



Spina Bifida and Hydrocephalus Association of Canada

# upDate

Summer Edition 2004

## 2003-2004

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Ashok Bhargava,

Sylvie Girouard

### SBHAC National Staff

Executive Director

Andrea Salmon

Marketing & Fund Development

Mona Remillard

## Message from the President

Colleen Talbot

### *It has been a long hot summer for those of us on the West Coast!*

I hope everyone is enjoying some quality holiday time.

The office has been busy organizing golf tournaments, preparing direct mail campaigns, sending out requested materials and making preparations for the workshop and AGM in September.

The meeting will, in keeping with our direction, focus on ways to increase the strength and capacity of our spina bifida and hydrocephalus associations. Individuals from coast to coast will come together to work on our shared goals.

This will be my last meeting as president of SBHAC. I would like to take this opportunity to thank everyone for supporting me. I have had the pleasure of working with many dedicated volunteers over the years and am well aware of the value of their work.

Collectively, we are the stewards of our cause and must all continue to work diligently to secure a bright future for all individuals with spina bifida and their families. I still believe this can only be done if we combine our strengths and endeavours.

I would also like to say thank you to our long term staff members, Andrea Salmon and Mona Remillard, for their support to the board and the association in general. The amount of work produced by these two individuals, with limited resources, is tremendous and is vital to the success of our national movement.

I look forward to continued participation as SBHAC Past President and supporting the new President.

*Have a safe and happy summer.*

## Notice of Annual General Meeting

**Saturday, September 11, 2004**

**Notice is hereby given** that the Annual General Meeting (AGM) of the Members of the Spina Bifida and Hydrocephalus Association of Canada will be held:

**Saturday, September 11, 2004 at 3:00 p.m.** (Toronto time)

The meeting will take place at the **BMO Financial Group Institute for Learning**, 3550 Pharmacy Avenue, Scarborough, Ontario, M1W 3Z3, for the following purposes:

1. To receive and consider the financial statements of the Association as at and for the period ended April 30, 2004, together with the report of the auditors thereon;
2. To elect Directors to fill vacancies on the Board
3. To consider and, if deemed appropriate, to pass special resolutions to confirm amendments to the by-laws of the Association
4. To appoint auditors for the fiscal year May 1, 2000 to April 30, 2001
5. To transact such other and further business as may properly be brought before the meeting or any adjournment thereof

Dated at Winnipeg, Manitoba this 12th day of July, 2004.

By the order of the Board of Directors of the Spina Bifida and Hydrocephalus Association of Canada.



SBHAC  
has produced a

### **New Bookmark!**

Please contact  
the national office  
if you would like  
to order.

# 2nd Annual CEP Ontario Region Charity Golf Classic

## Rolling Meadows Golf & Country Club

June 4th, 2004 Niagara Falls, Ontario

**Mona Remillard, SBHAC Marketing and Fund Development, and volunteer Denise Bryant, had the privilege of attending the 2nd Annual CEP Charity Golf Classic on behalf of SBHAC.** Again, it was a pleasure to see so many familiar faces from last year, and also to renew and make new acquaintances.



Cecil Makowski, Vice-President CEP Ontario Region, Mona Remillard, SBHAC Marketing and Fund Development, André Letarte and Barbara Dolan, CEP National Representatives

The Charity Golf Classic was held at Rolling Meadows Golf & Country Club. A special thank you goes out to Cecil Makowski, André Letarte, Barb Dolan, Carol Fraser, Donna Lazure, Tom Edwards, John Edwards, Bob Huget, and Joe Chang. Also to all the golfers and wonderful sponsors that also make this event such a success. The dedication, support, and commitment of the CEP members helps SBHAC achieve its goals throughout Canada. \$25,000.00 was raised successfully this year.



Cecil Makowski and Mona Remillard

**2nd Annual CEP - Manitoba Charity Golf Tournament** will take place again this year at Kingswood Town & Country Club, Winnipeg, Manitoba Sunday, September 12, 2004. Last year \$10,000 was successfully raised.



Wendy Sol, SBHAC Board of Directors, and Don Boucher, CEP National Representative

Wendy Sol on behalf of SBHAC attended the **Alberta Area Council 6th Annual Charity Golf tournament in Fort Saskatchewan, Alberta** on June 27th, 2004.



We would like to thank Integra Lifesciences Corporation for giving SBHAC the financial support to reprint our Hydrocephalus shunt cards.

*SBHAC wishes to thank Ginette and Nathalie from the Spina Bifida and Hydrocephalus Association of Québec in assisting SBHAC with numerous translations of public awareness materials.*

SBHAC WAS SELECTED TO PARTICIPATE IN MLCCs DONATE- A-DOLLAR CAMPAIGN. THE FUNDRAISER RAN FROM APRIL 19TH - 25TH AND WAS HELD AT MLCC LOCATIONS ALL OVER MANITOBA, RAISING OVER \$19,000.



## Rock & Roll

**The History of Rock & Roll Musical Tribute was a resounding success.**

The May 29th fundraising promotional concert gave people a chance, if they're old enough, to reminisce about the golden age of Rock & Roll. Everyone had a fun night and enjoyed the food, company, and entertainment.

A compact disc was produced for the concert, so people could take the memories home with them. CDs can be purchased from SBHAC for \$20.00 each.



SBHAC sends condolences to the family of Wayne Rayner. Wayne passed away on April 13th, 2004. Wayne was on the SBHAC Board of Directors for many years.

## All Aboard for the Future

**All Aboard for the Future is a project that SBHAC is undertaking to achieve good governance for the long-term sustainability and relevancy of SBHAC.** This project will help the next generation of board members and current senior leaders develop and expand skills that are relevant to running an organization on a national and local level.

All Aboard for the Future will increase the awareness that current and potential board members have about aspects of being a board member such as legal liabilities, role definitions, and communication. This project has received funding under Health Canada's National Voluntary Health Organizations Initiative.

## Bursary recipients for 2004



Frances Miller

**The bursary recipients for the 2004 - 2005 school year are**

- **Frances Miller** - Attending the Northern Alberta Institute of Technology in Edmonton, Frances is studying Business Administration.
- **James Cotton** - Attending Queen's University in Kingston, Ontario, James is studying for a Bachelor of Science degree (Biochemistry)

The Bursary Committee thanks everyone who applied for a bursary. Good luck to all of you in your studies.

## Distribution of shunt cards

SBHAC's continuous distribution of shunt cards is still a success. Here is what Isabelle had to say, *"It was one of my goals this year to have all the patients carry shunt cards. It will be greatly appreciated. Thanks again,"* Isabelle Casavant, Coordinator, Spina Bifida Clinic, Shriners Hospital for Children, Montréal

## We have a great opportunity for you to support us.

**Made available by Shoppers Drug Mart through the Shoppers Optimum Program.**

To donate your Shoppers Optimum Points, please go online to: [www.shoppersdrugmart.ca/donate](http://www.shoppersdrugmart.ca/donate) and browse the Shoppers Optimum Section. Then click on "donate your points". If you are not presently a Shoppers Optimum Member, next time you are in a Shoppers Drug Mart, ask for a card, which will be issued to you right on the spot at no cost.



Braden, friend Courtney Krentz, dad Mike, and brother Justen

# Braden Close

Submitted by Catherine Close

Braden, with help from his family and friends, raised \$2364, a new record, in his 3rd Annual "Do It for Spina Bifida" bike ride. The money is donated, half to Spina Bifida research, and half to the "Rutley Crescent Park Project," which is a playground project in Braden's neighborhood. To date, Braden has raised \$6470 in three years, with half of the proceeds going towards the SBHAC Research Fund.



## Hope is in the air

**Living with a serious illness is not easy. Often, needed care is hundreds of kilometres and thousands of dollars away. Thankfully, there's Hope Air.**

Hope Air is a registered charity that helps Canadian citizens and landed immigrants in financial need get to needed medical care outside of their home communities. Since 1986, Hope Air has arranged over 44,000 flights from hundreds of communities across Canada. Based in Toronto, Hope Air's unique service exists through the generous support of private and public citizens.

To request Hope Air's services, call 1-877-346-HOPE (4673), or go to [www.hopeair.org](http://www.hopeair.org). Please submit requests three or four weeks in advance of a scheduled appointment.

Cassandra and Walter Skomoroh



Nicholas and Nora Didora



## Message from Finland

**Sari Laakkonen, a 29-year-old Finnish woman who has spina bifida, has a five-year-old son with spina bifida.** In an effort to bring people together and open a line of dialogue, Sari has a website that lets parents with spina bifida who have children with spina bifida, talk to each other.

The website address is:

<http://groups.msn.com/spinabifidaparentswithsbkid.com>.

## Dreams Take Flight

**Dreams Take Flight is a non profit organization that flies physically, mentally, or socially challenged children throughout North America.**

Volunteers who work for the Air Canada family in Canada and the United States run *Dreams Take Flight*. Air Canada donates the aircraft.

Nicholas Didora and Cassandra Skomoroh were two children who flew from Winnipeg to Florida on April 21, and spent the day at Disney World.

## Medtronic's Hydrocephalus Therapy Booklet

**Medtronic is a leading medical technology company that has published a booklet that helps people with hydrocephalus and their families understand the condition and its treatment.**

The booklet explains hydrocephalus, and includes information on

- diagnosis
- treatment
- complications
- emotional support

If you are interested in receiving this information, **free of charge, please call Medtronic Neurosurgery at 1-800-268-5346 ext. 5319**

## SBHAC'S Privacy Statement

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1-800-565-9488 or via email at: [spinab@mts.net](mailto:spinab@mts.net)

### Nova Scotia

#### \$50 000 raised in one day

Submitted by Francis Durand

We all sang *the sun will come out tomorrow* on June 4th, and it did. June 5th was so far the best day of the year for many reasons. First, because of the hot sunny day - well, not really. It was because of the 13th Annual SBHANS Slo-Pitch Fund-Raising Tournament.

It was a struggle to get to this wonderful day, but we made it and it turned out to be a great day. I would like to say a big thank you to the 36 teams for their great support in raising around \$50 000.

I want to thank our sponsors and supporters. I also want to send out a big thank you to my volunteers. We did, however, run into a few problems this year. We only had 36 teams, which required changing the schedule at the last minute. We also had a lot of problems trying to get volunteers. This tournament required over 50 people for the event, and as of May 26th, I only had 15 people. So that things ran smoothly, I decided to ask the teams to self-umpire and keep score. Thank goodness they all agreed to this because I still only had 15 people as of June 4th. This worked so well, we will be doing this again next year. Speaking about next year, plans are already underway for the 14th Annual Ball Tournament on June 4th, 2005.



Ashok Bhargava, SBHAC Board of Directors, Parminder and Jassal, and Colleen Talbot, SBHAC President

### British Columbia

Submitted by Pauline Dooley

Ashok Bhargava (left), Parminder & Emin Jassal (middle), and Colleen Talbot (right) attended the Scott Road Sikh Temple in Surrey on Father's Day. They attended the temple in the morning and set up a display promoting awareness of folic acid and also how our association helps families. Many thanks for the generous donations made by people attending temples.

### North Saskatchewan

Christine Scherr presented a cheque to the Children's Health Foundation on behalf of the Spina Bifida and Hydrocephalus Association of North Saskatchewan at a Radiothon.

Laurel Scherr was presented with an award on May 13th, 2004 for Community Development and Social Activism. Laurel and four other women won the award for their work on the Everybody's Playground Committee. Laurel helped raise \$200 000 in three years. The money was raised despite many obstacles, and it was used to build a playground facility.

Everybody's Playground is Saskatoons first, and only, totally accessible and inclusive playground facility. Laurel Scherr is the President of the Spina Bifida and Hydrocephalus Association of North Saskatchewan



Laurel Scherr



Christine Scherr

Do you have a story that you would like to share with our members? Write to us or email us at [spinab@mts.net](mailto:spinab@mts.net)

# Sommers & Roth

## Barristers and solicitors

The **Sommers & Roth** 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 their client, they do not charge for their services. For free consultation

- call 1-800-961-7356 or (416) 961-1212
- fax (416) 961-2827
- visit [www.sommersandroth.com](http://www.sommersandroth.com)

*“When one door of happiness closes, another opens”*

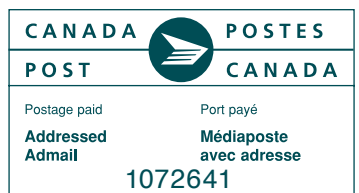
but often we look so long at the closed door that we do not see the one which has been opened for us. - Helen Keller



**Spina Bifida and Hydrocephalus Association of Canada**

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Winnipeg, Manitoba R3B 0V3



SBHAC'S primary source of financial support is through donations from companies, unions, service groups and the general public, if you wish to assist us in providing our services and programs please call 1-800-565-9488