club of St. Albert
Teammates for Kids Foundation

Eastern Star
Union No. 52 Benevolent Society (Civic Service Union)
Atco Electric (Echo Foundation Trust)
Waiward Steel
Alberta Building Trades Council Charitable Foundation
Edmonton Public School, Teachers' Charity Trust Fund