



## How did ASBAH start?

ASBAH grew up in the 1960s as parents came together to form self-help groups and to help their children with spina bifida and/or hydrocephalus to lead full lives.

There is a network of over 80 autonomous associations in most parts of the country. They provide financial and practical support and counselling. Some have started up workshops, others are beginning to provide housing for young adults, others have holiday accommodation, and some still function as small social groups or meet for fund-raising.

ASBAH is a registered charity and 95% of its work is financed by voluntary contributions. It has an Appeals Department working in many different ways to raise money. ASBAH works nationally to press for a better chance in life for the disabled, to influence legislation and public opinion. It also has an international voice and helped to form an International Federation for Hydrocephalus and Spina Bifida in 1981.

## Facing facts

**SPINA BIFIDA** occurs very early on in pregnancy – within the first 25 days. It is a fault in the development of the spine and spinal cord. One or more of the bones of the spine

(vertebrae) fail to close properly leaving a gap. This can mean that the vitally important spinal cord and nerves are likely to be damaged and this often results in paralysis below the level of the fault – the spina bifida. Walking may be impaired or impossible. Very often there is also the problem of incontinence. Problems with the spine – curvature and twisting – can develop later in life.

The cause is not yet known, but it is probably a combination of hereditary and environmental factors. Current research is trying to establish whether a lack of certain vitamins in the mother's diet is one of the causes.

**HYDROCEPHALUS.** About 90% of people with spina bifida also have hydrocephalus known commonly as 'water on the brain'. It can also occur independently.

There is an excess, not of water, but of cerebro-spinal fluid (CSF) in the brain due to blockage of the ventricles (cavities) of the brain. The main outward sign is a large head, and if the pressure is not speedily relieved, brain damage or even death can result. Relieving the pressure is usually done by the insertion of a valve which drains the excess fluid into the abdominal or heart cavities. Valves, unfortunately, can cause problems. They are liable to infection or blockage at any time which can be life-threatening.

## Research

Research is being conducted into the nature, causes and prevention of neural tube defects as well as improved methods of screening pregnancies. Such fundamental work remains important because, although advances in early detection and selection have meant fewer young spina bifida patients, some are still being born and surviving. There is a danger that their plight and that of their parents may be overlooked in the increasing interest in the problems of teenage and adult patients. Research can also help us to understand and improve the quality of life of those who are disabled.

There are, unfortunately, never enough funds available to carry out all the deserving research projects that are put to ASBAH.

YOUR LOCAL CONTACT IS:

*If you would like more information about ASBAH  
or would like to help, get in touch with:*

**ASSOCIATION FOR HYDROCEPHALUS  
AND SPINA BIFIDA**

**22 Upper Woburn Place, London WC1H 0EP  
Telephone: 01-388 1382**

# ON EQUAL TERMS

the work of  
**ASBAH**

THE ASSOCIATION  
FOR SPINA BIFIDA  
AND HYDROCEPHALUS





## Growing up on equal terms

We are seeing for the first time a significant number of young people with spina bifida and hydrocephalus growing up in this country and other parts of the world.

This is due to advances in surgery and treatment since the 1950s, which have given them a chance. Now ASBAH is trying to do what it can to give them hope – hope of an independent and enjoyable life.

For this to happen it is necessary that they are given equality of opportunity in schooling, in social terms, in employment and housing – not preferential treatment, but an equal chance.

Getting over the many problems of a physical handicap is one thing. Surmounting the barriers that exist in society for anyone who is disabled can be even more crippling. It robs those people who have a disability of the chance to be themselves and take their place as members of society.

Campaigning and education in order to help remove these barriers is part of ASBAH's role. Meanwhile it is also there to support and give advice to the growing numbers of young adults with spina bifida and hydrocephalus who are trying to make their way.

## ASBAH's role

### Practical support and friendship

ASBAH has a network of fieldworkers (social workers who know the particular problems of those with spina bifida and/or hydrocephalus). They visit new parents, families and those with spina bifida and/or hydrocephalus in their homes, giving advice and practical help with ASBAH's backing. ASBAH hopes to increase this service as funds become available.

### Financial help

Coping with a handicap cannot only be stressful, worrying and tiring, but also expensive. ASBAH is able to help by giving financial support where necessary through grants for special needs such as hospital visiting, driving lessons, special equipment, holidays, and sometimes, sadly, to help with funeral costs.

### Daily living advice

ASBAH's Disabled Living Advisers travel round giving advice on equipment, clothing, incontinence aids, etc, and one of them specialises in advice on mobility and driving.

### Education, training and employment

Advice and help is available from ASBAH for children in different schooling situations and young people going on to

further education and training. ASBAH aims to provide information for teachers on the special problems of those with spina bifida and/or hydrocephalus. There are 'hidden problems' encountered by young people with hydrocephalus – problems of learning, perceptual and spatial awareness and concentration, which can hinder progress, particularly if staff and employers are unaware of them. ASBAH sponsors some young people through the Sheltered Placement Scheme, and offers work experience at National Office. It gives information about different employment possibilities, as well as advice and support to employers.

### Housing

Disabled people are often barred from living an independent life because of lack of housing choice. ASBAH aims to give information on housing options available, and actively to encourage and support the setting up of different schemes.

### Independence training courses

ASBAH started these several years ago and they have spread around the country, giving young people the chance to learn how to cope on their own or with the minimum of assistance.

### Five Oaks

ASBAH's centre in Ilkley, West Yorkshire, provides residential accommodation for young people attending college in the area; short stay holidays; short stay care; independence courses and a variety of holidays and activity courses.

### Information

ASBAH's Public Relations Department is kept very busy giving information on all aspects of dealing with the effects of a disability. Publications play a major part in the information service. LINK is the bi-monthly magazine.

### Young People's ASBAH

A young people's group within ASBAH, known as 'LIFT' was started in the 1970s so that young people with spina bifida and/or hydrocephalus could join together socially. It gives them a voice so that they can run their own organisation and so that they can eventually campaign for the kind of lives they would like to lead. A LIFT Bulletin is sent out to members.

There are about 15,000 people in Britain today with spina bifida and/or hydrocephalus. They have different problems and degrees of disability – some can lead active lives, others are severely disabled and use wheelchairs.