

SPINA BIFIDA & HYDROCEPHALUS ASSOCIATION OF ONTARIO
ANNUAL REPORT 2008 - 2009

Information Education Support




Spirit. Breakthrough & Hope
Spina Bifida & Hydrocephalus
Association of Ontario

MESSAGE FROM

OUR HONOURARY PATRON



THE LIEUTENANT
GOVERNOR OF ONTARIO
David C. Onley



PURPOSE

To promote the welfare of people with spina bifida and hydrocephalus and help families cope with the daily challenges of living with these conditions. We strive for the day when the incidence of spina bifida and hydrocephalus is eliminated. These significant goals will be accomplished through education, awareness, advocacy and research. It is our sincerest hope that we can help children, parents, adults and their families live in a society that is sensitive, supportive and responsive to their needs.

People united in a common purpose offers the best hope of improving the quality of life for all those affected by spina bifida and/or hydrocephalus.

MESSAGE FROM THE CHAIR



This past year has been a real journey for SB&H as we found ourselves in the midst of a transition to a Board that is focused on governance and fundraising. The operational staff shifted their emphasis to fostering strategic linkages, awareness and securing stable and sustainable sources of revenue.

The Board has given a clear mandate to our Executive Director, Joan Booth, to align our small but mighty Association with larger and more influential brain disorder groups. These efforts will secure government funding for research and improve care and treatment. This strategy has been very successful to date through our membership in the Neurological Health Charities Canada (NHCC) collective. Similarly, we are building better relations with our provincial, federal and international partners, who experience like challenges and seek the same end results. All have received us warmly in our efforts to reach out, cooperate and collaborate.

Our folic acid awareness and education program has become prominent throughout Ontario. The Association's education campaign about normal pressure hydrocephalus (NPH) gained momentum and has been well received. We have been developing an exciting, new, and much-needed guide about hydrocephalus to inform health care professionals and support families.

The streamlined and committed SB&H Board of Directors continues to work effectively to reach the ultimate goal of bringing influence and leadership to the spina bifida and hydrocephalus community. We are constantly striving to build the Board with new members who bring enthusiasm, commitment and ideas around awareness, fundraising and support.

The success of our annual Charity Golf Challenge and first Spirit Wheel Walk Run event is both impressive and inspiring during these fiscally challenged times. There is no doubt that we are part of a passionate and dedicated community who are working harder than ever to raise awareness, support and funds for this worthy and very meaningful cause. The future can only bring improvements and enhancements to the lives of all persons affected by these conditions.

This year the Association allocated reserved funds to develop long-term partnerships and sustainable resources resulting in a year-end operating deficit of \$42K. The investment has shown promise to-date.

SB&H has turned the corner from reactive to proactive. We are committed to developing relationships with other charities, the medical community and financial supporters that will establish the building blocks for the future.

The SB&H Board of Directors truly believes we are on the right path to creating a better life for families. We appreciate your support. Thank you.

Marc Garson

WHAT WE DO

SUPPORTING FAMILIES

Each year, SB&H assists thousands of people whose lives are impacted by spina bifida and/or hydrocephalus (sb/h). Our team of volunteers and staff shape and deliver programs and services that provide essential information, education and support.

Understanding the complexities of spina bifida and hydrocephalus and learning coping mechanisms is crucial for children, parents and adults alike. Gaining this knowledge provides the necessary tools to make appropriate decisions to optimize health and manage day-to-day living.

Education & Information

In response to requests from around Ontario, we prepared and delivered customized packages that provide up-to-date, researched and comprehensive information on a variety of topics related to sb/h.

Furthering our initiative to help children and youth, from five to nineteen, gain a better understanding of their condition, we distributed hundreds of complimentary age-appropriate books. Educator's Guide and Handbooks given to parents enabled them to advocate for appropriate educational support for their children.

More popular and valuable than ever before, CURRENT magazine was a mainstay in SB&H's efforts to educate, inform and inspire everyone we serve and helped us reach out to those we were yet to meet. Each issue was filled with articles about the latest medical information, intimate and motivational stories, professional advice, and new resources.

I think SB&H is doing a great job. You provide a lot of information and recommend places for people to go if they need more information.

I thoroughly enjoy the "Current" Magazine and all other literature I receive. SB&H continues to grow and makes much needed services available to all individuals with sb/h.



Carrie Worobess

Care & Support

The Association and all of the resources at our disposal were there for adults, parents, youth, caregivers, and extended family. Through our toll-free help line, on-line community forum, support groups and attendance at rehabilitation clinics SB&H provided guidance, referrals and support.

We facilitated community networking opportunities in Huron County, London, Ottawa and the Greater Toronto Area as well as connected people of all ages with like experiences who wanted local support through our Linking Program.

Additional support was provided through our Scholarship and Bursary Programs which gave financial assistance to students with sb/h who wished to further their educational goals. We would like to congratulate last year's recipients.

Dr. E. Bruce Hendrick Scholarship

Ariel M. Brown-Cruz – Keswick

Stephanie Clements – London

Kelly Kolkin – Hamilton

Daniel Lamb – St. Davids

Chantelle Low – Brampton

Nicole Murphy – Campbellville

Emma Lee Warren – Trout Creek

Luciana Spring Mascarin Bursary

John Mahoney - Windsor



Kelly Kolkin with Dr. Robin P. Humphreys

When Graham was born, spina bifida was a surprise and a mystery to me. When you have a child with medical problems, it is very comforting to speak to parents who have experience. Hospitals do miracles to fix as many things as are fixable, but not everything is fixable. So it was a revelation to me to talk to the staff at SB&H and hear that kids with spina bifida and hydrocephalus do in fact survive and thrive. And then I received a huge folder of information - information that was written for new parents, information that was up-to-date and relevant to living in Ontario.



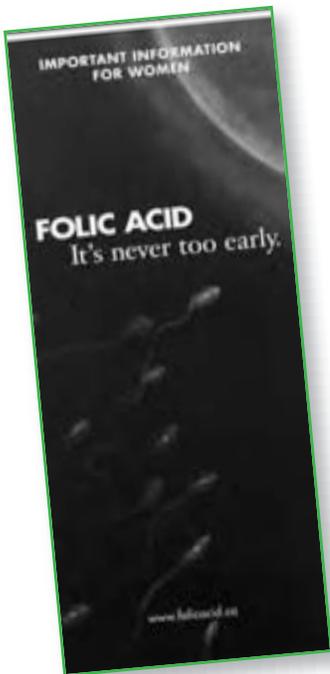
Graham and Derryn Gill

Awareness

Normal Pressure Hydrocephalus

Our normal pressure hydrocephalus (NPH) awareness campaign educated the public and healthcare providers about this emerging condition that has increased dramatically as baby boomers age. NPH typically affects adults over 55 and is particularly difficult to diagnose. Our initiative helped individuals and family members recognize symptoms and obtain early treatment.

NPH literature was distributed to neurologists, neurosurgeons, gerontologists, long-term care facilities and retirement homes throughout Ontario. The continuation of these efforts was supported by our Medical Advisory Board under the direction of Dr. James Drake, world-renowned neurosurgeon specializing in the research and treatment of hydrocephalus.



Folic Acid - "It's Never Too Early"

Until every baby is born healthy, this awareness campaign to inform women about the benefits of folic acid **MUST** continue.

Taking a multivitamin supplement containing .4 mg of folic acid has been proven to reduce the incidence of neural tube defects, such as spina bifida, by more than 70%. This is a critical message for all women of child-bearing age.

In the past 12 months, we distributed tens of thousands of folic acid brochures to doctors, public health units, hospitals and fertility clinics to raise awareness of this simple means of primary prevention. We counseled women one-on-one, attended health fairs and maintained the **folicacid.ca** website.

Kids On The Block

Winning awards and smiles from thousands of school children in Ontario, Kids on the Block puppet troupes educated and entertained. Everyone who took in a show learned about disabilities and stereotypes. It is all about changing attitudes from a very young age and taking the DIS out of disability. The show features Valerie, a puppet with spina bifida, and uses a unique spina bifida script. SB&H is one of several partners who underwrite this clever, outstanding program.



Building and Strengthening Relationships

Working toward common goals with like-minded individuals and organizations in 2008-2009 has begun to show results.

At their inaugural meeting in November, the new SB&H Medical Advisory Board (MAB) set an ambitious agenda – to raise the profile of and lend credibility to SB&H as well as demonstrate the depth and expertise attached to the organization.

Our alliance with Neurological Health Charities Canada has garnered commitments from federal and provincial governments to study the impact of neurological conditions with the goal to improving treatment, care and outcomes.

Taking the lead, SB&H established strategic partnerships with stakeholders and funders to strengthen our presence and enhance support programs and services in communities province-wide.



Research

SB&H worked collaboratively with government as well as leading research facilities like the Hospital for Sick Children, St. Michael's Hospital, and the University of Toronto. We continued to support on-going studies about all aspects of spina bifida and hydrocephalus. Our goal is to improve the quality of life of all individuals living with sb/h and their families.

BY THE NUMBERS

(in Ontario)

1,267,955

SB&H website hits

1,129,151

folic acid website hits

141,060

website visits

63,642

NPH brochures and bookmarks distributed

37,105

individuals received support, information and education

33,657

folic acid awareness materials provided

26,400

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

14,843

educational materials about spina bifida & hydrocephalus distributed

4,392

volunteer hours provided

3,000

readership of each issue of *Current* magazine

2,016

help line calls logged

649

customized information packages provided upon request

590

registered users of SB&H Online Community Forum

346

complimentary age-appropriate books informed youth

279

people volunteered in community programs, fundraised and provided office support

FUNDRAISING

This year our energies were focused on the development of strategic partnerships with corporations that align with our initiatives. Much effort was given to enhancing existing fundraising and awareness programs to maximize their potential. In addition new ways to generate revenue to ensure long-term sustainability of SB&H's programs and services were created.

To our partners, we say THANK YOU!

SB&H Joins Imagine Canada's Ethical Code Program



SB&H believes that transparency and accountability are essential to our success. With this in mind, in 2008 we applied and were approved as a participant in Imagine Canada's Ethical Code Program. The Code lays out a set of standards for charities to manage and report their financial affairs responsibly. By adhering to these standards, we are complying with generally accepted practices for soliciting and managing donor dollars. We are proud members.

3rd Annual SB&H Charity Golf Challenge

In May 2008 the Golf Challenge proved to be the single most successful fundraising initiative in our 35-year history. More than \$42,000 was raised. Participants obtained pledges and then challenged themselves to play 100 holes of golf in one day. It was a tall order but our golfers were up to it! This very special experience delivered a full day of fun, friendship and great spirit.

The success of this event was due to the many individuals who raised pledges, our sponsors and countless organizations who donated prizes. Special media guests helped raise awareness of our event and sb/h through their on-air and web endorsements.



Justin Parappally, Jeff Hyde, Eric Smith (Fan590), Bill Hayes (Q109), Shannon Smith, Gillian Akai

Claudio and Adriana Cinapri, father and daughter



Spirit Wheel Walk Run... a new fundraising and awareness initiative for SB&H

In celebration of Spina Bifida & Hydrocephalus Awareness Month we introduced the Spirit Wheel Walk Run (SWWR). This was a new opportunity for members and their families to get involved in a meaningful way. They raised funds for SB&H programs and services and sought to increase awareness for the conditions in communities province-wide. This would prove to be an instant hit. Caring individuals created their events where they live and for a distance of their choosing, on any day throughout the month of June. Fifteen community-focused SWWRs were conducted from North Bay to Hamilton. We were very grateful to everyone who participated in this inaugural event.



Andrew Butler is 14 years old and has spina bifida and hydrocephalus. Pictured here with his mother Mary, Andrew was one of the first to obtain pledges from North Bay residents.



Lori and Mitch Tange organized a walk with 30 close friends and family. Their son Hayden was born October 2007 with spina bifida and hydrocephalus. On June 14th Hayden's Possee walked 7 km at Cootes Paradise in Hamilton.

2009 "Thank Goodness It's Friday" (TGIF) Lottery Calendar... A Celebration of Children and Youth



A CALENDAR OF HOPE
Spirit, Breakthrough & Hope.
Three words that capture our mission

Our first ever! The 2009 calendar featured the vibrant colours and cheerful designs created by 12 children and youth ranging in age from 3 to 19, who have spina bifida and/or hydrocephalus. Their unique styles reflected the individual nature of each of these young artists and provided insight into their extraordinary spirit and optimism. Through their works of art and personal stories we created a colourful, fun and beautiful calendar. The success of this major fundraising effort was a direct result of the commitment and dedication of more than 120 SB&H members, their families and friends, volunteers and community partners who sold 3,000 of these remarkable wall calendars. In it's 15th year, the lottery calendar fundraising and awareness initiative generated close to \$30,000 in revenue.

Emily has spina bifida and hydrocephalus. When she was born, her parents were told that she would never walk. Emily has had three major surgeries since she was 24 hours old. By her second birthday, she was walking with a walker. Emily is now a happy three year old little girl wearing braces for support, dancing, jumping and tries to run to keep up with her friends.



Emily Beauchamp,
age 3, artist

Community Comes on Strong

Biking for the well-being of others.

Josée Litalien, has been bicycling across Canada to raise awareness of spina bifida and hydrocephalus. For the past two years, she has spent time each summer crossing a portion of the country west to east. This cross-country marathon was inspired by her love of the outdoors and seeing first-hand how both a cousin and friend were affected by spina bifida.

More than just a wedding.

In lieu of wedding favours for their guests, Iryna and Steven Rizzuto made a donation to SB&H in memory of Steven's brother, Timothy Pio, who died the day he was born from complications of spina bifida. Everyone who attended the October wedding was touched by this very thoughtful and emotional gift.

Running for Pierce.

Born with spina bifida, Pierce Arani will never be fleetest of foot. That is why his mother runs for him. Beth Horodyski dedicated each of 21.1 km she ran at the Labour Day Oakville Half Marathon to her four-year-old son, as she has done every time she participated in a race. A group of more than 10 runners called "Pierce's Pacers for Spina Bifida" participated in the race and raised close to \$2,500 for SB&H.

Raising funds for NPH.

This is the second time that Karen Howard walked a rigorous half marathon, in Prince Edward County. Karen was diagnosed with normal pressure hydrocephalus (NPH) and for a long time could not walk. When she finally recovered, she took on this challenge. That's not all. Through pledges, she raised thousands of dollars to support our NPH education and awareness programs.

SB&H hits the runway.

Last November a "Frosty Fantasy" Fashion Show was held in Newmarket. This great event brought out an audience of more than 200. A portion of each ticket sold was donated to SB&H. Thank you to everyone who made this possible.

Cars for SB&H.

We were very fortunate to be able to continue our long-standing relationship with both the Corvette Club of Ontario (CCO) and the Ontario Camaro Club (OCC). Both Clubs gave SB&H generous donations resulting from the proceeds of various member events held throughout the year.

Students give back.

Teachers, students and parents of St. Teresa's Elementary School in Peterborough raised over \$800 in honour of Samantha Williams who had spina bifida and hydrocephalus and was a grade 8 student at the school. Proceeds came from various fundraising events including a family bowling night and a raffle.



Beth Horodyski and son Pierce. "We want to model to Pierce that sometimes things are difficult to do, but if you persevere, you can do it," says Beth. "It doesn't matter if you win or not. Just doing it is most important."



Josée Litalien arrives in Toronto.

The Association would like to thank the thousands of people who bought a calendar, made a donation and participated in, or conducted an event to raise funds and increase awareness of spina bifida and hydrocephalus. Together with the generosity of our partners and sponsors we were able to meet our objectives and to make a positive difference in the lives of children, youth, parents and adults living with the challenges of these conditions. Our achievements were made possible through the support of SB&H members, volunteers and the community, who continued to give from their hearts.

SB&H is extremely grateful to the following corporations, foundations, service clubs, associations and friends for their generosity and for helping us sustain and advance our work.



Marc Garson, SB&H Chair receives a donation from the Corvette Club of Ontario.

Corporations & Foundations

Alice & Murray Maitland Foundation (The)
 Arrow Hedge Partners Inc.
 Baskin Financial Services Inc.
 BMO Financial Group
 Catherine & Maxwell Meighen Foundation (The)
 Johnson & Johnson Medical Products
 Conmed Linvatec Canada
 Cormark Securities Inc.
 Druxy's Inc.
 George Lunan Foundation (The)
 Harry E. Foster Charitable Foundation (The)
 Holger & Claudette Kluge Family Foundation (The)
 Hood Packaging Corporation
 J.P. Bickell Foundation
 Lanxess Inc.
 Leon's Furniture Limited
 L.V. Lomas Chemical Limited
 S.C. Johnson and Son, Limited
 Samuel & Rose Levy Charitable Foundation (The)
 Scotia Capital
 Scotia Private Client Group
 ScotiaMcLeod
 Stikeman, Elliott, LLP
 Vale Inco
 WD-40 Products (Canada) Ltd.
 Workopolis.com
 Wyeth Consumer Healthcare Inc.

Friends

Atul Goela
 Gordon Baker
 Heather Wills
 Iryna Chapkova
 John Skogstad
 Mark Tyler

Service Clubs & Associations

Corvette Club of Ontario
 Grand Bend Optimist Club
 Ilderton District Lions Club
 IODE Provincial Chapter of Ontario
 Knights of Columbus Centennial
 Ontario Camaro Club
 Royal Canadian Legion Branch #234
 Royal Canadian Legion #275

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.

THANK YOU FOR YOUR GIFT!

VOLUNTEERS

Volunteers are an invaluable resource and we are fortunate to have some of the very best. Through their generous gift of time, volunteers provide direction and leadership to the organization, assist with the delivery of our programs and services, fundraise and help to reduce our administrative costs. Through their efforts we were able to deliver on our mission.

Volunteers have helped shape SB&H for 35 years. Thank you all for your thoughtfulness and for sharing your talent and time. We truly appreciate each and every one of you who bring so much to SB&H.



Mary Dufton pictured with John Maclachlan

Mary Dufton

Past member, SB&H Board
Regular contributor to CURRENT
Ottawa Taster's Club
Calendar Seller
Adult Link

John Maclachlan

Executive, SB&H Board of Directors
Golf Committee
Board Development Committee
Parent Link



Marian Alexander

Calendar Seller
Regional Representative
Adult Link



Fritz Schneeberger

Calendar Seller



Tanya Fortier

Regional Representative
Pre-natal Fair Attendant
Calendar Seller
Parent Link



Reynaldo Acevedo

Office Support



Lisa Harper

Huron County Taster's Club
Calendar Seller
Adult Link

"Imagine what a harmonious world it could be if every single person, both young and old shared a little of what he is good at doing."

Albert Schweitzer

LEADERSHIP

Honourary Patron

DAVID C. ONLEY

Lieutenant Governor of Ontario

Board of Directors

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JOHN MACLACHLAN, 1st Vice Chair

CLAUDIO CINAPRI, 2nd Vice Chair

MARK TYLER, Treasurer

DERRYN GILL, Secretary

JUSTIN PARAPPALLY

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MAUREEN DENNIS, PhD – The Hospital for Sick Children

SANDRINE DE RIBAUPIERRE, MD – London Health Sciences Centre

RUTH DONNELLY, PhD, C.Psych. – The Hospital for Sick Children

MILES G. JOHNSTON, BSc, PhD – Sunnybrook Health Sciences Centre

ABHAYA V. KULKARNI, MD, PhD, FRCSC – The Hospital for Sick Children

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ADRIANNA RANGER, MD, FRCSC – London Health Sciences Centre, Victoria Hospital

MICHAEL VASSILYADI, MD, CM, MSc, FRCSC, FACS, FAAP – Children's Hospital of Eastern Ontario

HERTA YU, RN, MN, APN – The Hospital for Sick Children

Staff

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HELEN SKLARZ – Director of Development & Promotion

BARBARA ALDRIDGE – Information & Services Assistant

SHAUNA BEAUDOIN – Information & Services Coordinator

STEVE KEAN – Programs & Services Coordinator

JAY POLCZER – Development & Promotion Coordinator

JOHN THOMPSON – Development & Promotion Coordinator

Spirit. Breakthrough & Hope

SUMMARIZED ANNUAL FINANCIAL STATEMENTS

STATEMENT OF FINANCIAL POSITION

February 28, 2009

	2009	2008
ASSETS		
Cash and short-term deposits	\$311,145	\$333,888
Other current assets	56,043	71,680
Total current assets	367,188	405,568
Endowment investments and security deposit	229,962	227,029
Equipment	10,711	10,667
Total assets	\$607,861	\$643,264
LIABILITIES		
Accounts payable and accrued liabilities	\$26,212	\$26,392
Deferred contributions	7,129	2,857
	33,341	29,249
NET ASSETS		
Net assets invested in equipment	9,283	7,810
Net assets restricted for scholarships and research	229,972	228,932
Unrestricted net assets	335,265	377,273
	574,520	614,015
Total liabilities and net assets	\$607,861	\$643,264

STATEMENT OF CHANGES IN NET ASSETS

Year ended February 28, 2009

	2009		2008
	Unrestricted	Restricted/other	Total
Beginning of year	\$377,273	\$236,742	\$614,015
Revenues over expenses (expenses over revenues) for the year	(35,499)	(6,536)	(42,035)
Endowment contributions and reinvested interest income	-	2,540	2,540
Investment in equipment	(6,509)	6,509	-
End of year	\$335,265	\$239,255	\$574,520
			\$614,015

STATEMENT OF CASH FLOWS

Year ended February 28, 2009

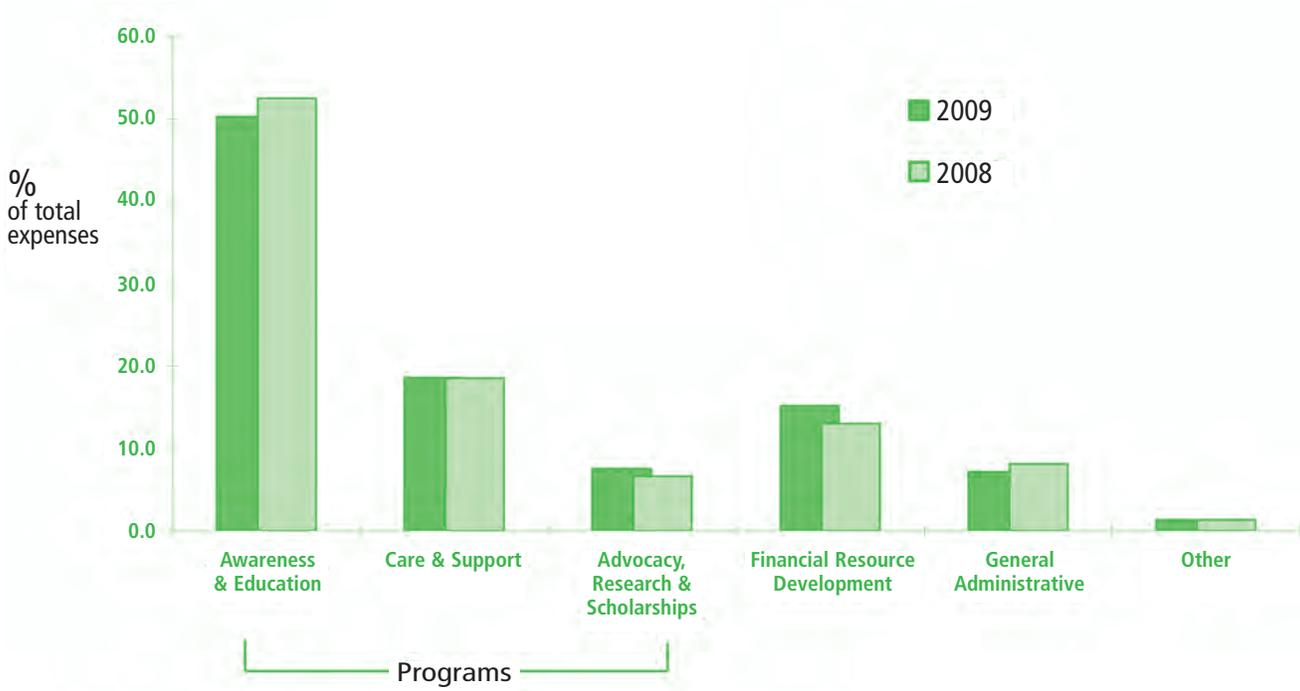
	2009	2008
Cash provided by (used for):		
General operating activities	\$(15,841)	\$77,492
Investment activities	(6,902)	11
Net increase (decrease) in cash for the year	(22,743)	77,503
Cash and short-term deposits, beginning of year	333,888	256,385
Cash and short-term deposits, end of year	\$311,145	\$333,888

STATEMENT OF OPERATIONS

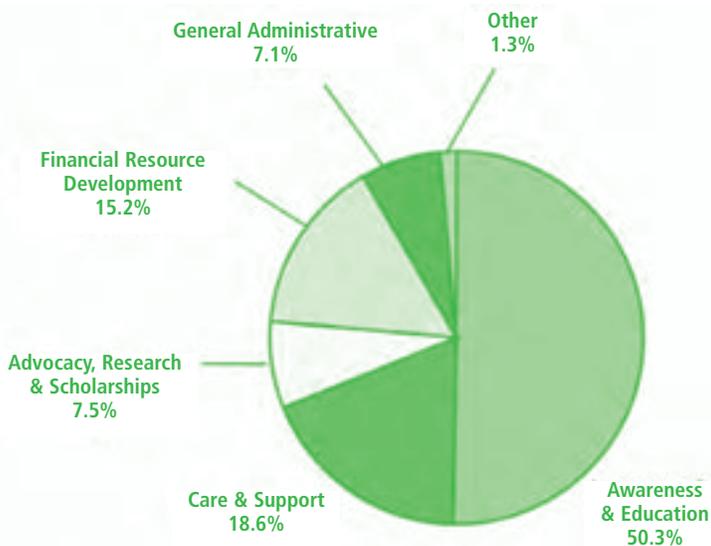
Year ended February 28, 2009

	2009	2008
REVENUES		
Fundraising activities, net	\$303,439	\$266,638
Contributions – general	119,488	162,725
Contributions – bequests	4,098	119,250
Membership dues, investment income and other	19,678	20,454
	446,703	569,067
EXPENSES		
Awareness and education	245,768	250,951
Care and support	90,784	88,299
Advocacy, research and scholarships	36,723	31,560
Financial resource development	74,269	62,357
General administrative	34,729	38,833
Amortization of equipment	6,465	6,179
	488,738	478,179
Excess of revenues over expenses (expenses over revenues)	\$(42,035)	\$90,888

Expenses Allocation Comparison



Allocation of Total Expenses 2009



Auditors Report on Summarized Financial Statements

The accompanying summarized statements of financial position, 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 28, 2009 and for the year then ended. Our opinion, dated May 28, 2009, on the complete financial statements was qualified only with respect to the completeness of donation and fundraising revenues which was not susceptible to satisfactory audit verification. 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 28, 2009

Cholkan + Stepczuk LLP
Chartered Accountants
Licensed Public Accountants



MISSION

To build awareness and drive education, research, support, care and advocacy to help find a cure while always continuing to improve the quality of life of all individuals with spina bifida and/or hydrocephalus.

VISION

To facilitate the reduction and ultimate eradication of spina bifida and hydrocephalus, and build a society that is sensitive, supportive and responsive to the needs of those living with or affected by these disabilities.

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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Charitable Registration #10799 9310 RR0001

