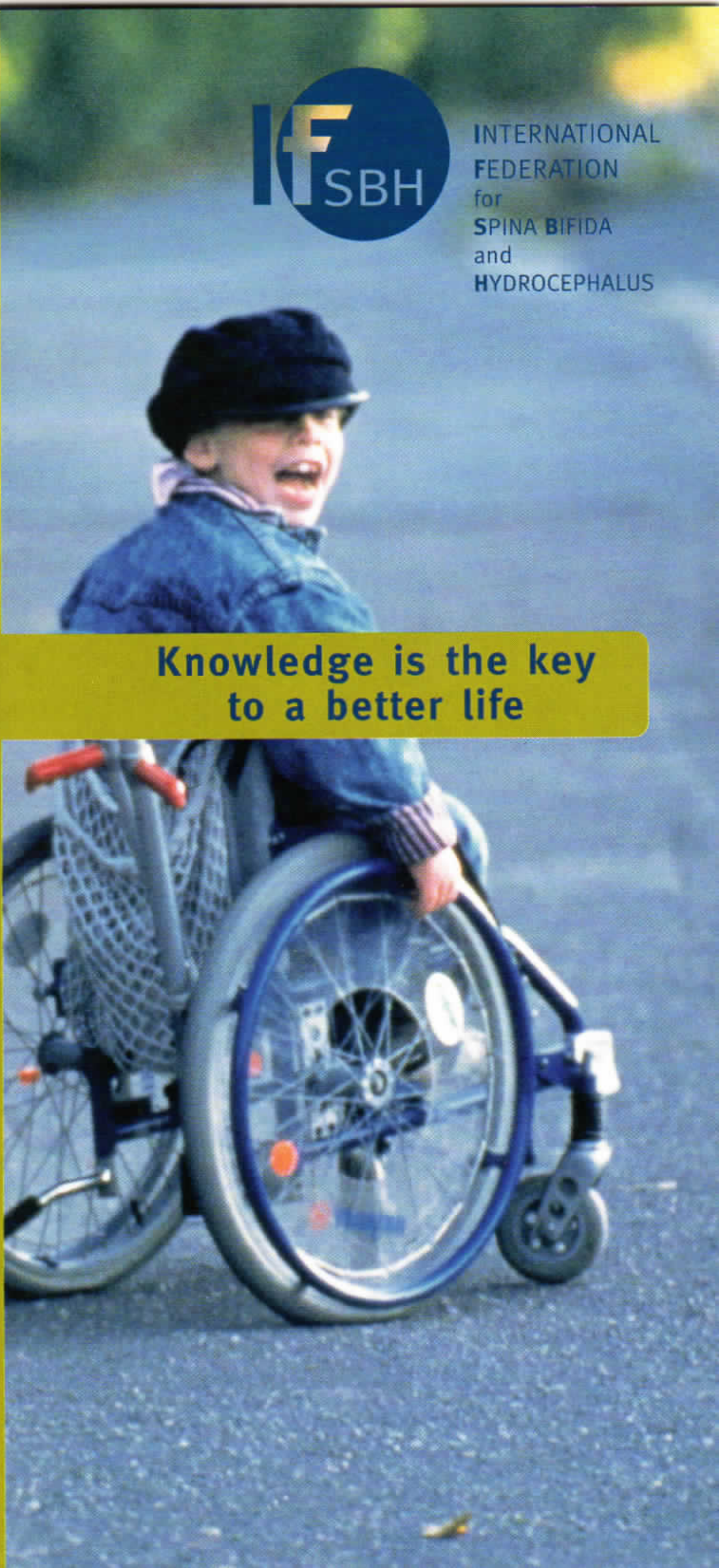
INTERNATIONAL
FEDERATION
for
SPINA BIFIDA
and
HYDROCEPHALUS

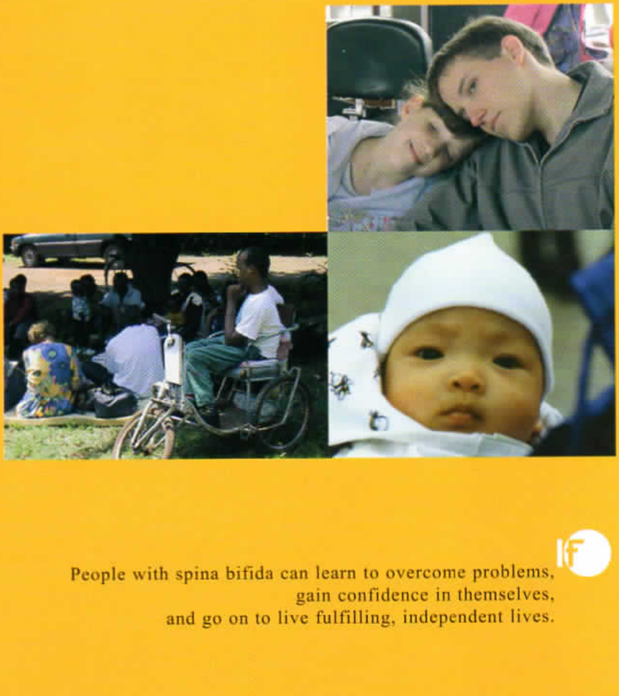
Knowledge is the key to a better life



WHAT IS SPINA BIFIDA?

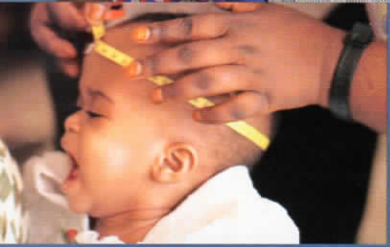
Spina bifida is one of the most common congenital birth defects, affecting 1 to 2 in every 1000 live born babies.
It is caused by a fault in the development of the central nervous system in the early stages of pregnancy, within the first 25 days after conception. The neural tube fails to close properly which causes damage to the spinal cord and the vertebrae. Because of these defects, people born with spina bifida usually have some degree of paralysis, which affects their mobility as well as their bowel and bladder control. More than 85% of babies with spina bifida also develop hydrocephalus.

People with spina bifida often need long-term care and medical follow-up. However, with proper support, most people with spina bifida learn to overcome problems, gain confidence in themselves, and go on to live fulfilling, independent lives.



People with spina bifida can learn to overcome problems,
gain confidence in themselves,
and go on to live fulfilling, independent lives.

WHAT IS HYDROCEPHALUS?



Hydrocephalus (excess fluid on the brain)
can be treated surgically

Cerebrospinal fluid (CSF) is produced in the ventricles or cavities of the brain. It circulates throughout the brain and spinal cord and is absorbed into the bloodstream. Normally there is a balance between the production and the absorption of CSF. If the natural circulation of CSF is obstructed fluid accumulates in the brain and hydrocephalus results. The excess fluid presses on the brain causing damage to the tissue. In babies and infants where the bones of the skull have not fully hardened the head enlarges.

Hydrocephalus often occurs in conjunction with spina bifida, but can also be the result of meningitis, tumours, cysts, trauma or intracranial bleeding which occurs more frequently following premature birth.

Hydrocephalus is treated surgically either by the insertion of a shunt, which is a valve and tube system, which diverts or shunts the excess CSF around the blockage or by an endoscopic third vertriculostomy (ETV) which creates a natural bypass for the CSF.

WHAT IS THE INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS (IF)?

IF is the worldwide umbrella organisation for these two impairments and has a contact network in every continent. Its members are national organisations for spina bifida and hydrocephalus in more than 40 countries. These national organisations support people with spina bifida and hydrocephalus in their daily lives.

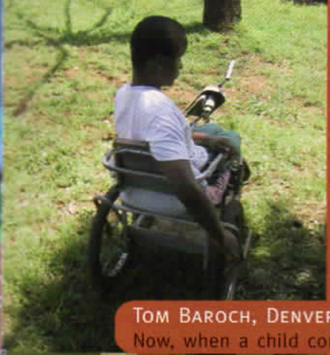
IF's mission is to improve the quality of life of people with hydrocephalus & spina bifida throughout the world and to decrease the prevalence of hydrocephalus and/or spina bifida by primary prevention. IF develops its global network, making knowledge from all over the world available through the IF-Knowledge centre. IF represents people with spina bifida and hydrocephalus and their organisations at the global level and has consultative status (special category) with the Economic and Social Council of the United Nations, as well as the Council of Europe.

IF – the global network through cooperation
and representation across borders

Guro Fjellanger, Norway
Travelling to different conferences and negotiations as a Norwegian minister on crutches, I was very often met with the question: "Did you have a ski-accident?". They were always smiling, but when I replied "No, I was born like this" the smile usually would disappear and they would say: "I'm sorry".

Olga De Wit, The Netherlands
Despite the fact that everybody has his problems, I still like to be around people with spina just because they understand and fill in the gaps without saying a word. This makes you feel so normal, and gives you the feeling of being part of a whole.

Mama Amina, Tanzania
My grandmother is a traditional healer herself and she told me "Your child was not bewitched. This is a God given problem, nobody has caused it. Amina is just a human being like any other." I have come across her problems and learnt a lot of new things and met people I otherwise would never have met.



Victoria Sandoval, Guatemala
My mother gave me the name Victory when she saw that I had spina bifida, and if I look at my life and where I am now, we really can call it a victory.

Tom Baroch, Denver, Colorado USA
Now, when a child comes by and says "Look mommy, that man walks funny...", I calm down the embarrassed parent and use the opportunity to educate both the child and the parent on spina bifida and folic acid.

WHAT DOES IF DO?

IF encourages the creation of national organisations for spina bifida and hydrocephalus and assists in the development of existing organisations.

IF encourages and supports primary prevention campaigns around the world.

IF holds annual study meetings and conferences.

IF spreads information and expertise throughout the world to families, individuals, professionals and volunteers involved with spina bifida and hydrocephalus through its website www.ifglobal.org, its monthly newsflashes and the IF-Knowledge Centre www.spinabifida.org.

IF encourages and initiates research into spina bifida and hydrocephalus through support, cooperation and funding.

IF has projects in developing countries cooperating with local and international NGO's to improve the care for families with hydrocephalus and spina bifida. The main focus is on supporting parent groups, knowledge transfer and training.

IF gives people with spina bifida and hydrocephalus a voice in other international bodies such as the United Nations, World Health Organisation, the Council of Europe and UNICEF.

IF gives people with spina bifida and hydrocephalus a voice at the global level

IF – THE DEVELOPING GLOBAL NETWORK

Cooperating towards a better life for people with
spina bifida and hydrocephalus

With member organisations in more than 40 countries, IF has contacts in every continent, making a unique network of experience and knowledge of the issues associated with hydrocephalus and spina bifida.

IF develops divisions based on language or continents to ensure maximum participation worldwide.

IF ensures that the voice of people with hydrocephalus and spina bifida is heard worldwide. New national groups are set up every year with IF's support and this helps the information network to grow.

IF encourages solidarity between people with hydrocephalus and spina bifida and their organisations from all parts of the world and through its own projects in developing countries.

IF works together with local and international NGO's towards better care for people with hydrocephalus and spina bifida.

Knowledge is the first step towards limiting the effects of an impairment. It ensures that people with hydrocephalus and spina bifida are full partners in decision making and that carers, professionals and people with spina bifida and hydrocephalus have access to the latest information. The IF-Knowledge Centre is based on its unique global network. The IF-Knowledge Centre is a user driven information bank on all issues, which support the improvement of the quality of life for people with hydrocephalus and spina bifida. It consists of medical, educational, social and lifestyle information, examples of good practice, prevention material etc. The IF-Knowledge centre is available at www.spinabifida.org. and can also be reached through www.ifglobal.org

IF-KNOWLEDGE CENTRE

If you would like further details on IF's work and a list of people to contact throughout the world,

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IFSBH

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