

April — June 2009 Issue 44

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BLAIN IS RUNNING AGAIN

Remember Blain Davis who ran 250 KM in the Sahara Desert in 2007 to raise money for CF?

He is running again! This time it's 250 in the Gobi Desert.

Blain is the father of Jack, and this is what he says about his son: He's 4 years old, full of energy and life. He loves to wrestle with his dad and colour with his mom. On the outside Jack looks like any other 5 year old boy. However, on the

inside there is a battle for his life. Jack has a fatal genetic disease called Cystic Fibrosis or CF. It is a disease that primarily attacks his lungs and digestive system. Three times a day, Jack endures a 1 hour session of inhaling medications and physiotherapy to help keep his lungs free of infection. He



Blain at the 2007 Sahara race

takes over 20 pills a day to help him digest his meals.

As a father of a son with a fatal disease, I struggle to find something tangible to help my son. My wife and I are diligent in giving him therapy and medication. But I have found something more that I feel I can do - RUN. I'm running through the Gobi desert in June 2009 to help raise research money to find a cure for Jack, CF and for

the thousands of other children who have this disease.

To follow Blain's progress, check out his website, www.gobi4cf.com. Blain is still looking for sponsors and for donations. If you are interested in supporting him or if you know someone else who might, follow the links on his website.

CFAR UPDATE

For over a year, our chapter has been working to plan and present a major event, one which is more than just a fundraiser, one

which can grow to become our signature event in Edmonton. There have been many bumps in the road toward getting this event off the ground.

However, we now have a date and a location for Year One. CFar will be held on **Sunday, September 13th at Fort Edmonton Park** and will be geared toward families and/or teams. Registration

will cost \$160 per team, but this fee will be waived for teams which collect over \$300 in donations. Participants will register at the entrance to Fort Edmonton Park at 2:00 in

the afternoon, gather at the Hangar, and on the "Go" signal, they will disburse throughout the park to solve puzzles, participate in specific challenges, and to answer questions. Following the Amazing Race,

participants will enjoy a BBQ and a whole variety of family entertainment and of course there will be prizes for the winning team in the race. Mark September 13th on your calendar and plan to join us for a day



22ND ANNUAL NORTH AMERICAN CYSTIC FIBROSIS CONFERENCE

Highlights of the 22nd annual North American Cystic Fibrosis Conference (NACFC) 2008 were presented by Joan Tabak, Josette Salgado, and Dr. Zuberbuhler at the Annual General Meeting March 1, 2009. Topics covered included newborn screening for CF, prevention of infection as key to preservation of lung function and better health of CF patients, and a snapshot of the most recent drugs in development for the treatment of CF.

I will begin with a discussion of the presentation on newborn screening and discuss the other topics in later editions of the newsletter.

Very detailed PowerPoint presentations of the topics are available at the NACFC website (<http://www.nacfconference.org/>) under the Plenary Archives link. Additional information on newborn screening was obtained from the Canadian Cystic Fibrosis Foundation and from Moskowitz et al, *Genetics in Medicine* 10(12):851-868 Taking the Battle to Extremes: Healthy Starts with Newborn Screening

P. Farrell, University of Wisconsin-Madison (www.research.med.wisc.edu/farrell/)

Newborn screening (NBS) involves pre-symptomatic detection and diagnosis of disease in newborn infants. NBS is conducted throughout Canada. However, the number of conditions screened for varies from province to province. Currently, Alberta, Ontario and Saskatchewan screen newborns for cystic fibrosis (CF). In 2008, British Columbia announced it will add CF to its screening program, and plans to start in fall 2009. For CF, it begins with measurement of immunoreactive trypsinogen or IRT in blood obtained from a newborn. IRT levels are elevated in newborns with CF, regardless of predicted or actual pancreatic sufficiency status.

The second step of screening involves either a second IRT test approximately one to two weeks after the first measurement (IRT/IRT) or performance of CFTR mutation analyses in newborns having an initial IRT concentration greater than a predefined cut-off (IRT/DNA). Infants with a positive newborn screen are then referred for diagnostic testing (sweat chloride testing and/or molecular genetic testing of the CF gene).

Benefits of newborn screening include early prevention of malnutrition, ability to pre-empt chest infection, and ability to obtain social support and genetic counselling.

Risks of newborn screening may be acquisition of infection through frequent clinic visits (reduced chances if proper infection control measures are in place) or stress associated with waiting for results or if false positive results occur.

The Canadian Cystic Fibrosis Foundation favours NBS since "early diagnosis and early treatment for CF have been shown to reduce hospitalizations and increase longevity, and have also been shown to result in improved height, weight, lung function, and a better start in life. Without newborn screening for CF, most people with the disease are not diagnosed until they show symptoms. By that time, early damage to the lungs and digestive system may be difficult to reverse."

In Edmonton, last year, of the 20 newly diagnosed CF patients, 8 were detected from newborn screening and the full genetic test is now available. For further information, a brochure on newborn screening is available from the Canadian Cystic Fibrosis Foundation website at (<http://www.cysticfibrosis.ca/pdf/Newborn%20ScreeningE.pdf>).

PRESIDENT'S CORNER WITH ALAN BARTMAN

We are definitely not slowing down in our efforts to fight CF, not even for the recession. The last year was another great one for the Edmonton and Northern Alberta Chapter. We had many successes with fundraisers – some new and some returning but all successful in both fundraising and awareness.

This next year promises to be another busy one for the chapter. We have our bi-annual Casino in June and are already working on 2

new exciting fundraisers namely CFAR (Cystic Fibrosis Amazing Race) and the new CF Spectacular (Night at the Mayfield Dinner Theatre). There are also several other new fundraisers in the works and that's in addition to the 20+ regular fundraisers we do each year. We held our Annual General Meeting for the chapter on March 1st at the Kinsmen clubhouse and this year it was followed immediately by our parent information session. Both

were a great success and it was nice to see a strong turnout.

I would like to welcome Stacy Hipkin to the board as a new Director at Large, and would also like to thank the rest of the board for continuing on this year with the chapter.

Thank you all for your support of the chapter over the last year and we all look forward to another prosperous year raising funds and awareness for cystic fibrosis research.

RIDE FOR THE BREATH OF LIFE

On Saturday June 20, 2009, many will participate in our Ride For The Breath of Life motorcycle ride.

The combined efforts of participants and volunteers will bring us one step closer to reaching the ultimate goal: a cure or an effective control for cystic fibrosis.



All money raised through pledges and donations will be used by the Canadian Cystic Fibrosis Foundation (CCFF) to fund cystic fibrosis research and treatment programs at 38 Canadian CF clinics and five transplant centres.

SMILES FOR LIFE

Up until June 30, you can get your teeth whitened at Dr. Timothy Mahoney's dental clinic in Wetaskiwin through the Smiles for Life campaign. At the reduced cost of \$250.00, you will get the whitening trays and gels to get your whiter teeth and you



get a tax receipt from the Smiles for Life Foundation for the entire amount. The money raised is donated to the Edmonton chapter of the Canadian Cystic Fibrosis Foundation. We'll be smiling too because every bit helps as we keep looking for improved treatments for CF.

CHAPTER AGM AND INFORMATION SESSION

On Sunday, March 1, we held the Chapter AGM and a Parent Information Day at the Kinsmen River Valley Place. The AGM concluded with the presentation of several awards. President Allan Bartman presented the Ron Moore Award to Darlene Bouclin. This is the highest award in our chapter and it is given to recognize individuals who have demonstrated exceptional dedication to fighting CF through on-going work to fund research and raise public awareness. As the award plaque says in a quote from Ron Moore, Darlene is able to "give life all you've got." She has been very active in many roles in the chapter for many years. Her most recent project was chairing the organizing committee for the Ride for the Breath of



Darlene Bouclin,
winner of the Ron
Moore Award

Life Motorcycle Ride.

The Volunteer of the Year award was presented to Julie Mitchell, currently serving as secretary on the chapter board, chair of the new CF Spectacular: Dinner Theatre event, and on several other event committees. Certificates of Appreciation were also announced for several people who have made a unique and significant contribution to our chapter recently. The certificates this year went to Lululemon Athletica, Dave Robinson, and Lisa and Shawn Grono. Nurse Joan Tabak, Dr. Zuberbuhler, and Josette Delgado all spoke at the Information session. Thanks to Sherri Selby, you can read about some of the information they shared in her article in this newsletter, "Highlights of International CF Conference."

June is Crazy

The month of June is very, very busy – both with our own and with third-party events. If we have missed calling on you to volunteer to help with events, but you are interested in helping, please phone or e-mail the CF office to let us know. Our volunteers will be really stretched to keep up in all the places where we are needed in June. Phone Emily or Kathy at 780-466-2265, e-mail ecfs@telus.net, or send in the membership/volunteer form enclosed with the last issue of the newsletter. The membership and volunteer form is also available on our website, www.cfedmonton.ca.

CITIE BALLET SHOWS GREAT COMMUNITY SPIRIT

On Sunday, February 22, 350 people enjoyed more than 20 dance numbers performed by a dozen dance studios from Edmonton. The show was a mix of ballet, lyrical, contemporary, and jazz numbers, with a special performance by Tara Williamson and Kelley McKinlay from the Alberta Ballet. The show highlighted cystic fibrosis and the challenges faced by those with CF. The final number, "Angels", was dedicated to those with CF and was accompanied by Aura, a trio of 13 year old girls from Edmonton.

This amazing show raised over \$6,000 for cystic fibrosis and provided a great venue to educate people about cystic fibrosis who would not normally know much about

it. Many thanks to the dancers that participated and to all those that attended. A huge thank-you to Citie Ballet and Francois Chevennement for all their hard work to pull this wonderful event together and for helping us to win the fight



FRENCH FLING: A WINE TASTING EXPERIENCE

On Friday, February 27, 2009, over 260 people attended the 1st Annual Wine Tasting event that was sponsored by our local Edmonton Kinsmen Club. It was a huge success, raising \$17,000 that will help to fund research to find a cure or control for cystic fibrosis!

Special thanks to Nick Lees who came out to emcee and to Leighton Sorenson who was our live auctioneer for the evening. We also want to thank our special guest and friend, J'lyn Nye, who has been a great supporter of raising funds and awareness for cystic fibrosis for many years. She brought in a great

amount of money on this evening through the "Dinner with J'lyn Nye" auction item. The lucky bidder and seven friends will spend an evening at Characters "Fine Dining" enjoying the fabulous food and wine.

The evening would not have been possible without The Edmonton Kinsmen, all of our great volunteers and three fantastic ladies who helped put the evening together: Paulette, Denise, and Laurie. Thank you to all of the sponsors and supporters of this event! We expect to hold the same event again next year, so watch for further information in the fall.

Thank You

Over and over we find ourselves filled with gratitude for the wonderful individuals, families, and businesses that help us raise money to support the fight against CF. We would like to enhance our expressions of thanks with something special. You can help if you

Thank You

are the parent or grandparent of children who love to make and share their art. Collect your child's artwork and send it off to us. We'll look for a sponsor for inexpensive mats and frames, and we will use them to say a most heartfelt thank you.

Thank You

ABC IS FOR . . .

ABC is for Amazing Big-hearted Children.

Two junior high schools have organized fundraisers recently on behalf of helping people with cystic fibrosis. Needless to say, we are very impressed with how they combined their energy, their generosity, and their sense of fun to create events that they enjoyed themselves and which at the same time reached out to care for others.

In December, **Gerard Redmond School** in **Hinton** held a weekend wake-a-thon, which raised \$8500!! Wow! Chanda Guenette drove from Edson to attend the school assembly on our behalf. She

spoke briefly about CF and accepted the cheque on behalf of the Foundation.

Then in February and March, **Clover Bar Junior High** in **Sherwood Park** ran several challenges (best skit, holding arms in buckets of ice water the longest, running races while holding a fish in one's teeth, etc.) to raise \$1,468.41. At their assembly, students listened very attentively to Blain Davis as he told his story about having Jack diagnosed with CF and about his Sahara Desert Ultramarathon.

Thank you to the students, parents, and staff of both schools.

2009 NATIONAL ANNUAL GENERAL MEETING

This year's annual general meeting of the Canadian Cystic Fibrosis Foundation will run from April 30 to May 2. This year the Charlottetown, PEI chapter is our host. Along with our president, Allan Bartman, two additional board members and our office staff will be attending the business meetings, workshops, and the medical /scientific presentations which fill the conference agenda. If you would like to listen to the medical/scientific presentations, you can do so from home. See the information below.

**CCFF LIVE
WEB CAST**

Saturday
May 2, 2009

The Canadian Cystic Fibrosis Foundation invites you to participate in our Web cast during the Foundation's Annual Meeting and Conference. Web participants will have the opportunity to ask panel members questions and make comments during the presentations.

MEDICAL/SCIENTIFIC CONFERENCE
9:00 a.m. – 11:20 a.m. [\[Atlantic Daylight Time\]](#)

TTopics: Breathe (Basic Research and Therapy), Alternative channel pathways in CF treatment Update, *B. cepacia* research update, infection control

LIVING WITH CF
1:30 p.m. – 4:30 p.m. [\[Atlantic Daylight Time\]](#)

TTopics: Sinus Care, Employment Issues, Personal Transplant Stories





Canadian Cystic
Fibrosis Foundation
Fondation canadienne
de la fibrose kystique

To register visit www.cysticfibrosis.ca

Pour s'inscrire, visitez www.fibrosekystique.ca

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Edmonton and Northern
Alberta Chapter

Calendar

April 2009 – July 2009

- Apr. 7 - Chapter Board Meeting
Apr. 15 - Hockey Draft entry deadline
Apr. 30 –
May 1 - National Annual General Meeting, P.E.I.
- May - Mail campaign mailout
May 2 - Kin CF Day
May 5 - Chapter Board Meeting
May 31 - Great Strides Walk
- June 2 - Chapter Board Meeting
June 5-7 - Alberta Cycle Orange County Chopper fundraiser for CF
June 8-9 - Casino
June 19 - Advocis golf tournament for CF
June 20 - Ride for the Breath of Life Motorcycle Ride
June 20 - World Health Club Aerobathon for CF
- July - Akita golf tournament for CF

REFLECTIONS ON NINTH TRANSPLANT ANNIVERSARY

I am celebrating my 9-year anniversary since my double lung transplant March 19, 2000:

Wow, has it been that long? I recall when I first was “listed” – that is, having gone through the pre-transplant work up to determine if I would be a suitable candidate – how depressed I was that I had gotten to this state with my health and concerned about the wait for new lungs (average 2 ½ years wait) – would I hold that long? 7 ½ months later, I was the second choice for transplant – the first person declined. I even remember that my husband and I were not 4 blocks from the hospital in a taxi after a night out for supper when we got the call. We raced to the hospital and made ready for surgery. I expected a “dry run” whereby I would wake up with the same old lungs because the fragile donor lungs were no longer healthy. Instead, I woke up attached to tubes and monitors and a new clamshell shape scar on my chest. After 18 days I was back home, taking a whole new set of drugs, and rehabilitating such that I even had to learn to cough again. I went from FEV1 of 26% to an FEV1 of 100+ %, which has been miraculously maintained over the years. I have been able to hike and travel, obtain a masters degree, teach kids and now work as a technician part-time in a lab at the university.

What is the secret of my success? Most certainly, the top-of-the-line care I received from the CF and transplant teams, and the support of my husband and family helped greatly. Do I have good genes? Was it because I wasn't in a more severe state of lung function prior to the transplant? That I also did not have to wait so long for a transplant

so that I was in better shape to withstand the surgery? Was it because I was strong enough that I didn't have to go on bypass during the surgery, improving the odds of recovery? That my donor and I were virus free, reducing the need for post-transplant anti-viral therapy? That I recognize that there are responsibilities for keeping healthy after transplant? Bottom line is I don't know except that the stars have aligned such that I am still here, alive and kicking.

What could I suggest to others? First and foremost, I would love it if lung transplant were not in the cards for treatment for CF. Instead, wouldn't it be great to inhale the corrected gene that fixes everything, no surgery required, or if those surgeons really need something to do, to be able to grow new lungs in the laboratory from our stem cells after they were corrected for the defect. For now though, I would hope that people with CF would be able to keep their lungs as intact and healthy as possible for as long as possible, to act sooner rather than later when an infection starts, to use the oral or inhaled antibiotics to the completion of the dosage regime (and not quit beforehand because you feel better) in order to prevent bacterial resistance, to keep up with the physio or physical activity and all those things the doctors, nurses and parents have said. And believe me, I do really understand how onerous some of these tasks can be, especially when your normal friends don't have to do all these things. Having CF does not mean that there are things you can't do, it's that you usually have to do more to be able to do the things you want to do. There is also hope for better treatments for CF in the near future.

IN MEMORY OF CHARLENE . . .

Condolences go to the family and friends of Charlene Piccolo. She will be remembered for her bright smile, sparkle and kindness. Her children were the lights of her life and the love her life was her husband, her high school sweetheart.
Breathe easy Charlene