THE EDMONTON CYSTIC FIBROSIS CONNECTION

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Canadian Cystic Fibrosis Foundation
Edmonton & Northern Alberta Chapter

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National Annual General Meeting

In April, CCFF's annual AGM was held in Cornwall, Ontario. Patti Magnan and Salima Nurani, board members, and Emily Westwood and Yvonne Wupori, office staff, attended from the Edmonton & Northern Alberta Chapter. Before the actual AGM and conference, Salima attended "Brand Camp" to join with other representatives to discuss vision and market branding strategies for our foundation. As stated by Dr. Yves Berthiaume, "a mission is not a vision. Our vision was to have more adults than children with CF. This vision has been achieved." Brand camp discussed a new vision, "for adults to live a normal life, not living attached to medical treatments". Emily and Yvonne participated in a one-day workshop for chapter personnel.
The conference theme, Mission Possible, addressed both the progress that has been made as well as our goals for the year 2010, the Foundation's 50th anniversary.

Highlights for progress include:

Last year was the best year ever for fundraising by our Foundation.
Our Foundation will be receiving royalties from a patent developed from research which we funded. The expectation is that it will realize approximately $200,000 annually until 2021.
Newborn screening for CF was adopted in two Canadian provinces, first Alberta, then Ontario.
Another breakthrough from CCFF funded research, a project has produced a vaccine for B. cepacia in mice and secondarily they have developed a mechanism to weaken these drug resistant bacteria so that it can effectively be killed, again in mice.
Progress is being made on the Canadian (CF) Patient Data Registry (CPDR**).** This is a vital research resource and is also very important in the development of good quality of care for CF patients.

Plans for the next three years include:

Increasing the investment in CF research
Providing assistance towards bringing new therapies for CF to market
Strengthening our foundation with a new CCFF vision and brand
Improving care and treatment for Canadians with CF

(*With thanks to George Cornwell, president of South Saskatchewan Chapter)*

CF Sahara

Blain Davis, father of a son with CF, is engaged in intensive training in preparation for a 250 km race in the Sahara Desert in October. The event is a self-supported footrace to raise money towards finding a cure for CF. The race consists of six stages, lasting 7 days, with distances ranging from 10 to 50 miles (20-80 km) per stage. There will be checkpoints positioned along the course every 7 or 8 miles (10-12 km). Competitors must carry all their own food, gear and clothing needed to complete the 150 mile (250 km) course.
Blain has produced a DVD which shows him in training for this marathon. **If you know of anyone who would be interested in making a donation to CF Sahara in support of Blain's efforts**, please call and we will send them a package with the DVD.

Breath of Life® Award Winner – Sue Zukiwsky

At the June 5 meeting of the Chapter board, President Caroline Warren presented Sue Zukiwsky with the Breath of Life award as a token of thanks for all she has done. The award recognizes outstanding and long-term contributions to a CCFF chapter in a leadership capacity. Sue has been a chapter volunteer and member of various committees for many years, and has served as both Vice President Fundraising, and as President of the Chapter. She continues to serve our chapter as a volunteer and committee member and as our Past President.

Our third annual Great Strides walk, held Sunday, May 27, was the most successful ever.
Based on the previous 2 years, the budget for this event was set to $21,000.
Our current count suggests that we will almost double our expected income! This year's Walk was held in West Edmonton Mall.
Next year we will be moving to an outdoor venue, Gold Bar Park, where we expect to be able to continue making this a family event as well as an important fundraiser for the fight against CF. We do need new committee members to plan this event for next year, so please call to sign up now!

PRESIDENT'S CORNER

As many of you know, this has been a tough time for our chapter – we have lost several friends – family members really. Some of these very special people battled the effects of cystic fibrosis every day. Some of these very special people supported those that battled CF. Proof of their dedication to the fight against cystic fibrosis is seen in our memorial donations, a number that is always too high, this year being no exception.
Dealing with these times is always a very personal struggle – no one can really tell you how to handle it, you have to find your own path. I've watched several people cope with amazing strength and passion for those they've lost. I've seen a young man put on several fundraisers in his girlfriends name within weeks of his loss. I've seen a lady, who was extremely active on one of our committees' with her husband; continue on that committee - without missing a beat - after the loss of her husband. I've seen a man become the top fundraiser for an event months after his friend lost his battle to cystic fibrosis.
These people, and so many others like them, are the absolute power of our volunteers and supporters. Our chapter is having an amazing year financially – in part due to these people's dedication. To each of you, my heartfelt thanks – not just for what you have done, but what I know you are still doing. You have already made a difference.
Caroline

Clinic News

Thank you to all of you who participated in the research "Mapping and Isolation of Genes Influencing Severity of Disease in Cystic Fibrosis" (or the CF Gene Modifier project). As you may recall there was a $10 per blood draw you were offered and you could choose whether you wanted the money or donated it.
$1370 was given to the CF Foundation Edmonton chapter and $2280 to the clinic. Thank you as we work together to help those with cystic fibrosis.

Jacob Hofer works part-time driving a mixer truck for Camrose Concrete. He and his brother John each donated money raised from ten hours of work to the CCFF. The owner of Raven Rock, the company they work for, provided a matching donation. Jacob's children Matthew and Hannah are holding a cheque for $1000.00 for the CCFF.

On Saturday, May 5, The Wetaskiwin Kinettes raised $1365 for CF by providing rides in a monster truck provided by Bruce Urban of Western RV.

Tips for Summer

"*Summer Tips for CF Care"* and *"Travel Tips for Persons with CF"* are two brochures published by our Foundation to assist persons and families with CF. Both brochures are available on the foundation website www.ccff.ca by clicking under "Information designed for you" on to "Persons with CF".

Run for the Lung

26 runners and walkers joined the 2nd Original Joe's Run for the Lung event on Sunday, June 10, 2007. The Run began and ended in front of the Original Joe's Restaurant & Bar location in Terwillegar. The 5K race (or run or walk!) was followed by an award presentation and a complementary barbecue. The first Run for the Lung was organized by a friend of Jessie McQuitty's. When 65 Roses Sports Club chairman Rob Sokil and staff from Original Joe's planned this year's Run, the event was again intended to honour her. Sadly, Jessie became very ill and passed away before June 10 so we ran in her memory.
While the number of participants was small, the event was a wonderful successful financially, raising $10, 260.00 in total. Many thanks to the participants who collected pledges and ran, walked, or rolled (in a wheelchair). Also many thanks to Original Joe's, Sokil Express Lines, and Avanti Salon and Spa for corporate sponsorship, and to the volunteers.

22ND ANNUAL CYSTIC FIBROSIS ROSE & THORN MIXED CLASSIC 2007

The 22nd Annual Cystic Fibrosis golf tournament has taken on a new look from the tournaments of past years. The committee gave a lot of thought to the suggestions made from golfers at last year's event, the 65 Roses Ladies Classic. This year the tournament will be a mixed event. The Edmonton Chapter has always been family oriented and it was felt that ladies might like the opportunity to play with their spouse, son, nephew, father or just a special someone. Ladies only teams are encouraged to register as well.
Entry fees are $220.00 per golfer and the cost includes your cart, breakfast, green fees and lunch as well as each player's mulligan. At the time of writing this item, there are still some spaces left for golfers as well as for sponsors. Please contact the office for more information.

Monday, August 20th, 2007
The Links Golf Course, Spruce Grove

Registration $220.00	7:30 am
Continental Breakfast	7:30 - 8:30 am
Shotgun Start	8:30 am
Buffet Luncheon	1:30 pm

Custom Motorcycles on Display

Two Airgas Chopper motorcycles, designed and built by Orange County Choppers (OCC) using Airgas gases and hardgoods, have begun their nationwide tour. Airgas is an official supplier of cutting and welding gases, welding consumables, and other industrial and MRO supplies to OCC, the nationally known designer of customized motorcycles.
One chopper, featuring a gas tank that resembles an Airgas cylinder, reflects the proud history of Airgas with its "old school" design. The other bike represents the bright future of Airgas, with its sleek, streamlined frame. The two choppers will be on display in Edmonton all day on July 30, 2007 at the Airgas Canada location, 15515 – 115A Avenue. Come and see!

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Edmonton and Northern Alberta Chapter

CF Stinks

Calendar

July 20	Go for Green Hole-in-One Challenge – Katch Kan Canada
July 30	Orange County choppers tour – Airgas Puritan Medical
July 31	Chapter Board meeting
Aug. 1	Akita Drilling golf Tournament
Aug. 20	Rose & Thorn golf tournament
Aug.29-30	Casino
Sept 4	Chapter Board meeting
Sept. 11	Parent Support Group (1900 hrs @CF office)
Sept 29	Fight for the Cure (pro wrestling) at Beaverlodge, AB
Sept 30	Fight for the Cure (pro wrestling) at Bezanson, AB
Oct. 2	Chapter Board meeting
Oct. 9	Parent Support Group

"Ride for the Breath of Life" Motorcycle Run

More than 100 motorcycle riders came from Edmonton, Drayton Valley, Barrhead, Ponoka, Red Deer, Calgary and other places in Alberta to participate in our 2nd "Ride for the Breath of Life". Riders gathered at the Husky station at Acheson, northwest of Edmonton, to register and to hear special guest J'Lyn Nye from Global TV. The riders who had assembled there drove a scenic route west and south of Edmonton through the Pigeon Lake area to the community hall at Falun. At the same time, a second group of riders assembled at the Co-op in Airdrie and made their way north to Falun.

J'Lyn Nye and Deb Grey thank John Luchyk from Drayotn Valley for his outstanding fundraising for the Motorcycle Ride and the fight against CF.

At Falun, bikers enjoyed a BBQ'ed bison burgers complements of Jack Zenert and the Bison Producers of Alberta and all the fixings complements of Falun Co-op and Joan Losinski and her crew of volunteers from Wetaskiwin. Former MP Deborah Grey emceed the program. Prizes were awarded to highest fundraisers as well as in a few other categories. The top 3 fundraisers brought in $5200 (hooray Drayton Valley!), $3000, and $2500 in pledged donations. The Rock Riders, a group of bikers who came up from Calgary, received the Carey Losinski trophy for having the most bikers from one group.

VOICES OF HOPE

Condolences go out to the family and friends of Brianna Drake who passed away April 7, 2007
Brianna got a new lease on life when she got her transplant in June 2002.
Brianna served as the Western Vice-Regional Representative on the Adult CF Committee from 1999-2000, and as the Western Regional Representative in 2001. She will be remembered for her feisty spirit, brilliant mind, wittiness and love of animals. She was very creative and loved to sew and write music.

On May 16, 2007, Jessie McQuitty passed peacefully in her sleep. In 2004, Jessie made headlines when she received a living donor lung transplant from her mother and aunt, the fourth one ever done in Canada. She will be remembered for her smile, determination and love of life. Condolences go out to her extended family and friends. In Jessie's own words
Breathe...Laugh....
Love...Cry...Dream...Wish...Sleep...
Live...Hope...Smile