



CF Connections

Calgary and Southern Alberta
Chapter

April 2011 Newsletter

Breathing life into the future®

Editor's Message:

Happy Easter!! First and foremost, I would like to thank the staff at the children's cystic fibrosis clinic for putting together a wonderful parent info day. Also, I would like to thank everyone who got new/renewed their memberships this year. At the parent info day we raised \$805.00 which is so awesome. But it's not just about the money, it's also our community coming together, and having more members and volunteers for grant applications, sponsorships and networking. So thank you to everyone who participated. If you haven't purchased yours yet, please consider getting a yearly membership, it helps on so many levels. Also for those who renew their memberships, or sign up for a new one, you will receive a new free car magnet to celebrate our new logo and name! On another note, we still need lots of volunteers for our many events in the spring, if you would like to get involved, please contact the office at 403-266-5295. I hope you enjoy this month's newsletter as much as I enjoy putting it together for you ☺

Cara Wiley

2011 CALENDAR OF EVENTS

Coin Boxes - All Year
Parent Information Day - March 12th
May is CF Month
Banner Hanging – May
Mums for Mum - May 5th, 6th and 7th
Shooting for the Cure – May 7th
Casino Event - May 11th and 12th
Great Strides™ Walk – May 29th
CARSTAR Soaps it Up! – June 11th
65 Roses Ladies Golf – June 27th
Friends of CF Golf (Carstairs) – July 4th
Friends Fore CF Golf (Medicine Hat) – July
Ride for the Breath of Life® - September 17th
FrightLites® – October
Calgary Chapter AGM – October
An Evening of Fine Things - November
Wrapping for a Cure - December

KIN EVENTS

High River 10th Annual Dinner and Dance - March 6th
Kin/CF Day – May 1st
Stamper City Kinette 3rd Annual Daisy Chain of Loonies - April 30th
Kinsmen Children's Hospital Home Lotto – May, June and July
Kinsmen pre-parade, Mile of Dimes – July
Kinsmen Wheels, Stampede week – July

Inside This Issue:

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*The deadline for the May Newsletter is Friday
April 22nd 2011*



TO: Cystic Fibrosis Canada Trustees and CF community
FROM: Maureen Adamson, Chief Executive Officer
DATE: March 28, 2011
RE: ADEKs®

Unfortunately, we have recently learned that Axcan Pharma Inc. has discontinued the sale of ADEKs® in Canada due to regulatory issues with Health Canada. There is a limited supply of the product available until depletion.

Axcan has indicated that it intends to seek approval from Health Canada to offer an alternative product in Canada. However, this process may take several months to over a year to complete. Cystic Fibrosis Canada is working with CF clinics and Health Canada to identify an interim solution. We will provide you with more information, as it becomes available.

In the interim, individuals with cystic fibrosis who take ADEKs® or their families are encouraged to contact their clinic to discuss options for a recommended substitute.

We will communicate with you on an ongoing basis as we work with our partners to address this issue expeditiously.

Thank you for your patience.

Insurance for Persons with CF

Accessing life, travel or extended health insurance can be challenging for individuals with cystic fibrosis. To help understand and navigate options that might be available to persons with cystic fibrosis, we have partnered with INGLE Insurance to develop a specialized insurance resource for the cystic fibrosis community. To learn more, visit <http://cysticfibrosis.ingleinsurance.ca/>

Ingle International and Imagine Financial provide access to a wide range of insurance products and information.

Note: The Web site and call centre are intended as a resource for the cystic fibrosis community; however, Cystic Fibrosis Canada cannot guarantee the information provided or that products will be available. Ingle will help individuals navigate the insurance options and assist in finding a product, if one is available. If no product is available, Ingle will explain why and discuss alternatives that may exist.

RBC Foundation supports name logo change.

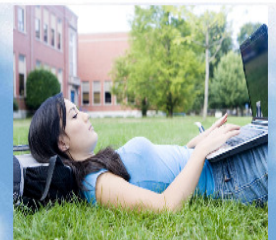
New print materials created with the Cystic Fibrosis Canada name and new logo and translation have been funded through a grant by the RBC Foundation.

"Cystic Fibrosis Bugs: *the good, the bad and the ugly*"

Medical Panel Live Webcast

Participate in our interactive session to learn more about:

- current research on CF bugs
- new therapies to fight infections
- infection control strategies



Saturday, April 30, 2011
10:00 am — 12:30 pm (EST)
(simultaneous translation)

Register at <http://webcasts.welcome2theshow.com/cysticfibrosiscanada2011>



Breathing life into the future™

From your CF Team at ACH

Thanks so much to all the parents and families who joined us on Parent Info Day 2011. We appreciated all your feedback!!! We look forward to planning the next day for 2013.

“tell me and I’ll forget; show me and I may remember; involve me and I’ll understand.”
Chinese Proverb.

3rd Annual Super Bowl Party

The 3rd Annual Super Bowl Party in honour of Scott Nay, was held in Lethbridge. A whopping \$1,436.00 was made at this annual event held by his friends, Trevor Westbrook and Michelle Balderson. Scott was diagnosed with cystic fibrosis at less than 3 years old and unfortunately passed away at the age of 33 years in January 2008 from complications with his double lung transplant. A huge thank you goes out to Trevor and Michelle for this yearly tribute they put together - Scott was very lucky to have had friends as special as you!

Help Cystic Fibrosis Canada help your kids!

A message from a CF mom and volunteer:

Time has a way of creeping up on you doesn't it? My daughter Erin will be 14 in October. It amazes me that it's been 14 years since she was diagnosed with Cystic Fibrosis! Thirteen years ago I joined the Canadian Cystic Fibrosis Foundation by going to a general meeting at the old Children's Hospital. I was nervous about attending and didn't know what to expect..... but I knew I needed to do something to help her.

I have met some wonderful people through the foundation. The ones who have amazed me the most are a few ladies who have been with us for over 20 years while having no family members with CF! They have persevered and stuck with us. They could have easily gone to another cause, but thankfully they haven't.

I am told there are about 200 families in Calgary affected by CF. But I have to tell you, I haven't seen many new faces coming out to help over the past 13 years.

I know how you feel. You work, you're tired, there's always so much to do and so little time to do it. It's easy to sit back and think, "Someone else will do it". But really, who will?

CF doesn't affect as many people as other more common diseases. We are a small community and we have to work hard to get our share of fundraising dollars. The economy is not what it used to be and drug companies have already ceased to produce Ultrase and Adek's due to its small market.

As a parent of a teen with CF I know only too well that it's up to me to contribute. It's up to me to participate in my daughter's race to live. There are many great research projects working towards better drugs and a possible cure for CF. But without funds, the whole process is slowed down. It's as simple as this, how long do you want this to take?

I had coffee with the President of our Calgary and Southern Alberta chapter the other day. I always enjoy visiting with Jeanette Demers Weir because she is always so enthusiastic about finding new ways to raise money. It doesn't matter how busy she is, she finds the time to be involved. I asked her once how she did it. She simply replied: "well, how can I not"?

There are many ways to contribute to our fight against CF. You don't have to be a member of the executive if that intimidates you. You can pick one of our events and join the committee. Or if you have connections to sponsorships we have many events that need sponsorships! The Ladies 65 Roses golf tournament is coming up. Maybe you can get some silent auction items from local businesses. Check with your employer about possible programs that will match your volunteer hours with a cash donation. Get a group of your co-workers to join you in a Wrapping For A Cure shift next Christmas. Get your school involved. Use your hobby or passion and turn it into a fundraiser. Get creative. Give Kirsten a call at our CF office, she has a few projects on the go. I'm sure she would love to have you join her!

My point is, **help us help your kids!** We're in this together! But time is of an essence!

Monique Rodger
Calgary and Southern Alberta Chapter volunteer



**The Kinette Club of Stampede City
3rd Annual Daisy Chain of Loonies**

**When: Saturday April 30th 2011
Where: North Hill Centre**

**We are selling Raffle tickets for \$1.00 each, with
the winner receiving a
\$500 West Jet voucher.**

**Help us create the Daisy Chain of Loonies, by
purchasing a ticket from any Kinette of Stampede
City, or come on down to the North Hill Centre
and join the fun!!**

Proceeds to Cystic Fibrosis Canada



GearUp4CF

Blair Smith will be participating in his first GearUp4CF, a fundraiser for Cystic Fibrosis. Along with 23 other people, he will be cycling from Banff to Vancouver. That's 1200km in nine days! The ride starts on June 18th. Over the past six years, GearUp4CF has raised a total over \$600,000 for Cystic Fibrosis Canada!

Blair is dedicating his ride to his wife Sandra, who had a double lung transplant recently. Blair is also dedicating his ride in honour of all of their CF friends who are either post-transplant, waiting for transplant or lucky enough to have transplant as a thought for the distant future.

Blair will be hosting a fundraising event on Saturday, May 7th to help him reach his goal of \$10,000. Everyone is welcome to attend. Tickets can be purchased in advance, as per below. Saturday, May 7th

Local 002 Public Tavern & Kitchen (2 Richard WaySW)
Tickets are \$20 per person (includes 1 burger and 1 bottle of beer)
Email to buy tickets bsmith@chandos.com

**To read Blair's Bio or for more information
about the ride, please visit gearup4cf.org.**





**FRIENDS FORE CF CHARITY GOLF
TOURNAMENT**

**When: June 18, 2011
Where: Cottonwood Coulee Golf Course
in Medicine Hat.**

**Charity BBQ starting at 11:00am and a shotgun
golf start at 1:00pm.**

**Entry fee will be \$100 and includes 18 hole of
golf, a golf cart, steak supper, a valuable prize
and on course events.**

**The theme this year will be CRAZY 8's! Feel free
to enter as an individual or as a team of 4 or 8 or
more!**



**CLARESHOLM KINETTES
ANNUAL WALK AND ROLL**
SUPPORTING CYSTIC FIBROSIS CANADA



- When:** Saturday, June 4th, 2011
- Where:** Amundsen Park
Clareholm, AB
- What:** A 5km family and community-oriented run/walk/bicycle event; registration includes refreshments.
- Details:** For more information or to register speak with any Clareholm Kinette member or call April (403) 625-4018
- Fees:** \$10 for anyone over 12 years
\$7 for anyone 12 and under

Proceeds to Cystic Fibrosis Canada

MUMS FOR MOM

Is spring really coming? Just in case the snow isn't quite finished, we will once again be spreading some fabulous color to Moms throughout Calgary. We will be selling our potted mums, leading up to Mother's day, with proceeds going to CF and a chance to get out and chat with people about what Cystic Fibrosis is and what we need. I am really excited to say I ordered 1000 plants this year so I would love some help spreading them around!

I will need volunteers to sell plants downtown from 10:30 - 2 p.m. on Thursday May 5 and Friday May 6. We have graciously been allowed to sell plants at the Suncor building (the old Petro-Canada building), Fifth Avenue Place (kitty corner to Suncor), and the third location on Thursday will be Banker's Hall Plus 15, and on Friday, Banker's Court Main Lobby. Our friends at North Hill Center are also supporting us to sell plants there on Saturday, May 7. If you have a buddy or relative - it is a nice way to spend a few hours together. I am also looking for a helper to deliver mums to one or two of the downtown locations around 10:30 a.m., even if they can't stay to sell. We could either meet early on the day or I can drop them to you the night before. The mums are in large boxes of 30 so there is some lifting involved.

Please give me a call at (403)226-2807 or send an email to suey@godfrey-godfrey.ca if you would like to help in any way.

Sue Godfrey

DONATE OLD COINS & SPARE CHANGE TO SUPPORT CYSTIC FIBROSIS CANADA



Support Cystic Fibrosis Canada - Calgary & Southern AB Chapter by donating your old coins and spare change!

Visit us at North Hill Centre's EARTHWEEK EASTER AND ENVIRONMENT event Saturday, April 23, 2011

Satisfy your sweet tooth by visiting our booth and purchasing a delicious jar of yummy jellybeans for \$3, all proceeds to Cystic Fibrosis Canada.

Kids can enter our colouring contest for a chance to win prizes, including passes to the Calgary Zoo!

If you cannot be at North Hill Centre, and would like to donate coins or receive a coin collection box to collect spare change with, contact our office at (403) 266-5295.



65 Roses Ladies Golf Classic Earl Grey Golf Course Monday June 27, 2011

- ❖ Golfers and volunteers needed
- ❖ Sponsorship opportunities available
- ❖ Prize donations welcome

For more information contact the Cystic Fibrosis Office at 403-266-5295 or Visit our website at www.cfcalgary.ca

16th Annual Friends of CF Golf Classic

Planning for the 16th Annual Friends of CF Golf Classic is underway, with this year's date set for Monday, July 4th at the Carstairs Golf Club. This year's registration form is included with this newsletter. Over our first 15 years, we have been able to raise some \$115,000 for cystic fibrosis research and we look forward to another great day with friends of the CF community. Registration fees will remain the same for 2011 at \$150 per player with an \$80 tax receipt issued for all participants. Registration includes: 18 holes of golf, scramble format, lunch, dinner, prizes for everyone. Please indicate on the registration form if you will require a cart. Carts may be rented at the participant's expense.

We look forward to seeing everyone in Carstairs in July! Better weather than 2010 guaranteed!

For registration forms, please visit <http://bit.ly/friendsrego2011>

Matt McWhirter
Chairman, Friends of CF Golf Classic
403.860.6216
mmcwhirter@shaw.ca



Taking Steps to Cure Cystic Fibrosis

Calgary & Southern Alberta communities have two walk locations to choose from this year!

Calgary and Area Great Strides Walk

North Glenmore Park - West End

May 29th

- Registration starts at 10:30am (**new time!!**)
- Walk starts at 12:00pm (**new time!!**)
- BBQ, entertainment, prizes, games and awards ceremony to follow the walk

Online registration for Great Strides is open! Register today, collect \$100 or more in donations and be entered into a draw to win a \$3,000 family shopping spree at Zellers, The Bay or Home Outfitters.

Lethbridge and Area Great Strides Walk

May 29th

Henderson Horseshoes - Group Picnic Shelter

- Registration & lunch runs 12:00pm - 1:30pm
 - Walk starts at 1:30pm
- Refreshments and announcements to follow the walk

Online registration is now **open!!!**

Visit <http://www.cysticfibrosis.ca/en/GreatStrides/index.php> to register or sponsor an individual, or to join a team.



Cystic Fibrosis Canada

Breathing life into the future®

Lunch and Learn May 10th 2011

Lethbridge Public Library Main Branch in their Board Room.

Event will start at 12pm with lunch provided.

Registration is required by May 6th by calling Marlene at 403-360-9116



Carnage in Coaldale Demolition Derby

Saturday, June 4th, 2011

Spectators \$5.00 - 10 and under FREE



For Registration Info Contact:

Jay 403-359-2678 or Lee 403-312-7022

Or email contact@coaldalekismen.com

Full size and mini cars

Cars to be Safety Tech'd by 11am SHARP

Location will be south of Coaldale on Highway 845 just past the Canal (West side of road, follow signs)

For more details or to download a registration package, please visit our website at www.coaldalekismen.com

Rain delay date is June 11, 2011



UPCOMING VOLUNTEER OPPORTUNITIES

Please contact Kirsten at the office if you are interested in any of the volunteer opportunities below.

EARTH WEEK, EASTER AND ENVIRONMENT

Saturday, April 23, 2011 - North Hill Centre

Cystic Fibrosis Canada will be at North Hill Centre for this one-day event; we will be selling jars of jelly beans, conducting a coin collection and old coin donation campaign, along with a colouring contest and Great Strides promotions.

Event runs 10am – 4pm, volunteers needed 12pm – 2pm and before and after for setup.

Office Help – Special Projects

Volunteers are needed to help out at the office on special projects during the month of April. Tasks such as data entry, folding, labelling and outbound phone calls.

If you can spare 1-3 hours to volunteer between 9am – 5pm on Mondays, Wednesdays or Thursdays please contact us.

Small groups of 2 or 3 people would be beneficial for some of the special project work.

Great Strides Walk May 29 – North Glenmore Park

Do you want to be a part of TEAM Great Strides? Volunteers are needed in the following areas:

- Logistics Team (setup/take down)
- Food & Beverage Team
- Promotions Team
- Organizing Team
- Recycling Team
- Welcome Team
- Sponsorship Team
- Prizes Team

Prizes and Donations Team

Our Chapter has several events coming up between now and June which require a variety of prize donations of all shapes, sizes and values.

Volunteers are needed to help solicit prizes and donations for events such as 65 Roses Ladies Golf and Great Strides.

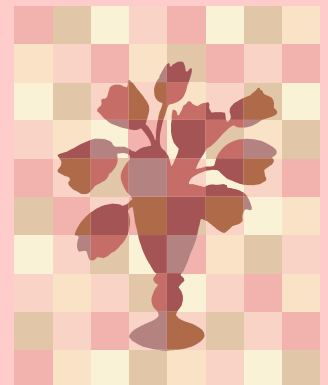
Events Calendar Guru

A home-based volunteer opportunity, we are looking for someone to post and maintain our Chapter event listings on cysticfibrosis.ca.

All of us at the Calgary and Southern Alberta Chapter of Cystic Fibrosis Canada offer our deepest sympathy to families who have recently lost loved ones. We extend our sincere thanks to those who have sent donations in memory of:

Frieda McClaren
Lily Macnab.

(Lily' Macnab was our Office Coordinator who started in the late 1980's and stayed with us until the late 1990's. CF was her most treasured charity and we remember her fondly.)



DATE: _____ FAMILY NAME: _____

ADDRESS: _____

CITY: _____ PROV: _____ POSTAL CODE: _____

PHONE: _____ EMAIL: _____

CF Connections Monthly Newsletter (Included with membership): Email Canada Post

Adult Member #1	Adult Member #2	Children	Age:
Name:	Name:	Name:	
Daytime #:	Daytime #:		
Business #:	Business #:		
Cell #:	Cell #:		
Fax #:	Fax #:		
Email:	Email:		

Enclosed is my membership registration fee of \$20

Enclosed is my tax deductible donation of \$35 \$50 \$100 \$500 Other _____

Total: _____

METHOD OF PAYMENT

CHEQUE (payable to: Cystic Fibrosis Canada)

VISA

MASTERCARD

CARD #: _____ EXP: _____

SIGNATURE: _____

Optional Information:

How did you hear of our organization/cystic fibrosis? _____

Are you interested in volunteer opportunities with the Chapter? Please indicate:

- Organizing an Event Placing Coin Boxes General Volunteer Publicity
 Presentations Events Great Strides™ Walk Office
 Chapter Executive Other (Specify): _____

Submit membership form by mail, fax or email to:

CALGARY & SOUTHERN AB CHAPTER
1130F 44 Ave SE Calgary, AB T2G 4W6
T 403-266-5295 F 403-262-7556 E inf@cfcalgary.ca
www.cfcalgary.ca www.cysticfibrosis.ca

Trevor Phillips

Better get to know our Children's Clinic Liaison and CF Adult

10 things you may not know about me are.....

1. I have Cystic Fibrosis
2. I am married
3. In my lifetime, I have taken over 300,000 pills
4. I enjoy hiking
5. I have had over 12 surgeries
6. I like to vacation in British Colombia
7. I graduated with honours from engineering
8. I used to be a door-to-door salesman
9. My favourite memory of university is Campus for Christ
10. I have 2 brothers and 1 sister.



FREE new kite car magnet!!!

Cystic Fibrosis Canada - Calgary and Southern AB Chapter

**1130F – 44 Avenue SE
Calgary, Alberta T2G 4W6**

**Tel: 403-266-5295
Fax: 403-262-7556**

www.cfcalgary.ca



Calgary & Southern AB Chapter