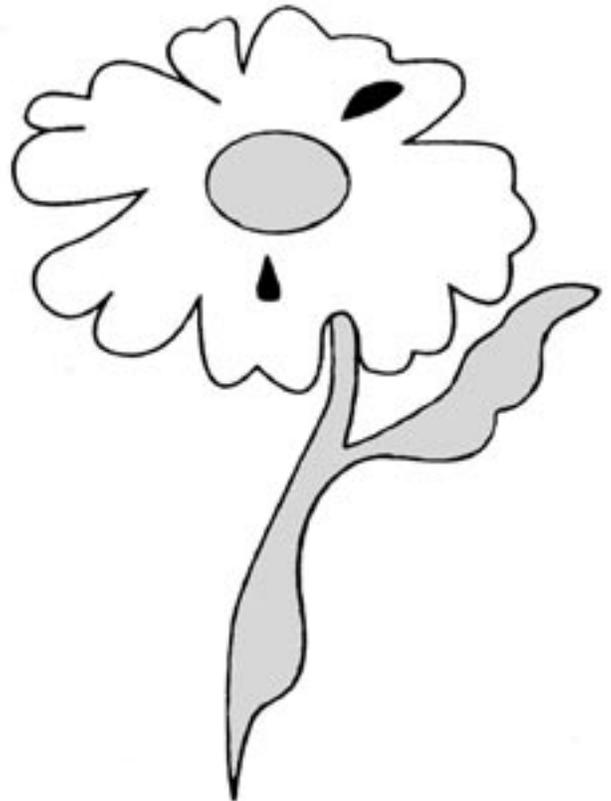




# Annual Report

Spina Bifida and Hydrocephalus Association of Canada

**Year ending April 30, 2004**



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REGISTERED CHARITY (BN) NO. 107999328RR0001



The *heart of the flower* represents the brain, which in the case of persons living with spina bifida, is often affected by hydrocephalus.

The *daisy's petals* are cloven, thereby representing the various lesions caused by spina bifida and hydrocephalus.

The *daisy's leaf* and stem are irregular, and depict the unusual form of the spinal cord and backbone of a person who has spina bifida.

The *beauty* of a flower is equally meant to reflect the beauty of people with spina bifida who, in spite of their challenges, live happy and productive lives.

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# President's Report



*At the beginning of each year, we look forward to new opportunities, challenges and successes. This past year, we were not disappointed! We encountered many of each.*

For the past several years, SBHAC has focused its developmental programs on strengthening all of the associations whose mandate is to provide support to those affected by spina bifida and/or hydrocephalus and related issues. Workshops and training sessions have been provided with the intention of creating a stronger, linked body within our collective structure so that each level can provide the best services and programs possible.

This year started with a May training session on Fund Development that brought together representatives of SBHAC as well as members of Spina Bifida and Hydrocephalus Associations from across the country. Fundraising initiatives vary from region to region and from local to national level. The discussions explored ways of working together to maximize the results of our fundraising efforts and therefore improve funding available for attaining our goals.

In conjunction with SBHAC's AGM, "Gathering of the Minds", a sequel to several previous organizational meetings, was held in October in Toronto. Issues discussed included the future of SBHAC and its Member Associations, expected accomplishments, services, finances, structure and relationships within those structures. The meetings gave participants time to review the SBHAC Action Plan that was created in November 2001, to determine where best to focus efforts for the future, and to establish measurable plans for the future.

These meetings resulted in a review and update of both the Strategic Plan and the Fund Development Plan for SBHAC, with input from stakeholders from across the country.

"Benchmarks of Excellence" workshops were presented in three regions, with attendance of representatives from 6 provincial associations.

Several fundraising initiatives were refined during the year while new plans were instituted. A first national fundraising effort, the sale of ribbons during the Spina Bifida and Hydrocephalus Month, met with limited success but more importantly, has paved the way for future efforts in cooperative ventures. An evaluation of the initiative has resulted in several improvements to the campaign. A second attempt will be made in June of next year.

The Communication, Energy and Paperworkers (CEP) Union continues to be a major supporter of the association. That support has expanded into sponsored events this past year. A successful golf tournament was held last year in both Niagara Falls and Winnipeg with plans being made for more of the same this coming year.

A new program, Giving Every Month (GEM), has been developed to accommodate donors who wish to make a monthly donation with minimal effort. The plan allows donors to assign a certain amount as a regular donation that can be deducted from their bank account or credit card or paid by post-dated cheques. Although the donation plan can be stopped by the donor at any time, it does give the association some assurance of regular monthly revenue.

During the Spina Bifida and Hydrocephalus Awareness Month, events held in Winnipeg included a Soup and Salad Day, a "Kick-Off" at the Peak of the Market, a television appearance on the "Big Breakfast", a "Tag Day" and a Mini-Hoops Celebrity Basketball Event.

In another successful fundraising initiative, Manitoba Liquor Marts came on board by accepting donations for a one week "Donate a Dollar" campaign.

Donor confidence is most important, as is the ability to keep accurately recorded



data. SBHAC applied for and received a license to use the Ethical Fundraising Logo in an effort to assist donors who are inundated by requests for money, and to identify itself as a transparent and accountable charity.

In keeping with accurately recording data, SBHAC is currently upgrading its donor software. The Winnipeg Foundations, The Blennerhassett Family Foundation, and the Manitoba Community Services Council have contributed funds to this project.

SBHAC Board has been expanded to include two members who bring the perspective of our prime supporter, the CEP Union, as well as their personal skills, to the table. Ken Stickle (retired) and Wendy Sol are two individuals who have been very active in promoting our association within the CEP ranks and will now continue to promote SBHAC programs and services amongst their colleagues and contacts.

SBHAC realized a long-term goal this past year. An Endowment Fund will enable us to prepare for a more secure future for our association was created with the assistance and guidance of The Winnipeg Foundation. The SBHAC Endowment Fund was established with an initial contribution of \$15,000.00. The Winnipeg Foundation will continue to manage the Fund and will contribute a matching fund of \$7500.00 this year. Monies contributed to the fund through bequests, donations or legacies are invested by the Winnipeg Foundation with the net income from those investments being provided to SBHAC on an annual basis.

SBHAC received a generous donation of \$10,000 from ING Canada as well as the support of many Corporations and Foundations in Canada. Our support reached beyond the US/Canada border,

to Integra NeuroSciences, who funded the SBHAC Shunt Cards. This program is so popular, we now have to go to reprint. All of these efforts and the continued financial support of Member Associations have resulted in our ability to overcome an accumulated debt situation. We are ready to seek out more opportunities!

As in past years, two students were awarded bursaries to assist them in pursuing their post secondary education. The recipients this year were from New Brunswick and Saskatchewan.

Public education activities continued and pressed into new areas. A Public Service Announcement about Spina Bifida Occulta was distributed widely across the country. The French version of the SBHAC Educator's Guide was reprinted with financial assistance from the Ronald McDonald Children's Charities (RMCC). Distribution of folic acid information continues at an increasing rate along with a new campaign targeting students in high schools.

Two enterprising young members of SBHAC, Matt Pregent and Stefanie Barber from BC initiated the SBHAC On-Line Support Network (Chat Line). They sought to facilitate personal communication between individuals interested in issues related to spina bifida and hydrocephalus. The success of the service was immediate and continues to grow.

The research agreement with the Canadian Institute of Health Research is in its second year of its three years. We look forward to the results of this project entitled, *Developmental Issues Related to Cerebrospinal Fluid Transport and the Importance of Extracranial Lymphatic System*. Two other SBHAC funded projects, *Maternal Diabetes Mellitus and the Risk of Neural Tube Defects and Maternal Ethnicity and the Risk of*

*Neural Tube Defects* should also provide valuable information.

Contributing greatly to SBHAC's continued success is the strength and dedication of our staff members. Andrea Salmon and Mona Remillard run an efficient office providing the necessary support to the board and we appreciate their commitment.

At the 2004 AGM, I will be stepping down as President of SBHAC. Over the past several years, I have enjoyed the opportunity to work with people from across the country and am grateful for their support. It is reassuring to watch the gradual progress of our association through somewhat difficult times. We have been steadfast in our commitment to maintain a voice and a support system for individuals with spina bifida and/or hydrocephalus and their families in all areas of Canada. I look forward to a new role as Past President.

Colleen Talbot  
PRESIDENT



# Summarized Annual Financial Statements

<b>Balance Sheet at April 30</b>	<b>2004</b>	<b>2003</b>
<b>Assets</b>	<b>\$</b>	<b>\$</b>
Current assets	112,505	130,058
Capital assets	<u>861</u>	<u>1,230</u>
<b>Total Assets</b>	<b><u>113,366</u></b>	<b><u>131,288</u></b>
<b>Liabilities</b>		
Accounts payable	4,763	4,827
Deferred grant and deferred revenue	<u>40,000</u>	<u>75,000</u>
	<b><u>44,763</u></b>	<b><u>79,827</u></b>
<b>Fund Balances</b>		
General Fund	1,362	(15,538)
Research Fund	58,480	58,877
Scholarship Fund	<u>8,761</u>	<u>8,122</u>
	<u>68,603</u>	<u>51,461</u>
<b>Total Liabilities and Fund Balances</b>	<b><u>113,366</u></b>	<b><u>131,288</u></b>

## Statement of Operations & Fund Balance—General Fund

<b>Year ended April 30</b>	<b>2004</b>	<b>2003</b>
<b>Revenues</b>	<b>\$</b>	<b>\$</b>
Grants	91,800	89,194
Donations	128,979	108,349
Fundraising	37,653	12,285
Membership fees	12,134	19,199
Conference/AGM	-	8,635
Other	<u>13,280</u>	<u>3,880</u>
	<b><u>283,846</u></b>	<b>241,542</b>
<b>Expenses</b>		
Contract Fees	7,380	6,414
Wages and benefits (See Note 1)	107,346	101,629
Office and administrative costs	25,687	47,698
Printed materials and fundraising costs	26,154	23,551
Public awareness	12,559	7,425
Conference, meetings and travel	1,341	10,704
Volunteer Board Development	<u>86,479</u>	<u>72,776</u>
	<b><u>266,946</u></b>	<b><u>270,197</u></b>
<b>Net revenue (expense)for the year</b>	<b>16,900</b>	<b>(28,655)</b>
<b>Fund Balance, beginning of year</b>	<b><u>(15,538)</u></b>	<b><u>13,117</u></b>
<b>Fund Balance, end of year</b>	<b><u>1,362</u></b>	<b><u>(15,538)</u></b>

### Note 1: Wages and Benefits

Wages and Benefits expense includes personnel costs for the administrative, research, scholarship, educational development, fundraising, public awareness and volunteer development activities of the Association.



### Statement of Operations & Fund Balance—Research Fund

Year ended April 30	2004	2003
Revenues	\$	\$
Donations	9,098	17,768
Interest	<u>864</u>	<u>506</u>
	<u>9,962</u>	<u>18,274</u>
Expenses		
Administration fees	109	449
Grants awarded	<u>10,250</u>	<u>-----</u>
	<u>10,359</u>	<u>449</u>
Net revenue (expense) for the year	(397)	17,825
Fund Balance, beginning of year	58,877	41,052
Fund Balance, end of year	58,480	58,877

### Statement of Operations & Fund Balance—Scholarship Fund

Year ended April 30	2004	2003
Revenues	\$	\$
Donations	2,539	3,732
Fundraising	-----	1,503
Interest	<u>100</u>	<u>27</u>
	<u>2,639</u>	<u>5,262</u>
Expenses		
Administration fees	---	11
Scholarship awards	<u>2,000</u>	<u>2,000</u>
	<u>2,000</u>	<u>2,011</u>
Net revenue for the year	639	3,251
Fund Balance, beginning of year	<u>8,122</u>	<u>4,871</u>
Fund Balance, end of year	<u>8,761</u>	<u>8,122</u>

### Auditor's report on the summarized annual financial statements

The accompanying summarized balance sheet and statements of operation and fund balances are derived from the complete financial statement of Spina Bifida and Hydrocephalus Association of Canada at April 30, 2004 and for the year then ended upon which then we expressed an opinion without reservation in our report dated July 8, 2004. 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 Canadian 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.

*BDO Dunwoody LLP*

Winnipeg, Manitoba  
July 27, 2004

BDO Dunwoody, LLP  
Chartered Accountants



# Contributors

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*SBHAC is indebted to the generosity and support of numerous organizations and individuals for the resources to carry out our mission,. We are pleased to acknowledge the contributions of the following Corporations and Foundations.*

## **ANNUAL FINANCIAL SUPPORT OF \$1000 OR MORE**

Cara Operations Limited  
EJLB Foundation  
F.K. Morrow Foundation  
ING Foundation  
Mackenzie Financial Charitable Foundation  
MDS Inc.  
National Life  
PPG Canada Inc.  
Standard Products Inc.  
Talisman Energy  
TD Bank Financial Group  
The Julie-Jiggs Foundation  
The Paterson Foundation  
Toyota Canada Inc.  
Zurick North America Canada

## **ANNUAL FINANCIAL SUPPORT OF \$500 OR MORE**

IOF Foresters  
L.V. Lomas Limited

## **ANNUAL FINANCIAL SUPPORT OF MORE THAN \$100**

Cook Engineering  
Davidson and District Donor Choice  
DUCA Financial Services Credit Union Ltd.  
Engineered Air - Resman Community Services  
Fond de Charité des Employés de Bowater  
Gemini Fashions of Canada Ltd.  
New Flyer Industries Ltd.  
Newalta  
Pollard Banknote Ltd.  
Purdy's Chocolates  
The Second Cup  
Turkey Head Sailing Association  
Tyco Electronics Canada Ltd.  
Wawanesa Mutual Insurance Company

## **ANNUAL FINANCIAL SUPPORT OF \$100 OR LESS**

Andrew Sheret Limited  
B P Accounting Services  
Barber Motors (1963) Ltd.  
Cavell & Cavell  
Cottage Advertising Specialties  
FWS Construction Ltd.  
Gateway Industries  
Kent & Duffett Charters Accountants  
Leon's Furniture Ltd.  
Mondo Foods  
Mums Unlimited  
Silpit Industries Co. Ltd.  
SMED International  
Wood River Donor's Choice



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## **SPONSORS**

SBHAC wishes to acknowledge those who have supported us through special events/programs.

Actuarial Consulting Services  
American Income Life Insurance Co.  
Articles de Bijouterie Corporative  
Battenfeld Grease (Canada) Ltd.  
Buntin Reid Paper  
Caley & Wray  
Cascades Boxboard First Ontario Fund  
Castrol Canada Inc.  
Cherniak Smith  
Crocus Investment Fund  
Datamark Systems  
Edwards & Carfagnini  
Endurapak  
GCIU  
Georgia Pacific  
Global TV  
Grand & Toy  
Hilroy  
Just for Looks Hair  
K.T. Holdings  
Manitoba Federation of Labour  
Manitoba Hydro  
MTS Communications Inc.  
Multipak Limited  
Muddy Waters Smoke House  
Natural Bakery  
Northern Telephone Limited  
Peak of the Market  
Peninsula Inn  
Petro-Canada, Customer Order  
Sack Goldblatt & Mitchell  
Sanco Supplies Ltd.  
Servico  
Sysco Winnipeg  
Tapper Cuddy  
T.E.A.M.  
Turtle Beach  
Winnipeg Free Press

## **SPECIAL PROJECTS**

General Electric Canada Inc.  
Health Canada  
HRDC (Summer Student Program)  
Integra NeuroSciences  
Manitoba Community Services Council  
Ronald McDonald's Children's Charities  
The Blennerhassett Family Foundation  
Winnipeg Foundation

## **UNION SUPPORT**

We appreciate the support of the Communications, Energy and Paperworkers Union of Canada, who have maintained a high level of support to SBHAC as their charity of choice.

## **INDIVIDUAL SUPPORT**

Both the financial support and volunteer participation of individuals are extremely important to our organization, and we wish to express our appreciation to the individuals who have supported SBHAC during the past year.



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## MISSION STATEMENT

*The mission of the Spina Bifida and Hydrocephalus Association of Canada is to “improve the quality of life of all the individuals with spina bifida and/or hydrocephalus, and their families, through awareness, education and research, and advocacy, and to reduce the incidence of neural tube defects.”*

## STATEMENT OF PURPOSE

- To foster and promote the human rights and well-being of those with spina bifida and/or hydrocephalus
- To promote research into cause, improved treatment and prevention of these conditions
- To promote, encourage and stimulate the client’s care, treatment, education, socialization, vocational development and normalization
- To promote the need for providing competent personnel to aid in the treatment, care, education, adjustment and rehabilitation of people with spina bifida and/or hydrocephalus
- To promote public awareness and action by initiating a national effort to inform the public about spina bifida and hydrocephalus

## ACTIVITIES

- 1-800 Help Line
- Associations across Canada
- Support Networking across Canada
- Resource Library
- Fact Sheets
- Annual Educational Conference for caregivers, professionals, volunteers, members and parents
- Educational guides and materials for schools, professionals, parents and the general public
- Research Grants to Canadian Researchers investigating issues surrounding spina bifida and hydrocephalus
- Bursary Program for post-secondary students with spina bifida and/or hydrocephalus
- Public Awareness Programs
- Spina Bifida and Hydrocephalus Awareness Month in June



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## **Board of Directors 2003–2004**

**President**  
Colleen Talbot

**Past President**  
Janice Lenson

**Vice-President**  
Lorelei Hall

**Treasurer**  
Sharon Seev

**Secretary**  
Jacque Tisher

Linda Randall

Curt Salmon

Mel Murray

Randal Prime

Gene Layton

Cindy Smith

Ashok Bhargava

Ken Stickle

Wendy Sol

## **Provincial/Regional Spina Bifida and Hydrocephalus Associations**

Spina Bifida & Hydrocephalus  
Association of British Columbia

Spina Bifida & Hydrocephalus  
Association of Southern Alberta

Spina Bifida & Hydrocephalus  
Association of Northern Alberta

Spina Bifida & Hydrocephalus  
Association of Saskatchewan South

Spina Bifida & Hydrocephalus  
Association of Saskatchewan North

Spina Bifida & Hydrocephalus  
Association of Manitoba

Spina Bifida & Hydrocephalus  
Association of Ontario

Spina Bifida & Hydrocephalus  
Association of du Québec

Spina Bifida & Hydrocephalus  
Association of New Brunswick

Spina Bifida & Hydrocephalus  
Association of Nova Scotia

Spina Bifida & Hydrocephalus  
Association of Prince Edward Island

Newfoundland & Labrador  
Association for Spina Bifida & Hydrocephalus

## **Staff**

**Executive Director**  
Andrea Salmon

**Marketing and Fund Development**  
Mona Remillard



Accredited as an adherent to the Canadian Centre for Philanthropy's Ethical Fundraising and Financial Accountability Code. Information about the Code can be found at the website [www.ccp.ca](http://www.ccp.ca).

