



## NEWS RELEASE

# Celebrating 40 Years of Supporting the Ontario Spina Bifida & Hydrocephalus Community

*"I never expected that going to the SB&H Annual Meeting to receive my scholarship could inspire me in a way that would define me as a person and my relationships with the people I met. The experiences of that day provided me with the mindset and a firm belief that a powerful lyric together with a great melody can give people something to believe in."*

**Danny Lamb**

**Musician, Lead Singer with the band "Mrs. Johnston"**

**May 31, 2013 (TORONTO, ON):** A small group of dedicated parents seeking better care and support for their children **with spina bifida and hydrocephalus (sb/h) came together in 1973 to form the [Spina Bifida & Hydrocephalus Association of Ontario \(SB&H\)](#).**

SB&H is celebrating 40 years of helping thousands of people like Danny and their families cope with these complex, incurable neurological conditions and lead full, productive lives while supporting breakthrough research in the field.

Now the leading charitable organization of its kind in the province, SB&H provides comprehensive resources and support to a wide range of Ontarians, from expectant and new parents through to older adults.

As [Spina Bifida and Hydrocephalus Awareness Month](#) approaches in June, SB&H Board Chair Marc Garson reflects on the progress over the last 40 years. "Who could have imagined the dramatic reduction in the incidence of spina bifida? This has been driven largely by the increased awareness and use of folic acid, a key focus of our education campaigns. It is also unlikely that our founders could have predicted that SB&H would become a real player in the world of brain injury research, treatment and care through our participation in the [Neurological Health Charities Canada \(NHCC\)](#). The establishment of our world-class Medical Advisory Board to support our causes and provide direction, guidance and wisdom is also a major achievement."



Currently, SB&H key initiatives include:

- **[Folic Acid](#):** Spreading the word about the need for women to take a daily multivitamin containing 0.4 mg of folic acid to reduce the risk of birth defects such as spina bifida by up to 70%;
- **Youth Transition:** Developing resources to help teenagers and young adults transition to post-secondary education, adult healthcare, and living independently while coping with the unique challenges of sb/h;
- **[NPH Education](#):** Raising the consciousness of the public and healthcare professionals about Normal Pressure Hydrocephalus (NPH), a highly treatable condition that is often misdiagnosed as Alzheimer's or Parkinson's Disease in adults over age 55.

Building a supportive community has been a top priority at SB&H for 40 years. The annual [Spirit Wheel Walk Run \(SWWR\)](#) in June, for example, fosters the connections and acceptance that are so important to families living with sb/h. Families across Ontario help educate their communities and raise vital funds by hosting customized SWWRs. In recent years, the thriving SB&H community has also grown through the SB&H websites ([sbhao.on.ca](#) and [folicacid.ca](#)), [Facebook](#) and [Twitter](#).

To learn more about SB&H and June Awareness Month, please visit [sbhao.on.ca](#) or contact:

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### **About Spina Bifida & Hydrocephalus**

Spina bifida, a neural tube defect, is the number one permanently disabling birth defect in Canada and hydrocephalus is the top cause for brain surgery in babies. Many people with spina bifida need mobility supports such as braces, crutches, or wheelchairs and almost all will have some form of bladder or bowel dysfunction. Hydrocephalus is usually treated by surgically implanting a shunt to drain excess cerebrospinal fluid in the brain to other parts of the body.

*The Spina Bifida and Hydrocephalus Association of Ontario is a Registered Charitable Organization #107999310RR0001*

