

## About Spina Bifida, Hydrocephalus and the Spina Bifida & Hydrocephalus Association of Ontario (SB&H)

***One in 1,300 babies is born with spina bifida and even more have hydrocephalus.***

**SPINA BIFIDA** is a birth defect that occurs within the first four weeks of pregnancy. The spinal column fails to develop properly, resulting in permanent damage to the baby's spinal cord and nervous system.

**HYDROCEPHALUS** is a condition that results in an excessive accumulation of fluid in the brain. Without treatment, permanent brain damage or even death may occur. More than 85% of children born with spina bifida have hydrocephalus. Hydrocephalus may be present at birth and can also be acquired through head injury, brain tumour, haemorrhage, disease, the aging process and other causes that are still unknown.

There are no cures for spina bifida and hydrocephalus. These serious, complex neurological conditions can cause extreme degrees of disability, the effects of which can be life threatening. Some forms of spina bifida are so catastrophic that they result in death. Babies can be born without a brain (anencephaly). "Not compatible with life" – that's what parents are told. They live only for a few hours, just enough time for their parents to say good-bye.

Some children with spina bifida are quadriplegic; others require feeding tubes and are non-verbal. Many need wheelchairs or walk with the assistance of braces or crutches. Usually, surgery is required immediately following the birth of a baby diagnosed with either spina bifida or hydrocephalus. By the time children reach 18 years of age, it is not uncommon to have undergone more than 20 major surgeries. Not only does this put their health at risk, it is an emotional drain on the child, their parents and family members.

Often children with spina bifida have scoliosis – curvature of the spine. As adults, their scoliosis can worsen, causing breathing problems. They will be put on 24-hour oxygen therapy and many will die from respiratory failure.

Children with either spina bifida or hydrocephalus struggle for their very existence. They endure bowel and bladder dysfunction which can cause other medical conditions that may result in death. Seizures, impaired vision and headaches plague their young lives into adulthood. Some children have had multiple surgeries to be able to walk and others may have as many as 50 surgeries to correct or replace their shunts in the treatment of hydrocephalus. This, together with learning disabilities brings a social stigma that follows them for years.

More than 500 children, adults, their families and caregivers in Burlington, Hamilton, Stony Creek, Oakville, Milton and Waterdown are impacted by seemingly never-ending challenges. Since 1973 SB&H has been helping these families through support and information to guide them through difficult times and help improve their quality of life. SB&H also helps this community by providing education and awareness of the conditions. We receive no government funding and must rely on donations from non-profit groups, corporations, foundations and fundraising events.

**Funds raised through The Rotary Club of Burlington North "Walk for SB&H 2010" will enable us to sustain and enrich on-going programs and bolster our ability to respond to the changing needs of children and adults living with these conditions and provide a service to the community. We will:**

- Provide guidance and support for mothers and fathers who learn that the baby they are expecting has spina bifida or hydrocephalus. Our toll-free line offers easy access to counseling, information and one-on-one support for anxious parents.



- Outreach to all women of childbearing age with information about reducing the risk of birth defects such as spina bifida by as much as 70%, by taking folic acid prior to conception.
- Provide complimentary age-appropriate books to children from 5 – 19 to educate them about their condition in a way they can understand.
- Provide all parent members with school-age children, Educators' Guides and Parent Handbooks to help them manage special education needs and its challenges.
- Maintain our on-line Community Forum with more than 650 users. On-line peer support is made available for those who are isolated, both geographically and through limitations of their condition. Parents and adults can obtain information, learn about personal coping strategies and establish peer support networks.
- Continue our efforts to make everyone over the age of 55 aware of an emerging neurological condition, normal pressure hydrocephalus (NPH) which is often misdiagnosed as Alzheimer's or Parkinson's Disease, but is treatable.
- Provide education and information materials to local hospitals, health professionals, community health agencies such as walk-in clinics, and public health units, social services professionals, specialists, neurologists, geneticist, general practitioners and educators to make them aware of the unique challenges of spina bifida and hydrocephalus.