



**ANNUAL REPORT
2007 – 2008**

Spirit. Breakthrough & Hope

Message From Our Honourary Patron



**THE LIEUTENANT
GOVERNOR OF ONTARIO**
David C. Onley



THE LIEUTENANT GOVERNOR OF ONTARIO
LE LIEUTENANT GOUVERNEUR DE L'ONTARIO

2007 - 2008

As your Honorary Patron, it is with pleasure that I extend greeting to the Spina Bifida & Hydrocephalus (SB&H) Association of Ontario.

Throughout your thirty-five year history, you have encouraged individuals with spina bifida and hydrocephalus, and been a mainstay of support for their families in facing the challenges of living with SB&H. You have fostered the spirit of self-help, educated women of child-bearing age, and been a helpful resource to social service professionals as well as ably continuing your advocacy role and expanding public awareness.

As The Queen's representative in Ontario, I congratulate the Board of Directors and the hard-working staff and volunteers for another successful year dedicated to improving the lives of those touched by SB&H.

A handwritten signature in black ink that reads "David C. Onley". The signature is written in a cursive style.

David C. Onley

Purpose

SB&H believes that a day will come when spina bifida and hydrocephalus will no longer affect people's lives. And we're working to make that happen. It can only be accomplished through education, awareness, and advocacy that will drive research. It is our hope that we can facilitate the reduction and ultimate eradication of these conditions.

We want to build a society that is sensitive, supportive and responsive to the needs of those living with or affected by these disabilities.

Until that day, SB&H will continue to provide support, care and information to meet the needs of people living with these conditions. People working together offers the best hope of all for improving the quality of life of all people with spina bifida and/or hydrocephalus.

"The support and care SB&H has provided to our family cannot be repaid in our lifetime."

Clara McPherson
Parent



Spirit. Breakthrough & Hope

Message from The Chair



It has been almost a full year since I took on the role of Chair of the Board. A lot has happened in the past 11 months and there is a great deal of excitement about a number of initiatives underway.

We are thrilled to be part of a strategic alliance with a group of charities representing various neurological conditions. This group is operating under the banner “Neurological Health Charities Canada” (NHCC). In this venture, SB&H is joined by some much larger organizations including ALS Society of Canada, Multiple Sclerosis Society of Canada, Muscular Dystrophy Canada and Parkinson’s Society of Canada. The mandate of the NHCC is to raise awareness and advocate for federal funding to help improve the quality of life of people affected by these conditions. On behalf of SB&H, Past Chair, Derryn Gill and Executive Director, Joan Booth are leading the charge in this area. The alliance offers great hope for recognition, research and funding for the future.

Our recently established and world class Medical Advisory Board (MAB) will be meeting early in the fall to discuss ways to enhance access to and improve services. As well, the MAB will assist us in identifying best in class research initiatives and providing advice and direction to our Board of Directors. We are very excited about working closely with this talented group of surgeons, scientists, nurse practitioners and neuropsychologists.

The Board of SB&H is in the process of moving from an operational function to a leadership and governance role with an emphasis on fundraising and advocacy. This change is the result of a strategic review conducted by outside experts, who strongly recommended that we migrate in this direction. After careful review, the Board agreed to commence the process and we are hopeful that this will be completed by the fall. The operational and support work will continue under the domain and direction of the Executive Director and staff. In support of this positive direction, we are also re-aligning our staff resources to create more capacity for raising both awareness and funds.

In an attempt to create more strategic alliances and to partner and share information, resources and research, we are reaching out to the other provinces and national bodies, the United States, the United Kingdom and further abroad. As we are all in search of eradicating spina bifida and hydrocephalus, we must break down the silos and work collaboratively and cooperatively to reach the finish line. I hope each of you is as inspired as the Board to make a meaningful contribution to achieve our lofty goals.

As you review the Annual Report, you will note that we have a \$90,000 surplus for the fiscal year. It is important to recognize that this much appreciated gift is solely the result of an unexpected bequest and this should not be reflected upon as a general increase in fundraising. A careful review of the financial statements will reveal that it was pretty much business as usual and that our revenues are generally offset by our expenses.

Positively, our fundraising events are gaining momentum! The success of our second annual charity golf challenge proves that we are on the right track! The “Thank Goodness It’s Friday” lottery calendar and numerous community events have exceeded our expectations in terms of participation, fundraising and creating awareness of spina bifida and hydrocephalus.

I truly believe that we are at a tipping point and that we are on the brink of great achievements. Together with the continued support of our partners, sponsors and donors we will reach our goals.

Marc Garson

Contributing Generosity – Volunteers

Over the past year, we were privileged to benefit from the valuable contribution of volunteers at every level. From leadership on our Board of Directors, to program and service delivery, fundraising and office assistance, our volunteers thoughtfully chose SB&H and gave of themselves. 238 volunteers contributed 4,193 hours. To all of our volunteers we offer a heartfelt thank you.

Volunteers learned new skills, made new connections and experienced personal achievement. Many gained relevant work experience to further their careers while others found a meaningful way to give back to society.



Giving and receiving every step of the way!

THANK YOU ALL!

"Thank you for choosing me to be a volunteer at SB&H. I appreciate all your help. I sincerely believe I was the one who most benefited. I think your organization does great work." - Sophia

Bonnie E. Charbonneau Award of Distinction

The most prestigious award the Association bestows to acknowledge the exceptional quality that inspires admiration, hope, courage and strength in others.

This year, we honour **Rose Weinberg** for her outstanding contribution toward enhancing the quality of life of children with spina bifida and hydrocephalus. Rose has dedicated over 20 years to the Kids on the Block program. Through her commitment and tireless efforts, more than 500,000 school-age children learned about disabilities and accepting differences.

Citation of Merit

Given for outstanding leadership and community involvement.

Tanya Fortier Teresa Wammes



Rose Weinberg with KOB puppets and puppeteers.

What We Do - A Look at Programs and Services

The Association is here because people need us. For over a third of a century, we have supported those affected by spina bifida and hydrocephalus. Now is the time to celebrate our achievements.

We focused on public education and awareness activities regarding the prevention of neural tube defects such as spina bifida, through the proper use of folic acid. SB&H also launched a powerful awareness campaign for Normal Pressure Hydrocephalus (NPH), a condition that affects adults 60 years and older.

Our programs and services helped improve the quality of life of all individuals living with these complex and disabling medical conditions.

Care and Support

Thousands of people from across Ontario reached out for help from SB&H. We answered the call from adults, children, youth, parents, families and caregivers as well as health care and social service professionals. Through our toll-free help line, email, website and personal meetings we provided information, support and referrals to other services.

JULIA'S STORY

Ever since she was a little girl, Julia Chiarameda had a dream in her heart that made her smile. She always believed that she would grow up, get married and have a family of her own. Being born with spina bifida, Julia's life has been full of challenges. Some were physical, while others were more related to the attitudes of people in her life. There were a few who weren't convinced that her dream would come true. Julia knew better. She understood that a lot of work, commitment and a little faith in the world are what was needed to make dreams become reality.

Julia contacted SB&H to ask questions about women with spina bifida and hydrocephalus having babies. After extensive research, we provided the best information available and linked her with other women with spina bifida who had become mothers.

It seems she got what she needed. In March of 2007, Alexander Sloane was born – to Julia and her husband Jason – healthy, happy and just as she expected.



Julia, Jason and Alexander

In 2007, SB&H introduced a safe place for youth with spina bifida and/or hydrocephalus (sb/h) to gather on the Internet – “Click With Us”. The Youth Section of the SB&H website was designed to offer young people clear options for obtaining support, asking questions, finding resources, networking with their peers or simply playing games and puzzles. Visitors to the site are guided by six characters to which they can relate.

Our Online Community Forum is an important information and networking service for individuals in smaller communities who are isolated, both geographically and through limitations of their disability. Users learn about personal coping strategies and establish peer networks. Our commitment is to make certain that care and support services reach across the entire province.



Additional support was provided through:

- Meeting with hundreds of families at Ontario children's treatment centres
- Connecting individuals with like experiences through our Linking Program, for parents, adults and youth
- Facilitating Taster's Clubs for adults with sb/h to meet in a relaxed, supportive setting. The program's success was evident by increased attendance and the desire of volunteers to form new clubs.
- Group meetings held across the province for adults and parents
- Partnerships with other community groups to provide youth with opportunities for socialization.

Awareness and Education

Knowledge is empowerment. SB&H provided people affected by spina bifida and hydrocephalus with accurate, up-to-date information. Our assistance enabled them to make informed decisions regarding care, treatment and management of these conditions. Most importantly they learned coping strategies and became better self-advocates. They relied on the educational programs and materials provided by SB&H.

Our awareness initiatives informed the general public and education, medical and social service professionals about spina bifida and hydrocephalus. More people learned about prevention, symptoms, diagnosis and treatment through the Association's education activities this past year.

Our **"Folic Acid, It's Never Too Early" Awareness Campaign** informed thousands about the benefits of taking folic acid to prevent neural tube defects such as spina bifida. All women of childbearing age are at risk of having a spina bifida affected pregnancy. Getting vital information about folic acid helped prospective parents. Our awareness program ensures that consistent information is being provided in every community in Ontario.

We responded to hundreds of individual requests for information by researching and customizing information materials. Relevant information about every aspect of sb/h is prepared and distributed regularly to parents of newborns, individuals, family members, professionals, hospitals, children's treatment centres and other community partners.



Dr. James Drake, Chair of SB&H Medical Advisory Board

People like Paula Sarraf and her son Jordan leaned on SB&H this year for support and information to better understand their situation and how to deal with it. In her own words, Paula said,

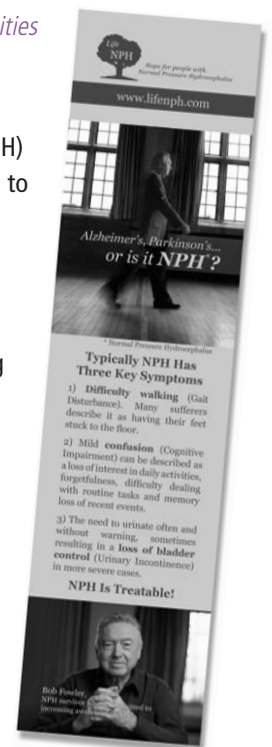
"They (SB&H) were a wonderful source of understanding, kindness, support and education that benefited our family greatly. We received vital information about hydrocephalus in the form of reading materials, journals and testimonials that helped us deal with Jordan's needs. The more we learned as a family, that we could utilize in our home environment, the greater the opportunities would be for Jordan to become a successful member of society."

As our population ages, the incidence of Normal Pressure Hydrocephalus (NPH) is on the rise. SB&H launched the first Canadian, **NPH Awareness Campaign** to inform the public and healthcare professionals of this little known neurological disorder. NPH is often misdiagnosed or undiagnosed but is treatable and virtually reversible. If left untreated, individuals will continue to suffer debilitating symptoms.

Kids on the Block (KOB) is an award winning education and outreach program performed in schools featuring puppets with and without disabilities. Children and educators alike learn about disabilities and stereotypes. SB&H supports this program through sponsorship and volunteer training with our partners.

Other education and information programs and services include:

- **Current magazine** and a community newsletter, together with our comprehensive website increases outreach to the public and people whose lives are affected by spina bifida and/or hydrocephalus.
- Our **Resource Centre**, one of the best places to locate current information about all aspects of spina bifida and hydrocephalus and other disability related topics.
- **Presentations** by noted professionals regarding cutting-edge research and available treatment options.
- **Community education** at health and pre-natal fairs as well as children's rehabilitation centers.



Jordan Sarraf

By the Numbers (in Ontario)

1,132,874

hits on the SB&H website

811,053

hits on the Folic Acid website

125,047

visits to our website

78,440

Folic Acid awareness materials provided

74,200

NPH brochures and bookmarks distributed

40,736

individuals received support, information and education

35,000

school children learned about sb/h through the Kids on the Block program

21,000

educational materials about spina bifida & hydrocephalus distributed

4,193

volunteer hours

3,000

readership of each issue of *Current* magazine

2,116

help line calls logged

795

customized information packages provided upon request

526

registered users on our Online Community Forum

480

complimentary age-appropriate books informed our youth

238

people volunteered in the community, fundraised and provided office administration

Building Relationships

At SB&H we understand that much more can be accomplished when individuals and organizations share hopes, dreams and goals and work together. We give a voice to our members' concerns and needs through participation in coalitions and alliances at local and provincial levels.

We entered into an exciting partnership with a group of neurological disease/disorder charities to form Neurological Health Charities Canada (NHCC). The group mandate is to advocate for positive change for those affected and improve their quality of life. The NHCC will serve as one voice, providing a stronger sense of community and influence. This will position neurological conditions as a major health issue in Canada and bring our common issues to the forefront of public policy.

A second strategic initiative was the expansion of our Medical Advisory Board (MAB) from one founding member, Dr. James Drake, to an esteemed group of eleven. The MAB includes surgeons, neuropsychologists, clinical nurse practitioners and scientists, lead by Dr. Drake. We believe this world-class board will provide us with the best in medical guidance and support, and bring a significant level of credibility to SB&H.



Derryn Gill Past Chair of SB&H (fourth from the right), with members of Neurological Health Charities Canada and Federal Minister Tony Clement (fourth from left).

Research

The Association supported research that contributes to finding a cure and improving the quality of life for all individuals with spina bifida and/or hydrocephalus and their families. We collaborated with leading research facilities, including the Hospital for Sick Children, Bloorview Kids Rehab, University of Toronto, St. Michael's Hospital and McMaster Health Sciences Centre.

Scholarship and Bursary Programs

Scholarships and bursaries were awarded to individuals with spina bifida and/or hydrocephalus to encourage and support them to achieve their educational goals.



Dr. Robin P. Humphreys presenting scholarship certificate

DR. E. BRUCE HENRICK SCHOLARSHIP

Amanda Johnson - Thunder Bay

Katie Meilleur - Richmond Hill

Jonathan Pantano - Ridgeway

Trevor Plug - Thorold

Curtis Preiss - Paris

Daryl Wakunick - Welland

Lindsay Wall - Kingston

LUCIANA SPRING MASCARIN BURSARY

Michael Lauzon - Windsor

Bonnie Youngs - Thamesville

Raising Funds and Community Profile

SB&H is the only organization in Ontario providing vital information and support to those living with the extraordinary challenges of spina bifida and hydrocephalus. To meet these needs, the Association generates 100% of its operating revenue through numerous fundraising initiatives and community support. These are the highlights.

2nd Annual SB&H Charity Golf Challenge

"I never thought when I started that I would actually manage to play all 100 holes – great day!"

The golf challenge is a unique event. Individuals must raise pledges to be eligible to participate. Then the fun begins. Golfers spend the day challenging themselves to play 100 holes of golf. The spirit and camaraderie makes it a great experience for everyone. More than \$25,000 was generated through sponsorships, pledges and a silent auction.

The success of the golf challenge is due to those who volunteered to raise funds and awareness for SB&H and to the generosity and support of our partners, **Codman, a Johnson & Johnson Company, Scotia Private Client Group and ScotiaMcLeod.**



2008 "Thank Goodness It's Friday" Lottery Calendar

This was a fantastic year for calendar sales thanks to the hundreds of SB&H members, their friends and families, volunteers and community partners who sold 3,000 of these beautiful wall calendars. Their interest and perseverance made this annual fundraiser a huge success. Our featured photographer Jared Black, is a young man with spina bifida and hydrocephalus whose unique perspective provided outstanding photographs. His talent was shared by thousands of Ontarians who either purchased or received a calendar as a gift. A thriving fundraiser for 14 years, this is the single most popular activity that engages our members.



Achieving their personal best – Members meet the challenge!

Karen Howard has normal pressure hydrocephalus and just walked her first half marathon in Prince Edward County, Ontario in October 2007. A tremendous challenge in itself, she also raised more than \$2,200 for SB&H programs.

It was also a first for **Renée Farrell**, a young woman with spina bifida. On the very same day, Renée ran 21.1 difficult kilometers in the Toronto Half Marathon and successfully raised \$1,800.

It has been said that attitude is half the battle and both of these women certainly had the right attitude. When they combined this with sheer determination and courage, they had the power to achieve their goals. Congratulations and thank you, Karen and Renée!

KAREN HOWARD'S STORY

"It has been a long and sometimes difficult journey from when I was diagnosed with adult onset Normal Pressure Hydrocephalus (NPH) to the present time. This is probably what makes my achievement very special to me. Also, the fact that I could complete the walk and raise money for hydrocephalus makes it more worth while." - Karen Howard

Before Karen was diagnosed, she lost the ability to speak, walk and talk. After receiving treatment for hydrocephalus and spending years in therapy learning to regain these basic skills, she decided she needed to be more active. As a graduate of physical education, sports had always been very important to her. So, with the help of her friends, she trained for the half marathon. Karen knew that she could not run the distance but if she took her time, she could walk it.

"If the money I raised means that I can make a difference in one person's life then it was worthwhile. By helping the Association in their campaign to raise awareness of NPH, a condition that affects adults, it is my hope that more people will receive accurate, early diagnosis and treatment."



Community organizations raise funds for SB&H

Service Clubs across the province conducted events throughout the year and donated proceeds to SB&H. We are very grateful for the continued support provided by branches of the Royal Canadian Legion, Lions and Lioness Clubs, Rotary International, Optimists and the IODE, Ontario Chapter.

Both the Ontario Camaro Club and Corvette Club of Ontario have been big supporters of SB&H for many years. Annually, they donate the proceeds from various fundraising activities and name our organization as their charity of choice.



SB&H has a new look at the LCBO

The Association was selected once again to participate in the LCBO's 600 store, province-wide Coin Box Program. The public supported SB&H by donating over \$8,000 in change. This year, we developed a new backer card to raise awareness of the benefits of folic acid to ensure that "every healthy baby is a victory". We would like to thank the LCBO, its employees and customers for providing this opportunity.



To the thousands of individuals who bought a calendar, made a donation, participated in or conducted an event, we offer our heartfelt gratitude. Thank you all for making a difference in the lives of children, youth, parents and adults living with the challenges of spina bifida and/or hydrocephalus.

Spirit. Breakthrough & Hope

Recognizing the Generosity of Our Donors

We are grateful for the generosity of our supporters, partners and friends.
Please know that your gift is important to us.

PLATINUM \$10,000+

Aur Resources Inc.

GOLD \$5,000+

AstraZeneca Canada Inc.
CIBC World Markets Children's Miracle Foundation
Harry E. Foster Charitable Foundation
Green Shield Canada Foundation
Bernie Schmidt
Therm-O-Comfort Co. Ltd.

SILVER \$1,000+

Alice & Murray Maitland Foundation (The)
Gordon Baker
Charitable Foundation of the Ontario Grocery Industry
CIBC
CVRD Inco Limited
Gowling, Lafleur Henderson LLP
Grand Bend Optimist Club
Holger & Claudette Kluge Family Foundation (The)
Johnson & Johnson Medical Products
Julie-Jiggs Foundation (The)
John MacLachlan
Million Dollar Roundtable Foundation
Daniela Protomanni
S.C. Johnson and Son, Limited
Royal Canadian Legion Branch #234
Wyeth Consumer Healthcare Inc.
Yamaha Motor Canada Ltd.

BRONZE \$500+

A & A King Family Foundation
Michael Bloom
BMO Financial Group
Burlington Lions Club
Ensurco Insurance Group
Georgina Foundation (The)
Ilderton and District Lions Club
International Order of The Alhambra Guzera Caravan #72
Ontario Camaro Club
Lanxess Inc.
Lioness Club Cobourg
L.V. Lomas Chemical Limited
Fiona Nicoll
Renee's Gourmet Foods Inc.
Shoppers Drug Mart
Stikeman Elliott LLP
Leon's Furniture Limited
TWM Compu Age
Tyco Electronics Canada Ltd.
Mark Tyler
WD-40 Products (Canada) Ltd.
Heather Wills

EMPLOYEE GROUPS

Bell Canada – Helping Hands Open Hearts
BMO Fountain of Hope Employees' Foundation
Hydro One Inc.
IBM Employees' Charitable Fund
Kodak Employee Chest
London Life Insurance Company
Ontario Power Generation
TELUS Corporation
Toronto Hydro Employees Charity Trust

GIFTS IN KIND \$300+

Bulova Watch Company Limited
CHFI & 680 News
Deerhurst Resort
Druxy's Inc.
Mizuno Canada Ltd.
Spin Master Limited
VIA Rail Canada Inc.

We would like to extend a special thank you to the many donors, not identified here, whose contribution enabled us to achieve our goals. Your generosity gives strength and hope to those in need.

Summarized Annual Financial Statements

STATEMENT OF FINANCIAL POSITION

February 29, 2008

	2008	2007
ASSETS		
Cash and short-term deposits	\$333,888	\$256,385
Other current assets	71,680	56,506
Total current assets	405,568	312,891
Endowment investments and security deposit	227,029	204,427
Equipment	10,667	12,422
Total assets	\$643,264	\$529,740
LIABILITIES		
Accounts payable and accrued liabilities	\$26,392	\$29,364
Deferred contributions	2,857	4,286
	29,249	33,650
NET ASSETS		
Net assets invested in equipment	7,810	8,136
Net assets restricted for scholarships and research	228,932	201,895
Unrestricted net assets	377,273	286,059
	614,015	496,090
Total liabilities and net assets	\$643,264	\$529,740

STATEMENT OF CHANGES IN NET ASSETS

Year ended February 29, 2008

			2008	2007
	Unrestricted	Restricted/other	Total	Total
Beginning of year	\$286,059	\$210,031	\$496,090	\$444,366
Revenues over expenses (expenses over revenues) for the year	95,638	(4,750)	90,888	463
Endowment contributions and reinvested interest income	-	27,037	27,037	51,261
Investment in equipment	(4,424)	4,424	-	-
End of year	\$377,273	\$236,742	\$614,015	\$496,090

STATEMENT OF CASH FLOWS

Year ended February 29, 2008

	2008	2007
Cash provided by (used for):		
General operating activities	\$77,492	\$(12,051)
Investment activities	11	(412)
Net increase (decrease) in cash for the year	77,503	(12,463)
Cash and short-term deposits, beginning of year	256,385	268,848
Cash and short-term deposits, end of year	\$333,888	\$256,385

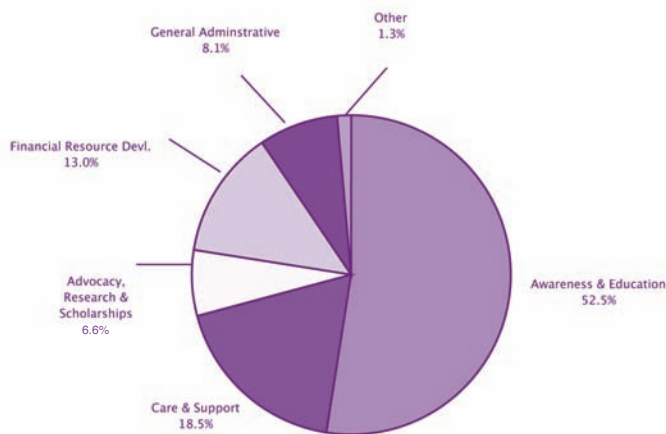
Summarized Annual Financial Statements

STATEMENT OF OPERATIONS

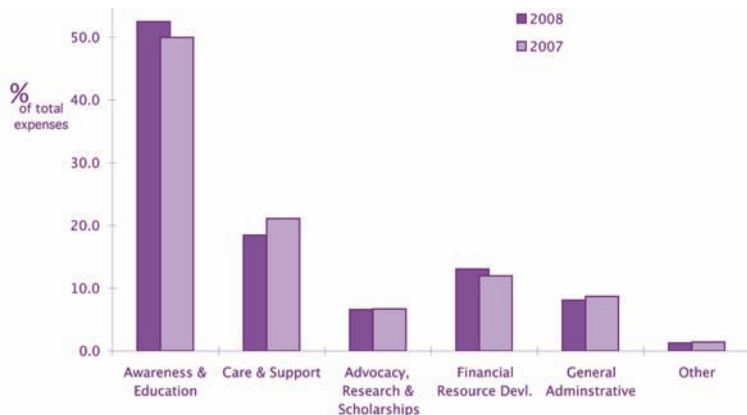
February 29, 2008

	2008	2007
REVENUES		
Fundraising activities, net	\$266,638	\$272,008
Contributions - general	162,725	161,643
Contributions – bequests	119,250	-
Membership dues, investment income and other	20,454	16,769
	569,067	450,420
EXPENSES		
Awareness and education	250,951	225,191
Care and support	88,299	95,016
Advocacy, research and scholarships	31,560	30,245
Financial resource development	62,357	54,024
General administrative	38,833	38,965
Amortization of equipment	6,179	6,516
	478,179	449,957
Excess of revenues over expenses	\$90,888	\$463

Allocation of Total Expenses 2008



Expenses Allocation Comparison



Auditors Report on Summarized Financial Statements

The accompanying summarized balance sheet and statements of operations, changes in net assets and cash flows are derived from the complete financial statements of Spina Bifida and Hydrocephalus Association of Ontario as at February 29, 2008 and for the year then ended on which we expressed an opinion without reservation in our report dated May 16, 2008. The fair summarization of the complete financial statements is the responsibility of management. Our responsibility, in accordance with the applicable Assurance Guideline of The Canadian Institute of Chartered Accountants, is to report on the summarized financial statements.

In our opinion, the accompanying financial statements fairly summarize, in all material respects, the related complete financial statements in accordance with the criteria described in the guideline referred to above.

These summarized financial statements do not contain all the disclosures required by generally accepted accounting principles. Readers are cautioned that these statements may not be appropriate for their purposes. For more information on the entity's financial position, results of operations and cash flows, reference should be made to the related complete financial statements.

Cholkan + Stepczuk LLP

Toronto, Ontario
May 16, 2008

Cholkan + Stepczuk LLP
Chartered Accountants

Leadership

The ladder of success is best climbed by stepping on the rungs of opportunity.

- Ayn Rand

Honourary Patron

HON. DAVID C. ONLEY

Lieutenant Governor of Ontario

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DERRYN GILL, Past Chair

JOHN MACLACHLAN, 1st Vice Chair

CLAUDIO CINAPRI, 2nd Vice Chair

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BARBARA ALDRIDGE – Information & Services Assistant

SHAUNA BEAUDOIN – Information & Services Coordinator

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JOHN THOMPSON – Development & Promotion Coordinator

Spirit. Breakthrough & Hope



COMMUNITY REPRESENTATION

Burlington/Oakville

Hamilton

Hanover

Kitchener/Waterloo

London

Mississauga

Niagara

Oshawa

Ottawa

Owen Sound

Peterborough

Richmond Hill

Sault Ste. Marie

South Georgian Bay

Sudbury

Toronto

West Lorne

Windsor

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