



Living with spina bifida and/or hydrocephalus (sb/h) can be challenging. Hydrocephalus Canada (HC) is here to help. Our programs respond to the unique needs of individuals with these conditions, their families, and caregivers in Canadian communities.

When you contact HC, you will receive personal support, guidance and educational materials to help you understand and cope with the issues that arise with sb/h.

Toll Free Phone and Online Help

You should never feel alone or isolated. By calling our toll-free help line, from anywhere in Canada, or by sending us an email you can access specific information about sb/h. You can receive advice on education, financial assistance information, family dynamics, accessibility and employment, to name just a few. By understanding your concerns, we can provide guidance and emotional support and help you advocate for your own needs. Our referral service can connect you to resources in your community.

Connections and Wellness

Share your experiences and knowledge through our growing network of support/ social groups that bring people together to meet others affected by spina bifida and hydrocephalus. Through our Linking Program, we encourage one-to-one support between individuals with similar experiences to share coping strategies and information about medical procedures, therapy and available community services. Participate in HC's Health and Well Being program.

Information and Education

- Hydrocephalus Canada is your best source for information about any aspect of spina bifida and/or hydrocephalus.
- Researched, quality information is provided on education, disability related issues and all medical topics such as bowel management, incontinence and tethered cord.
- Adults with sb/h receive complimentary books, publications and other materials to help manage daily living.
- Parent members receive Educator's Guides, Parent Handbooks and other helpful resources.
- Children and youth receive age-appropriate books through our Kidz & Youth Book Club that teach them about their condition and its effects in a way they can understand.
- The STAYING CONNECTED e-newsletter keeps you informed of the latest developments and features the personal stories from individuals and families impacted by spina bifida and/or hydrocephalus
- Publish and distribute "A GUIDE TO HYDROCEPHALUS", an informative resource for all affected by this condition, their caregivers and health providers.
- A resource centre housing the best and most recent publications and information about sb/h and disability related topics. This is a free lending library.
- Develop and host educational webinars, workshops and conferences.

Social Media

Online information, updates and peer support are available through the HC website, Facebook, Instagram and X (Twitter) feed. This is your opportunity to connect with other adults, parents or caregivers to talk about concerns and share information in a monitored setting.

Scholarship Program

If you have spina bifida and/or hydrocephalus, you can apply for a scholarship or bursary. The Dr. E. Bruce Hendrick Scholarship, a national program, and the Luciana Spring Mascarin Bursary, a regional program to encourage and support students, regardless of age, who are planning to continue their education at an accredited post-secondary institution.

Hydrocephalus Canada provides programs and services to individuals and their families living with the unique challenges of spina bifida and hydrocephalus across Canada.



About Hydrocephalus Canada

Our goal is to empower individuals impacted by hydrocephalus and spina bifida to experience the best life possible. We believe everyone affected:

- has the right to our attention, compassion and commitment
- has value and deserves to be treated with dignity
- requires and deserves access to safe, effective care
- benefits from, and offers benefit to, collaborative communities
- has the responsibility to be educated on the condition

Our current efforts are focused on:

- increasing awareness of hydrocephalus and spina bifida
- advocating for solutions to support prevention; early, accurate diagnosis;
- access to appropriate treatment; optimal outcomes; and, ultimately a cure
- developing education and support tools for patients, caregivers, healthcare professionals, policy makers and media
- establishing supportive communities that encourage inclusive, proactive conversations and activities, and
- funding meaningful, breakthrough research

**HYDROCEPHALUS
CANADA** | 
Championing Spina Bifida
& Hydrocephalus Communities

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