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President's Message



Hi Everyone!

Spring is fast approaching and I hope that everyone made it through the hard cold winter. The SBHAC office has been working on fund development projects such as the Corporate Appeal, Foundations Appeal, Direct Mail (and Reminder) and the Planned Giving Campaign. SBHAC will be conducting a national "signature" fundraising event in May, the Daisy Campaign, in which live flowers will be sold to not only raise funds, but to add to the public's awareness of spina bifida and hydrocephalus and the work of our associations across Canada. As well, SBHAC has just completed a collection can campaign in liquor outlets in Saskatchewan, and will be in PEI outlets in April.

The support and assistance of members of our Member Associations involved in the SBHAC national fundraisers is greatly appreciated, and a big thanks goes out to everyone for taking part.

In January Andrea Salmon and myself attended a scientific meeting in Ottawa where discussions were held on Folic Acid and Neural Tube Defects. It was very informative, with the consensus being that more research needed to be done.

There are many things happening at the national level, and new opportunities arising. It is the strength and support of everyone working together that makes SBHAC what it is. Thanks go out to Andrea Salmon and Mona Rémillard for their work in the national office.

I hope that this finds everyone well. Remember that it is with the support of one another that we can make a difference.

Thanks,
Lorelei

Conferences Around the World

The **Spina Bifida and Hydrocephalus Association of British Columbia** looks forward to hosting the **SBHAC AGM/Conference** October 13th-16th, 2005 at the Guildford Sheraton Hotel in Surrey, BC. The conference theme is "Movin' On! Managing Life-Sized Obstacles." There will be a variety of relevant medical presentations, with a separate track of speakers and workshops for Teens and Young Adults.

Keynote speakers will be Chris Johnson "Dr. Laugh" (Saturday) and Sam Sullivan (Friday), well-known advocate speakers for people with disabilities, Vancouver City Councillor, founder and active participant of the Disabled Sailing Association and the Tetra Society.

The conference will offer an opportunity for spina bifida organizations and other groups to showcase their talents, achievements on Friday. Tables for displays will be available on a first-come, first-serve basis. Book your table now! Registration information will be available on the website next month. For more information contact them at sbhabc@shaw.ca or call 604-878-7000.

National Coin Can Campaigns with Provincial Liquor Commissions

SBHAC received approval from the Saskatchewan Liquor and Gaming Authority to place coin receptacles in their liquor stores in December 2004. SBHAC would like to thank the Spina Bifida and Hydrocephalus Associations of North and South Saskatchewan's members who volunteered their time in the placement and pickup of the coin receptacles.

The Prince Edward Island Liquor Control Commission has approved the placement of coin receptacles in their province for the month of April 2005.

The Liquor Distribution Branch of the Province of British Columbia has granted the approval of placing coin receptacles in their liquor stores for the month of May 2005.

The Nova Scotia Liquor Corporation has selected SBHAC as the charity for their Cash Can Program for the month of July 2005.

June is National Spina Bifida and Hydrocephalus Awareness Month

"When life's problems seem overwhelming, look around and see what other people are coping with. You may consider yourself fortunate."

– Ann Landers

Across the Country News

Day care to raise funds for the Spina Bifida and Hydrocephalus Association of Manitoba (SBHAM).

The day care at Oak Bank, Manitoba is doing a Hop-Along fundraiser for SBHAM during spring break, end of March. The children will receive pledge cards and a sticker that says, "I hopped for SBHAM," and a drawing of the SBHAM logo – the Manitoba Crocus, for each child to colour. If you know of a group that would like to do a fundraiser please contact SBHAM president, Curt Salmon, at jcsalmon@shaw.ca or Hazel Birt at hbirt@merlin.mb.ca.

Bursary Applications

Bursary application deadline is May 15th, 2005. The application can be downloaded from our website at www.sbhac.ca. Good luck to those that apply! Remember to read and follow the application guidelines carefully.

Lucy MacDonald's Book Launch

Learn to be an Optimist



Lucy MacDonald, left and Mona Rémillard

On Saturday, November 27th, 2004 at Librarie Clio, Point Claire Plaza, Lucy MacDonald was on hand to autograph her new book, *Learn to be an Optimist*. Donations were received from the public who attended the event, and Librarie Clio gave \$2.00 for each book sold, and Lucy MacDonald matched the amount.

Did You Know?

There is a new website exclusively designed specifically for adult females who have spina bifida and/or expectant mothers.

http://health.groups.yahoo.com/groups/adult_females_with_spinabifida

Upcoming CEP Golf Events

Western Region

Plans are underway for the 3rd Annual CEP Western Region Charity Golf Classic on June 3, 2005 in Niagara Falls, Ontario.

Manitoba Area Council

3rd Charity Golf Tournament is scheduled for September 11, 2005 at the Kingswood Golf & Country Club.

Dryden local 105

Tournament will take place on September 5, 2005 at the Evergreen Golf Course in Dryden, Ontario.

Alberta Area Council

Will hold its 7th Annual Charity Golf Tournament on June 4th, 2005 in Fort Saskatchewan, Alberta

SBHAC appreciates the involvement of all CEP members across Canada who participate, and continue to support their charity.



Having a Child with a Disability

Leads to New Career

submitted by Susana Scott – Victoria's mother

On a November day, the 6th 2002 to

be exact, a beautiful little girl, 8lbs,

1oz was born. We were very excited.

We already knew when I was

pregnant the baby had spina bifida.

I did not know much about this

birth defect and so we did a lot of

research. We discovered the baby's

lesion was L4. The doctors explained

all the complications and scenarios

that go along with this.

We called our beautiful little girl

Victoria Grace C. Scott.

I worked for a few years as the special assistant to a Member of Parliament and later appointed President of the Treasury Board and Minister Responsible for the Canadian Wheat Board for the federal government. My primary role was to serve on behalf of the minister, constituents and businesses. I mediated between the constituent and government departments to resolve issues. This was a very fulfilling job because the smile and satisfaction on the peoples' faces was worth it. Through all my experience I realized that many people with disabilities were either not aware or did not have the proper resources to help them apply for government programs that are available to them.

I served businesses and constituents at this capacity for years at the minister's office. I later had to make a difficult decision but a gratifying one to leave the office and stay home to raise my little Victoria Grace. She was 1 1/2, and I felt deep inside that she needed me. It is a decision that I have no regret at all, but I did miss helping people. After a while at home, I partnered with an expert in the field of taxes, a Forensic Accounting and since then I am spreading the word to all caregivers, markedly disabled and totally disabled people about the tax credit programs for disabled people. With my knowledge of government policy and departments along with my business partner we have over 35 years experience in this specialized area. Since I have been at home with my new service to help people with disabilities, I have again put smiles on many faces.

Call me and find out if you are eligible. We will be happy to look into the matter for free and if there is a claim, there is a processing fee that is based on a percentage. I am able to serve anyone, anywhere in Canada. Email me at susana_scott@yahoo.ca.

Today, Victoria is doing wonderful and she is very happy, and I, her mommy am very happy too.

Conferences continued from page 1

International Federation for Spina Bifida and Hydrocephalus and the Spina Bifida Association of America are joining together to present a multi-cultural and multi-national conference. At this conference in Minneapolis, Minnesota, June 26–29, 2005 "Building Bridges to Advance Understanding," the conference will offer the most current information about the orthopedics, urology, neurosurgery and neuropsychology, as well as health, psychosocial and family issues, employment, sex, depression, latex allergy and learning disabilities. For more information: www.sbaa.org

The Spina Bifida and Hydrocephalus Association of Quebec will hold their Symposium May 27–29th, 2005 Hotel Duchesnay, Sainte-Catherine-de-la-Jacques-Cartier, QC. For more information contact them at www.info@pina.qc.ca.

The Motion Picture Theatre Associations of Canada and the National Advisory Council of Disability Organizations

have developed a program that will provide discounted admission to the support person accompanying a person with a disability to member movie theatres across Canada.

The card application can be accessed at www.Access2.ca. This card is good for five years and it enables an individual who requires support at a theatre to bring their support person with them for free (Famous Players and Cineplex Galaxy). There are other theatres that are joining in and they cannot charge more than \$3.00 for a support person.

The application form is fairly simple and people who have a CNIB card do not need to have another person sign the application. A photocopy of the card must be attached to the application form. The new policy starts on March 1st, 2005.

You did not make my life easier!

as presented by Matt Pregent, Network Liaison, SBHABC

On November 28, 2004 I sent an email to Toronto Airport complaining about how I was treated to catch my flight back to Vancouver on September 12, 2004.

It all started when I got to the airport and tried to get myself checked in. The airline agent who took care of my papers wasn't listening to me at all and she kept asking her supervisor for direction and approval. This just made the matter worse. I spent nearly 30 minutes trying to get myself checked in. They asked if I needed help getting

plane after I showed my boarding pass. I stopped him and I said, "I don't need help to wheel and you didn't ask if you could either."

On November 30th, I received an email from a woman from Greater Toronto Airports Authority (GTAA) who provides wheelchair services for Toronto airport. She agreed that those who were supposed to offer me assistance clearly failed and that the airline agent that checked me in should have clearly understood that I wished to remain independent and

What I know next once I passed the security gate, there were escorts looking for me because they apparently had a call saying that they had to escort me to the gate. I refused to be escorted and they called their supervisor.

to the gate, I said no. What I know next once I passed the security gate, there were escorts looking for me because they apparently had a call saying that they had to escort me to the gate. I refused to be escorted and they called their supervisor. The supervisor gave me no choice but to follow her to the gate. I was with Judi Haddy who was going to be on the same flight as well, so I didn't need to be escorted to the gate. I didn't even have time to ask for a different seat on the plane like I usually do because the agent from the gate came and got me about 30 minutes before boarding time. He was really rushing me and I had to argue with the guy because I needed to use the washroom. I felt like I wasn't allowed to do that. When I came out of the washroom, he started pushing my chair to the gate and through the doors to get me to the

was able to get to my flight unassisted. The email from GTAA was copied to the airline involved. Within a matter of two weeks after this email, I got a call from the airline wanting to hear more about my complaint and offered me "points" which I accepted. The agent (from the airline) that I talked to on the phone said that my complaint would be reviewed and that necessary steps would be taken to make wheelchair passengers travelling easier and pleasant.

The GTAA and the airline thanked me for writing to them and hoped that my next visit to Toronto will be more pleasant.

Editors note:

The GTAA has informed Mr. Pregent that they have asked their service provider to review his complaint, and to use it for retraining all the staff at the airport in matters of sensitivity.

Folic Acid Update

by Derryn Gill, SBHABC-chair

The January 2005 meetings of the Canadian Congenital Anomalies Surveillance Network

(www.healthcanada.ca/ccasn) featured an update on the history of folic acid research and the interim reports of the Canadian research studies. Folic acid, also known as folate or folacin is a B vitamin that is essential for the healthy development of a baby's spine, brain and skull during the early weeks of pregnancy. It has been known for many years that if a woman takes folic acid for at least three months before and after conception, it can reduce the chance that she will have a child affected by a neural tube defect (NTD), such as spina bifida.

Research has proven that:

- all women of child bearing age should take a daily multi-vitamin that contains a minimum of 0.4 mg of folic acid.
- women in a high risk group should take a multi-vitamin plus a daily supplement containing 4.0 mg of folic acid after consulting with their doctors.
- high risk groups include:
 - > women who have had a previous pregnancy affected by NTDs
 - > parents who have a personal or family history of NTDs
 - > women with insulin-dependent diabetes
 - > women who use certain anti-seizure medication
 - > women who are clinically obese
 - > women who abuse alcohol
 - > women of Celtic, Northern Chinese, Cree and Sikh heritage

In the years following 1992, when this research was published, studies showed that even though over 80% of women of child bearing age were aware of the need to take folic acid, only about 20% of them actually took a daily multi-vitamin. The average Canadian woman does not eat enough folate rich foods to ingest the equivalent of a folic acid supplement. These discouraging facts were borne out by research that showed that the incidence of neural tube defects in Canada did not drop significantly during the years 1992-1997.

In 1998, folic acid fortification of enriched grain products and cornmeal was mandated in Canada as a public health strategy to increase the folic acid intake of all women of childbearing age. Health Canada undertook a comprehensive population based study in

continued over

Newfoundland to assess the benefits and possible adverse effects of this intervention.

The results were as follows:

- rates of neural tube defects such as spina bifida fell by 78% after the implementation of folic acid fortification.
- no adverse effects of fortification were found
- during the time of the study, the proportion of women aged 19-44 years taking a vitamin supplement containing folic acid increased from 17% to 28%
- there were significant increases in serum and red blood cell folate levels for women and seniors after fortification

Health Canada concluded that based on these findings:

- mandatory food fortification in Canada should continue at current levels
- public education regarding folic acid supplement use by women of child bearing age should also continue.

Similar research is on-going in seven other provinces and in all cases the incidence of spina bifida has dropped since folic acid fortification of flour began. Before fortification the incidence of neural tube defects in Canada was greatest in Newfoundland and decreased across the country to the west. The percent drop in incidence after fortification was greatest in the provinces that had the highest pre-fortification incidence. The preliminary results show reduction of incidence of neural tube defects in all provinces as follows: Newfoundland 78%, PEI & Nova Scotia 59%, Ontario 49%, Manitoba 50%, Alberta 36%, British Columbia 20% and Nunavut 50%.

When asked about the cause of spina bifida we have always said that it is multifactorial – some part genetics, some part environmental. Researchers now have a better idea of what those factors are. One environmental factor is low maternal folate concentrations which can be caused by poor diet or by agents such as drugs that destroy folate. One genetic factor is an abnormality in one of the enzymes (MTHFR 677C>T) in the pathway of folate metabolism. The combination of abnormal enzyme plus low folate levels may lead to spina bifida. Supplying high folate concentrations even in the presence of this abnormal enzyme seems to lead to healthy babies.

Other tidbits picked up at the conference:

- babies conceived in the spring are at higher risk of NTDs
- babies whose parents have a lower socio-economic status are a higher risk
- shorter time between pregnancies puts babies at risk of NTDs

- maternal illness puts babies at risk (unfortunately, mothers may avoid anti-fever medications during pregnancy but elevated temperatures may cause NTDs because the enzymes involved in folate metabolism are destroyed by heat)

- a North Carolina study showed that after folic acid fortification the greatest reduction in incidence of NTDs took place in the babies of:

- > women over 30
- > women with higher education
- > women with good prenatal care
- > women who were non-Hispanic Caucasians

- the incidence of neural tube defects increases with the weight of the mother. After fortification of flour, no decrease in the incidence of NTDs occurred in the offspring of the heaviest mothers.

- other birth defects, particularly cardiovascular defects, urinary tract defects, limb deformities and pyloric stenosis, have decreased since folic acid fortification

- the survival rates of infants with spina bifida have improved during the time of folic acid fortification

- the number of live births of babies with NTDs has dropped since the inception of maternal screening

Folic acid taken at various dosages has been implicated in the reduction of blood pressure, strokes, heart disease, Alzheimer disease, lymphoblastoma and other forms of cancer.

The CCASN participants debated whether the 0.4 mg of folic acid presently recommended to women is enough to ensure maximum protection of the fetus and discussed whether more foods should be included in the folic acid fortification program. The participants concluded that the answers to these questions would have to wait until the cross Canada research project is finished in 2006.

What can we glean from this information? It would appear that if our goal is to ensure that all babies are born healthy, then we need to work to ensure that all mothers are healthy, well nourished, well informed and well prepared for pregnancy. Later this year Health Canada will begin a Healthy Babies initiative that will counsel women to stop smoking, stop drinking alcohol and taking recreational drugs, to exercise and eat properly and to get proper prenatal care.

What part can SBHAC play in reducing the incidence of spina bifida? As individual members we can inform our families and friends of the need to take folic acid for their own better health as well as for the health of their babies. Each of us can offer to present the folic acid information to prenatal/public health workshops. SBHAC

can provide the brochures, posters and speaking notes.

As an Association, SBHAC can continue its work with the Folic Acid Alliance Ontario (FAAO) (www.folicacid.ca) and the Spina Bifida and Hydrocephalus Association of Ontario (www.sbhao.on.ca) to inform all women of the need to take a multi-vitamin containing folic acid. And again you can help. We presently can offer the folic acid information in English, French, Chinese, Punjabi and Spanish. We want to produce a one page information sheet on folic acid as a PDF file on the FAAO website and we want to produce it in as many languages as there are spoken in Canada. If you or someone you know can translate our folic acid brochure into any language, please contact me (dgill@sbhao.on.ca) and we will start the process of telling ALL Canadians about folic acid. Every healthy baby is a victory.

SBHAC Research Committee Update

Submitted by **Cindy Smith**

SBHAC is in its final year of a three-year partnership with the **Canadian Institute of Health Research (CIHR)**, where research money SBHAC (\$10,250.00 per year) donates is matched dollar for dollar by CIHR. This partnership is funding a three-year research project, "Development issues related to cerebral spinal fluid transportation and the importance of the extracranial lymphatic system."

In 2004, SBHAC also funded (\$5,500.00) two studies by **Dr. Joel G. Ray** and his team from the **University of Toronto**. The first study examined the risk of neural tube defects (NTD) in overweight mothers. Results demonstrated that pre-gestational diabetes is associated with an increased risk of NTD. This study was published in the *QJ Med* in 2004. The second study demonstrated that the associated risk of NTD-affected pregnancies was higher among women of **First Nations** origin than among women of other ethnic origins. This study was published in the **Canadian Medical Association Journal** in August 2004.

Zellers Community Club Card

To all our members who donate their HBC Rewards Points to SBHAC, we thank you!

Our community club card number has now changed – so please go to your Customer Service Department and if you give them your old card, they will provide you with our new number to write on the back of your card. SBHAC was able to purchase a Canon Digital Camera for office use with the points previously collected – THANK YOU!

Sommers & Roth, PC Barristers & Solicitors

268 Avenue Road, Toronto, ON M4V 2G7

This law firm is recognized across Canada as a leader in the field of medical malpractice. They have successfully represented children with spina bifida and their families for many years.

They understand that most people have very limited or no financial resources to contribute to the cost of litigation. If they do not win a monetary award for our client, they do not charge for their services.

For **FREE** consultation call: 800-961-7356; 416-961-1212; fax 416-961-2827 or visit their website www.sommersandroth.com

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Spina Bifida and Hydrocephalus Association of Canada
977-167 Lombard Avenue
Winnipeg, Manitoba R3B 0V3

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Winnipeg, Manitoba R3B 0V3

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