Update

Spina Bifida & Hydrocephalus Canada

Fall 2008

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INSIDE

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President's Message

2008 brought changes to our office staff at National. The new **Executive Director, Jody Stadnyk** has been working hard since May. We welcome Jody and look forward to working with her to bring SBHAC to great places. **Bonnie Hidlebaugh, National Communication & Development Coordinator** is working hard to bring in revenues from new national fundraising initiatives like the Hope Classic and Scare a Ghost campaigns. Elise Dawson, our summer student, adds to the support of Jody and Bonnie. 2008-2009 will see positive outcomes that will strengthen SBHAC as a national identity, while creating stronger relationships with member associations across Canada. I wish to express my gratitude to our staff and volunteers across Canada who make SBHAC the success that it is.

Lorelei Fletcher
President

THE HOPE CLASSIC
FOR SPINA BIFIDA & HYDROCEPHALUS

The 1st National run, walk., wheel event took place on Saturday August 16, 2008. Five regional Spina Bifida & Hydrocephalus associations hosted the event with the support of local sponsors.

British Columbia—raised $27,000

Northern Alberta—raised $12,000

South Saskatchewan—raised $1,500

Manitoba—raised $1,500

Nova Scotia—raised $2,500

The Spina Bifida & Hydrocephalus Association of Canada would like to thank the Running Room for their generous support and encouragement. We look forward to a bigger and better

Hope Classic in 2009.

Together—we can make it happen!

"The Mission of SBHAC is to improve the quality of life of people living with Spina Bifida and/or Hydrocephalus and their families through awareness, education, advocacy and research, and to reduce neural tube defects."

"La mission de l'ASBHC est d'améliorer la qualité de vie des personnes vivant avec le spina-bifida et/ou l'hydrocéphalie ainsi que celle de leurs familles par la conscientisation, l'éducation, le defense des droits et la recherché afin de réduire les malformations du tube neural."

JOURNEY OF LOVE

IN MEMORY

GABRIEL LEWIS-JAMES

Clare Lewis and her daughter **Louise Lewis-James** will be raising awareness and funds for the Spina Bifida and Hydrocephalus Association of Canada while walking across northern Spain on **El Camino de Santiago de Compostela** aka The Way of Saint James. They leave on August 21, 2008 from St Jean Pied de Port in France and will take approximately five weeks to complete their journey, averaging between 20-30 km a day. The total distance is 775K.

Why, you ask, would these two courageous women take on this difficult and tiresome journey? Gabriel Lewis-James, the son of Clare and brother of Louise, was diagnosed with hydrocephalus when he was one year old. He had many surgeries throughout his life to have shunts installed, fixed, replaced and repaired. In August 1999, at the age of 17, Gab died suddenly at summer camp. The family believes his hydrocephalus may have played a part in his death. Described by his family and friends as a spirited guy who had many friends, he touched many lives and is missed still today.

HE DEFINITELY LIVED BY THE MOTTO "GO BIG OR GO HOME"

Louise explained the reason they chose the Spina Bifida & Hydrocephalus Association is to commemorate her brother by supporting a foundation that is significant to so many families. "The research it supports is very important and the assistance the association provides to families at difficult times is invaluable. I also believe it's important to promote charitable organizations that aren't in the media every day; I feel people often forget about all the less common, and non-cancer related problems. Unless it's taking up page space people in the media tend to forget!" Louise is using Facebook to spread the word about her trip as she currently lives in England..

WHY WALK THE CAMINO?

"There are many reasons why I am going on this pilgrimage with my mum.
I want to slow down my life a little bit.
I want to be outside and meet new people from all over the world.
My mother walked the Camino in 2002 and at the time, I thought she was completely nuts! Who wants to carry a 20 lb backpack and walk in the blazing sun for 20-30 km per day? It sounded completely crazy! She walked with a good friend and they came home with beautiful pictures and even better stories.
There is also something that pulls people to walk the Camino in the footsteps of pilgrims of years gone by. As I get older (and a bit more mature), I can see past the pain of the walking and imagine what my mum got out of it. I think it will give me a chance to confront the grief I still carry over the sudden loss of my brother in 1999. It will allow me time to reflect and concentrate on the happy memories, and the silly moments that are slowly fading from my memory. Going on this trip with my mum will give us a rare opportunity to spend quality time together without any life stresses. Her partner Mark, will be joining us part way through the trip as well. I understand that the journey is difficult and tiresome, and can be frustrating and very hot, but I'll be taking it one step at a time.
My brother, Gabriel, loved the outdoors and I just know he would have loved to join us on this trip."

Gabriel will be with them– in their thoughts and in their hearts, and he will be smiling— proud of these two women who have taken on this "journey of love". Gone but not forgotten- his memory lives on.

Clare Lewis and Louise Lewis-James

Louise was born and raised in Ontario, Canada and now lives in Cambridge, England with her husband. Her mother Clare was born in Wales She and her partner Mark live in Ontario. Louise's brother Rheal lives with his wife in Ottawa.

> *I am using Facebook to spread the word about my trip as I live very far away from my family and friends. Any support will be greatly appreciated.*

The Spina Bifida & Hydrocephalus Association of Canada website has a link to this campaign. A paypal account has been set up for donations being made in Europe and the UK.

Jenna's Story– direct mail campaign April 2008– July 2008

Jenna's Story

Jenna is a 4 year old girl, who lives in Winnipeg, Manitoba with her parents and younger sister Kiahna.

Jenna's parents were not prepared for the shocking news that their newborn baby had spina bifida and hydrocephalus. When she was one day old, she had surgery to close the lesion on her back and to put in a shunt to manage her hydrocephalus. Jenna stayed in the hospital for 5 weeks before she got to go home to her family.

In her first 2 years of life, Jenna underwent five surgeries. Four of them were for shunt replacements, and one was for eye surgery and heel cord lengthening. The physical and emotional scars have made the very word "surgery" a painful reminder. Yes, their life is full of doctor and therapy visits, which is tiresome, but without these supports, and answers to prayer, Jenna would not be where she is today.

Spina Bifida has affected Jenna's ability to walk or stand on her own. She gets around her home by crawling on her tummy or wheeling around on her castor cart. Jenna is a determined, bright, sociable little girl who loves to laugh and be silly. Her favorite activities are playing dolls, helping in the kitchen, looking at books, and playing with playdough. She attends preschool 2 days a week, and looks forward to going to Kindergarten in September! Her favorite place to visit is her Nana and Papa's house.

Jenna's parents feel very blessed to be her Mom and Dad. It hasn't been easy coping with all the special needs that are part of dealing with her spina bifida, but Jenna's loving spirit makes it all worthwhile! It is a joy to know and love Jenna.

What if I told you that 1 in 1300 babies are born with a neural tube defect such as Spina Bifida?

And what if your child or grandchild was one of these babies?

The Spina Bifida & Hydrocephalus Association is the voice of those like Jenna who need our ongoing support. ***Help us to help them*** .

Please send in your donation and make it happen!

Notice for Annual General Meeting 2008

The Annual General Meeting of the Spina Bifida and Hydrocephalus Association Canada was held in Winnipeg on Sunday September 14, 2008.

The purpose of the meeting is to receive annual reports and to determine the SBHAC board members for 2008-2009

Board of Directors

2008-2009

Lorelei Fletcher—President
Jody Sabroe—Vice-President
Linda Renault—Secretary
Brent Buss—Treasurer
Colleen Talbot—Past President
Judi Haddy—Director
David Dunphy—Director
Sarah Williams—Director
Chera Giesbrecht—Director
Linda Randall—Member-at-large
Shelley Elder—Member-at-large
Ken Stickle—Member—Special Skills
Wendy Sol—Member– Special Skills
Dr. W. Arnold—Member—Special Skills

Bursary Recipients

Congratulations to the 2008 bursary recipients

Erica Rayner–Summerside,PEI– registered at Academy of Learning Business College, Charlottetown, PEI in Administrative Assistant Program.

Darcy Gallant–Pointe du Chene, NB– registered at St. Thomas University, Fredericton, NB in the Bachelor of Arts Program with a major in Political Science with plans to enter law. He wishes to become an advocate for persons with disabilities.

We wish them all the very best in their endeavors.

THE HOPE CLASSIC

FOR SPINA BIFIDA & HYDROCEPHALUS

Save the Date

2nd Annual run walk wheel

AUGUST 15 , 2009

The Giving Day

The Hbc Foundation has finalized the date for this year's "***The Giving Day"*** exclusive shopping event designed to help organizations, like ours, to raise much-needed funds.

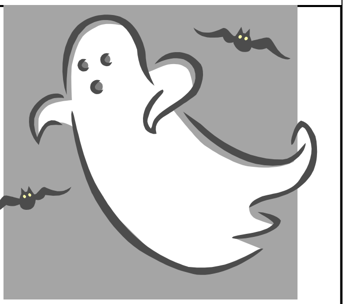
"The Giving Day" will be held on Saturday, November 1st at Bay stores across Canada.

The tickets are **free of charge** to our associations. You can sell these tickets to your donors, partners and friends for $5. You get to keep **100%** of funds raised for each ticket sold.

Information on ***"The Giving Day"*** will be available on the Bay Website at the end of August. Associations that participated previously in this event, will be receiving a detailed mailing from the Bay around the same time.

Scare a Ghost Campaign

October 2008



The Scare a Ghost campaign is a unique way to decorate for the Hallowe'en season at no cost to the participating establishment, while raising funds for your association.

The printing cost of the "Ghosts" and stickers will be donated by Wyeth, the makers of Centrum and Folic Acid. Final details will be sent to all regional associations at the beginning of September.

BECAUSE "WE CARE" CAMPAIGN

CONGRATULATIONS to two of our associations who were chosen by their local Safeway store to participate in the "We Care" Program.

N SASKATCHEWAN- $9400 RAISED

MANITOBA - $18,200 RAISED

Thanks a **Million**

COMMUNICATIONS ENERGY & PAPERWORKERS UNION

(CEP)

The Spina Bifida & Hydrocephalus Association of Canada would not be where it is without the continued support and encouragement of the CEP membership, locals and corporate offices. Since 1985 they have raised and contributed over **$1,000,000** to SBHAC through golf tournaments, draws, matching gifts, special events and per capita funding. Hundreds of projects have been funded by their efforts over the years.

On behalf of all individuals living with spina bifida and hydrocephalus we express our sincere gratitude and look forward to your continued support.

Sincerely,

Spina Bifida & Hydrocephalus Association of Canada