

The Canadian Drumbeat



Canadians Abreast

December 2008

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Editor: Frances Halperin

President's Message – Darlene Prager

I have just completed another year as your president and it has been my honour and privilege to be associated with such inspiring, motivated women who are celebrating life to the fullest.

Another season of fun, camaraderie and achievements has come to a close and we're looking to 2009 to be yet another equally successful year for Canadians Abreast.

How time flies. It's been some time since our last newsletter and I've missed it. Because our membership is spread from coast to coast, The Canadian Drumbeat is a vital link in keeping members connected. While we may be many miles from each other,

I feel close when I read your personal stories and interesting contributions.

Keep this vital link alive by contributing your stories and information for all our members to read.

Talking of time flying . . . Did you know: Canadians Abreast has been active for six years? Let's take a moment to look back at what we've accomplished:

- We've become a registered charity
- We've travelled internationally to New Zealand, South Africa, Germany, Singapore and Australia
- We've participated in many festivals in both Canada and the United States.

• Crews have travelled to Whitehorse in 2007 and 2008 to compete in the World's longest canoe and kayak race, paddling for 746 km from Whitehorse to Dawson City through our country's remote and magnificent wilderness.

This fundraising adventure helped purchase diagnostic equipment for the new hospital in Iqaluit, Nunavut. Over \$48,000 was raised by the crews and that was a large part of the total funds raised.

What will we be doing in 2009? You'll be the first to know!

Paddles up!

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Canadians Abreast's Executive Members for 2008-2009

President: Darlene Prager
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- **British Columbia**
Lou Moreau
- **New Brunswick**
Joanne Belliveau
- **Nova Scotia**
Anne Harland
- **Ontario**
Jacquie Brand & Tammie Szabo-Fleming
- **Quebec**
Josette Poliquin

Halifax 2008 by Kathy Ng



When I offered to take on the role as Manager for Halifax, I said to myself "how am I going to do this ... I don't know who's on the team. Where do I begin?" Well, you know what ladies, when you just put it out to the universe, believe me, incredible things happen! After 8 months, I spent time with the most incredible bunch of strong, fun, fantastic, supportive, innovative and beautiful women of all! I got to meet great gals from different provinces throughout Canada. How cool is that???

A well put together practice by Marlene was followed by our song practice and assembling our costumes. At the Meet & Greet Bosom Buddies gave everyone travel bags filled with goodies. Karen Lavigne was thrilled when we presented our Circle of Hope pendant and gift bags (containing various city pins and gifts assembled by our gals and supporters. It was a delightful evening as we enjoyed delicious nibbles but, with so many people, the food vanished almost instantly! So many people! We were greeted by the Governor General of Nova Scotia!

Most of us stayed a short walk from the site. The weather was great on both race days. Suzanne Bodner and Marlene did a terrific job in keeping the boat together; Suzanne, our co-manager, went out of her way to make us more efficient and keep



us on track, both in and out of the boat! Enjoying the venue, meeting old friends and making new ones were highlights for everyone! Lynda Lemaire courageously and bravely drummed for us and other teams, even though she was not at her best and won herself a medal! Lorraine, unable to paddle, cheered us on along with other supporters. Great drumming from Cathy Brklacic and perfect steering from Barbara Dunsmore! Thank you ladies!

Saturday evening - the Pink Festival - my most hectic and nervous moment: thinking of going onstage in our beautiful costumes! The banquet hall was filled with what seemed like thousands of people. I finally found my gals and we enjoyed our meal. Then, panic, as we discovered we had forgotten our song sheets! I was frantically working my Blackberry to copy the song, when our very efficient young waiter promptly and eagerly made 20 copies minutes before the performance! Special thanks to Frances who did an amazing job composing our song, including every paddler's home town and province. Thanks again Frances everyone else for their efforts.

We lined up and gracefully walked onto the stage in our smart looking red and white uniforms, garnished with a white banner announcing each city and province, balancing our princess tiaras and carrying our magic wands (donated by Sylvia Rickard's mother)

We were awesome up there, singing our song proudly. Other teams performed well but, of course, I think we deserved that special award for being the best dressed and most well put together team After all we came from across Canada and put it together with only one five minute practice!

It was extremely hot on Sunday, but races went well with a 200 meter. I even had a great swim in the waters of Lake Banook, even though my \$4,000 prosthesis floated away with me trying to catch it! The announcer thought I was being kinda pornographic

The Splash and Dash was wild, crazy and well organized. The carnation ceremony was beautiful! I was extremely honored to hold one end of the memorial banner carrying the names of all those who have lost their battle and, can you believe that I was holding the section of Canadians Abreast names! We sure came first in our lane and did very well in our last race! After all the goodbyes some of us wandered off to see more of the beautiful scenic coast and savour the mouth watering seafood!

My highlight of this whole event is being able to share the whole racing experience, laughing, crying and singing with the whole team, meeting new members of Canadians Abreast and spreading our message to others! None of this could have happened without everyone who travelled so many miles to join our awesome crew in Halifax! Thanks to each and every one of you.

Oh, forgot to mention the wild wedding party some of us crashed at our hotel with the wild dancing with the fun karaoke night. Still don't think I can sing.

I know I will be returning to the east coast to explore more of its beauty.

Inflammatory Breast Cancer . . . Spread The Word . . .



I found the lump in the shower. It was early Saturday morning on Thanksgiving weekend 1994. I noticed my nipple was retracted and a sudden feeling of dread and fear enveloped me as I crept back into bed beside my husband. Once I had convinced him it might be serious, we hugged silently.

Fast-forward to my bedside at Women's College Hospital after my biopsy, as my oncologist stood before me to give me the news. It was worse than I had ever imagined. She told me I had Inflammatory Breast Cancer (IBC), a rare and aggressive cancer I knew nothing about. Had never heard of it. I asked her for the odds. Well, 25 to 40 per cent of IBC patients survive five years she told me. I was quiet, as I tried to absorb it all.

For several years, I did not come across any women who had IBC. I found it hard to find information about it. Usually, it would be a measly sentence or two in books about breast cancer. Access to information about IBC is much better now, especially on the Internet. But, I still hear dreadful stories of women being misdiagnosed because it is still not that well known in the medical community and because of the way it presents itself.

So, I have two reasons for writing this article. First, I want to spread the word.

Second, I want to give hope to anyone unfortunate enough to get IBC. I am living, breathing proof that you can beat the statistical odds. Someone has to, so why not me, why not you or your friend?

IBC is rare—2 to 5 percent of breast cancer is IBC. It grows in tumour cell clusters, nests or sheets that clog the dermal lymphatics, causing skin changes. There can be a lump as in my case, but there is frequently no detectable lump. It has a faster doubling time than other breast cancers and IBC is more likely to have metastasized at the time of diagnosis than non-IBC cases. This is serious stuff.

Here are symptoms to watch for:

- Rapid increase in breast size
- Redness, rash, blotchiness of the breast skin
- Bruises in the breast area that do not go away
- Persistent itching of breast or nipple
- Lump or thickening of breast tissue
- Pain, soreness, aching of breast
- Warmth to the breast (inflammatory)
- Swelling of lymph nodes under the arms or collar bone
- Dimpling or ridging of breast
- Change in nipple, flattening or retraction

And here are a few other facts:

- IBC is more common in younger women than other forms of breast cancer, and it has been discovered in women who are breastfeeding, as young as 25, although this is rare.
- Women can get IBC when they already have another form of breast cancer.
- Because of its nature it's often been diagnosed as an infection or abscess. It could be an infection but a biopsy is best because it doesn't show up well on a mammogram or ultrasound.
- Now, the five-year survival rate for patients with IBC is between 25 and 50 per cent, which is significantly lower than the survival rate for patients with non-IBC breast cancer.

The standard treatment protocol for IBC is different too. It usually starts with chemotherapy followed by surgery, radiation, and perhaps hormonal therapy—prescription of Tamoxifen, and/or Letrozole (Femara) etc. I was on a clinical trial and ended up on the high-dose chemotherapy group of the study, which meant I was receiving double the standard dose in half the time (3 months), then surgery, radiation, followed by Tamoxifen.

I started my treatment in the late fall of 1994 and finished in June 1995. Later, about four years after treatment I had reconstruction—the tram flap method. I got tired of the prosthesis. One day after it slipped out and landed on a pile of leaves as I was raking and bending over in the front yard, I decided. O.K. this is enough. I want a real (well, sort of real) breast to go with the other one. So I went to see Dr. John Semple at Women's College Hospital and looked at his before and after pictures, was impressed and signed up.

I've been on a double-blind (neither patient nor doctor know if the dosage is real or a placebo) study for Letrozole and after five years, am now on a second study looking at the benefits of an additional five years of Letrozole. I found out I was taking the drug rather than the placebo during the first study and now suspect I am taking it again but don't know for sure.

Since IBC can look like a breast infection, there are more cases of misdiagnosis than there ought to be. Too many women are being treated with antibiotics or being told to keep on eye on it. Or worse, a doctor is telling a young woman that she is too young to get breast cancer.

Here is a quote from an IBC patient that I think says it all.

"Before my own diagnosis of IBC, I had not known that you could have a negative mammogram, not have a lump, and still have a very aggressive form of breast cancer called Inflammatory Breast Cancer. Now I, too, know what IBC is. My prayer is that information regarding this aggressive form of breast cancer be given to all women young and old, that family physicians be made aware of this aggressive form of breast cancer, and that they would impress upon their patients the importance of seeing a surgeon immediately ..."

Carol Mutton

Thank You. Messengers of Hope-Yukon River Quest 2008.....Lou Moreau

So where does one begin to describe the experience of a lifetime in a few short paragraphs? Even though the experience is now five months past, it is still a powerful memory, as strong as the "Mighty Yukon River" itself. I'm sure that the same is true for my nine Messengers of Hope team mates: Laura Connolly-Alberta; Sonja Kramberge, Loraine Warnock, Alexis O'Connor, Sue McCullough, Eleanor Nielsen, Carol Todd-Skuce, Laurie Brine, Darlene Prager- all from Ontario. They are more than team mates now...they are my soul mates, and I would follow them anywhere.



And why does one embark on the longest and most challenging canoe race in the world? Well, we each had our own personal reasons for doing what some people called "the craziest, riskiest, thing you could do"! Our individual motivations ranged from..."wanting to see the midnight sun"... "ultimate challenge"... "do it or die trying"... "pure fun of paddling with ten women in the Yukon"... "celebrating 10 years survival"... "celebrating my 60th birthday"... "crossing that finish line faster than before!" What we all shared in common was the desire to help women living in the Far North by raising money towards improved breast cancer detection services.

Together with the Messengers of Hope Team-2007 this goal was accomplished beyond our wildest dreams! A grand total of \$75,000 was reached and donated to the Iqaluit Regional Hospital, Nunavut. Our very presence in this race sent out a loud and clear message of hope, a message that there is life after breast cancer, and to always follow your heart because anything is possible.

This year the Yukon River Quest was celebrating its 10 Year Anniversary. It had grown from just 16 canoes in 1999 to a record 90 canoes, kayaks and voyageurs. There were 240 paddlers competing in this year's race from Canada, USA, Great Britain, Australia, France, Denmark, Israel, South Africa, and Latvia. Quite a daunting line-up! The race course from Whitehorse to Dawson City is a total of over 740 km which has to be completed in 70 hours, the average being 55-60 hours. There are only two mandatory stops along the way for a quick rest-up and time to re-fuel. The rest of the time the paddlers are on the water racing throughout the night and day. Thankfully, there is a midnight sun to guide us along during the long hours of the night. With this grueling schedule it is easy to see why some competitors are not able to complete the race. Fatigue, dehydration, hallucinations, disorientation, hypothermia, and capsizing, are just some of the major challenges along the way and the most common reasons for "scratches" i.e. needing to withdraw.

Unfortunately, after discussions with race officials, our Messengers of Hope Team #46, was among this group of "scratches". We had to withdraw at Carmacks, the half-way mark, due to safety concerns, namely leaks and cracks in our canoe. Although this was a huge disappointment for all of us, we knew in our hearts that it was the right decision to keep us all safe and healthy. However, six of the team did paddle almost non-stop for over 35 hours. We battled everything from an undersized and overloaded canoe, butt blisters, flu, pneumonia, hallucinations, peeing in a tiny bucket in a moving canoe, aching muscles, hypothermia, getting stuck on gravel bars, frozen shoulders, and did I mention extreme fatigue! In my mind, this alone made us all winners and the fact that our collective spirit was still very much willing to carry on right to the end. Sometimes it is not about completing the race, but simply being in the race. Having said that our hats do go off to last years Messengers of Hope-2007 who did successfully complete that race in 69 hours. You are all our heroes!

We had other heroes on this trip....the Paddlers Abreast team and their supporters from Whitehorse. They billeted us during our preparation week, fed us and nurtured us in Carmacks, and gave us their care and support all along the way. And then there were all the people back home, our friends, family, and dragon boat team mates, who had donated thousands of dollars

towards our fundraising cause and sent messages of support and little care packages for us to enjoy en route. Lastly, there was Darlene, without whom none of this would have been possible. Once again she taught me to dream the impossible and fight to the finish.

The whole experience was so much more than the race itself...although this was awesome! It was embracing the warmth and friendliness of the Yukon people, enjoying the magnificent scenery, the history of the Klondike, pushing our bodies to the limit, working collectively, watching the frantic follies, laughing drinking sourtoe cocktails (don't ask), first beers for Sue, dancing at "The Pit", and singing Sonja's song at the closing ceremonies. I owe all of these experiences and thanks to my new soul mates, Team #46, Messengers of Hope, Yukon River Quest 2008.

For my 60th birthday, I wanted to celebrate by being on the water, enjoying Mother Nature, doing what I love to do best (paddling hard), in the company of women, in the land of the Midnight Sun...Mission Accomplished.

Kilimanjaro 2008 by Akky Mansikka

In 2007, through our home team "Dragons Abreast, Yasmin and I heard of a request for breast cancer survivors to climb Mount Kilimanjaro as part of a study by Dr, Shaunna Burke of Carlton University. Valerie Pringle would be producing a documentary about the climb. Ben Webster would organize and lead the expedition and also produce the documentary. We signed up. Oooh the anticipation! For Yasmin it had been a 5 year wait since her breast cancer diagnosis and she saw her cancer as a mountain to conquer. She drew pictures of herself looking at the mountain in front of her and dreamed about climbing it



For me it was another adventure with a challenge. I felt that through challenges you learn more about yourself and others. Then there was the training. We both hiked and did yoga, and one week end, walked the Bruce Trail together in the Beaver Valley and Wiarton areas.

We met on the morning of June 24th, at Heathrow Airport in London, to start our journey to the mountain. Arriving late at night, in Nairobi, Kenya, we spent one night in luxury at the Nairobi Hilton. The next morning we met the rest of the group and flew to Kilimanjaro Airport in Tanzania. On route we caught a glimpse of the mighty mountain's snow capped peak poking through the cloud layer. On the way to our hotel on the mountainside, the bus stopped near Arusha, where we saw the formidable wall of mountain in front of us disappearing in the clouds. What a frightening sight when I thought "that is where we are going?" But there were sunflowers in the fields that Yasmin felt were greeting and welcoming us and that was a good sign.

We spent two nights at the hotel on the side of the mountain to get acclimatized. Then off we went to the north side of the mountain, to start on the Kenya side and finish on the south side in Tanzania near our hotel. After the kitchen staff packed the food and equipment and the porters weighed in their loads, off we set with our group of 37 people. First through corn fields, then rain forest where we spotted black and white monkeys with bushy tails, stopping for the night in low bushy vegetation. Our tents were cozy, the food was good, and company was great.

The next morning as the shrubs got lower we had terrific views of Kilimanjaro ahead of us as we hiked higher and higher. We camped at Second Cave at 3550 meters. After a breakfast of porridge and a fried egg on toast, we set off for Mawenzi Tarn, an elephant watering hole, which sits below the multiple summits of Mawenzi Peak. We passed the upper limits of vegetation and the landscape looked desolate and dessert like. We spent two nights there at 4300 meters.

Next we crossed the saddle between Mawenzi and Kilimanjaro to Kibo Hut which sits at the base of the crater, at 4750 meters. We had one rest day there before starting out on the ascent to the summit the following night. We started at one in the morning with our headlamps on. It was spectacular watching the trail of lights winding up the side of the mountain. The rising dawn over Mawenzi was beyond words and so was reaching Gilman's Peak on the top edge of Kibo Crater, at 5685 meters . There were tears, hugs, awe and wonder as we looked around the snow capped top and glaciers. We had arrived.

You can see our adventure, struggles and climb in a documentary by Valerie Pringle who was also made it to the top. After returning from the climb, Yasmin and I and the group worked on an HIV shelter and resource center for women in a rural part of Tanzania. Then we went on Safari in the Serengeti where besides seeing many animals up close in their natural habitat, we visited a traditional Masai village. We learned so much about life elsewhere, living life, and ourselves. The experience was unforgettable.

Ben Webster, along with Dr. Shaunna Burke will be returning next July to run the same expedition up Mt. Kilimanjaro. Once again there will be both a film and scientific research component. If you would like to join them please e-mail Shaunna at shaunnaburke@gmail.com

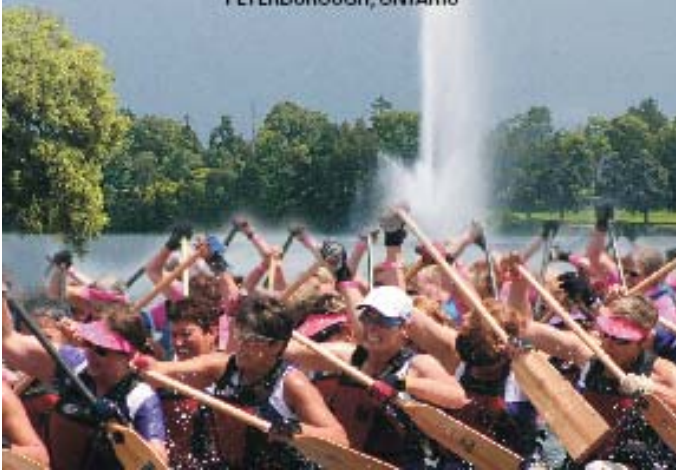
The International Breast Cancer Participatory Festival

hosted by



JUNE 11-13, 2010

PETERBOROUGH, ONTARIO



Peterborough
prepares to
welcome the world!

From Survivors Abreast
Peterborough

WE DID IT! WE GOT IT! COME ON 2010!

Our bid for the 2010 International Breast Cancer Commission Participatory Festival has come out on top.

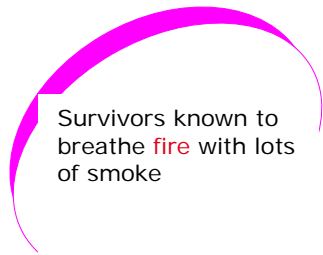
Other bidders included Christchurch, New Zealand, Liverpool and Windermere in England and Florence Italy.

All breast cancer survivor paddlers will be welcomed June 12 and 13 2010 on Little Lake in the centre of Peterborough Ontario.

One of the deciding factors for this event was probably the last 8 festivals held here that raised over \$1,000,000 for the Breast Cancer Assessment Centre at Peterborough Regional Hospital Centre.

We (Survivors Abreast) look forward to welcoming your dragonboat team in June 2010

Lois Steed
Survivors Abreast



Survivors known to breathe fire with lots of smoke

Canadians Abreast – Messengers of Hope, a dragon boat team of breast cancer survivors, is committed to raising breast cancer awareness and participating in events dedicated to the pursuit of a cure. This commitment has been made by our members across Canada, from Vancouver to the Maritimes, every one a living example of the joy and physical, emotional and spiritual benefits of dragonboat racing and every one a living example that there is life after breast cancer, the disease that has touched the life of every member

"We are women from across Canada, all ages, colours, shapes, sizes, from all walks of life. We are proud survivors, proud Canadians. We refuse to accept limitations and we'll be damned if we'll finish last!



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The Last Word . . .



I hope you've enjoyed reading this latest issue of *Canadians Abreast's* Newsletter.

Constructive criticism is *always* welcome. If you have a story, news or information for *Drumbeat*, please send it to me while you think of it. Don't wait for the next "call for contributions".

Thanks to everyone who contributed. Please don't take offence if your contribution has been edited or doesn't appear in this issue. I've tried to keep *Drumbeat* to a 'downloadable size' . . . and there's always the next issue. Your time and efforts are really appreciated.

All Provincial Representatives are listed on the front page. They'll be in touch with you from time to time with news, requests, updates, etc. etc. from your Executive. Please reply when you hear from them. And, of course, you can contact them if there's something you'd like to know. They're here to help and keep everyone connected.

Our website is being revised and updated. The plan is for it to be online early in the New Year. In the meantime, check out the online

jewellery sale.

I wish everyone a joyous festive season, whatever you will be celebrating and I hope you have a wonderful time with family and friends. Take care, stay fit and well; and I'm already looking forward to seeing you on the water.

Paddles up!

Frances