

story of survival



Charity works with 1,500 children and adults

THE Association for Spina Bifida and Hydrocephalus (Asbah) is a national charity based in Peterborough.

It currently works with more than 15,000 children and adults with spina bifida and/or hydrocephalus and their families and carers.

The charity employs a network of advisers across England, Wales and Northern Ireland to provide advice and

support to individuals, families and carers.

It supports parents before and around the birth of their baby, or diagnosis of the disability, and gives information and advice on a wide range of issues from health, to education to advocacy services.

A wide range of Asbah publications is available, covering issues from the lead-up to birth to those affecting the

adult with hydrocephalus or spina bifida.

These include leaflets on the role of folic acid in reducing the risk of spina bifida; ante-natal screening; genetic counselling; information for new parents; childhood vaccinations and education topic sheets.

The publications also cover aspects of living with the disabilities, including a book on

hydrocephalus, a series of continence topic sheets and a booklet on pregnancy for adults with spina bifida.

Asbah also sponsors medical, educational and social research.

□ To contact Asbah, call 01733 555988, write to Asbah, 42 Park Road, Peterborough, PE1 2UQ, e-mail info@asbah.org or log-on to the website at www.asbah.org

What is hydrocephalus?

HYDROCEPHALUS comes from the Greek words "hydro" meaning water and "cephalie", meaning brain.

A watery fluid, known as cerebro-spinal fluid or CSF, is produced constantly inside each of the four spaces or inside the brain. Normally it flows through narrow pathways from one space or ventricle to the next, then out over the outside of the brain and down the spinal cord.

It is then absorbed into the bloodstream and recirculates,

and the amount and pressure are normally kept within a fairly narrow range.

However, if the drainage pathways are blocked at any point, the fluid accumulates in the ventricles inside the brain, causing them to swell and resulting in compression of the surrounding tissue which can lead to brain damage.

In babies and young children, the head will enlarge, but in older children and adults, the head size cannot increase as the bones which form the

skull are completely joined together.

Hydrocephalus can be present at birth, but that does not mean it's hereditary - babies born prematurely are also at risk of developing hydrocephalus. Most babies born with spina bifida have hydrocephalus.

Some forms of hydrocephalus require no specific treatment. Other forms are temporary and do not require long-term treatment. However, most forms do require treat-

ment, and this is usually surgical. Drugs have been used for many years but they may have unpleasant side effects and are not often successful.

The usual treatment is to insert a shunting device. It is important to note that this is not a "cure" - the hydrocephalus and damage to the brain tissue remains. The shunt diverts the fluid from the obstructed pathways and into the bloodstream, and controls the pressure, preventing the condition becoming worse.