

FIVE OAKS

ASBAH's residential centre in Ilkley, West Yorkshire provides accommodation and specialist care and support for young people who enrol on Independence Training Courses, Activity Holidays and Vocational Courses. Five Oaks also offers respite and emergency care to help in a family crisis or to enable tired parents to go away for a short holiday safe in the knowledge that their child is being well looked after. ASBAH provides accommodation at Five Oaks for young people who want to undertake a course of study at local colleges.

LIFT – YOUNG PEOPLE'S ASBAH

LIFT, the young people's group within ASBAH was started in 1978. Young people with spina bifida and/or hydrocephalus and young able bodied people meet together for social contact. LIFT members supported by the National Office staff organise conferences, holidays and other activities and produce a lively Newsletter. Through the contacts, activities and confidence gained through their membership of LIFT, young people are better able to voice opinions and make their voice heard, and campaign for the kind of lives they would like to lead.

INFORMATION

In addition to the specialist advice and information offered by the various Departments within the Association, ASBAH provides a general Information Service on all aspects of disability. Publications play a major part in this and ASBAH produces and updates fact sheets and booklets. LINK is ASBAH's bi-monthly magazine.

FINANCIAL HELP

Coping with disability is very stressful, worrying and tiring. It is also very expensive. ASBAH directs people to appropriate sources of help and, when necessary, gives direct financial support through grants for special needs such as hospital visiting, special equipment, holidays, and, sadly sometimes to help with funeral costs.

RESEARCH

Research is being conducted into the nature, causes, prevention and treatment of these conditions. Such fundamental work remains important, screening techniques will not solve the problem, babies are still being born with spina bifida and/or hydrocephalus and surviving. Their needs as well as those of the growing population of young adults must be met. Research will help us to understand and improve the quality of life for disabled people.

There is never enough money available to fund all the research projects that ASBAH would like to support.

If you would like more information about ASBAH,
or would like to help please contact us.

THE ASSOCIATION FOR SPINA BIFIDA
AND HYDROCEPHALUS
22 Upper Woburn Place
London WC1H 0EP

Telephone: 01-388 1382.

Facing the Challenges

The Work of ASBAH
The Association for Spina Bifida and Hydrocephalus



Learning to cope with roads and pavements

22 Upper Woburn Place
London WC1H 0EP

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FACING FACTS

SPINA BIFIDA occurs very early in pregnancy, within the first twenty-five days. It is a fault in the development of the spine and the spinal cord when one or more of the bones of the spine (vertebrae) fail to close properly leaving a gap. This means that the vitally important spinal cord and nerves are likely to be damaged, often resulting in paralysis below the level of the fault. 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.

HYDROCEPHALUS More than 85% of people with spina bifida also have hydrocephalus, known commonly as water on the brain. Hydrocephalus can also occur independently.

There is an excess of, not water, but cerebrospinal fluid (CSF) in the brain due to blockage of the ventricles (cavities) of the brain. The main outward sign is accelerated growth of the head. The pressure should be speedily relieved in order to minimise the resulting damage. 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, if there is any indication of a valve infection or blockage medical help should be sought immediately.

There are more than 15,000 people in Britain today with spina bifida and/or hydrocephalus. They have different problems and varying degrees of disability. Some can lead reasonably active lives, others are severely disabled and confined to wheelchairs.

HOW DID ASBAH START?

Due to advances in surgical and medical techniques since the 1960's many more babies born with spina bifida and/or hydrocephalus are surviving. With help it is possible for these children, young people and adults to live fulfilled, independent and enjoyable lives. **ASBAH** was formed in 1966 to provide that help.

ASBAH exists to help achieve equality of treatment for everyone, in education, employment, housing and many other areas of life and to campaign, educate and inform society about the problems of disability but very particularly the potential of disabled people.

ASBAH works nationally to press for improvements in services, to influence legislation and public opinion and of course to help families and young people with spina bifida and/or hydrocephalus overcome the many problems they have to face. It also has an international voice and in 1981 helped to form the International Federation for Hydrocephalus and Spina Bifida.

By helping to remove the barriers, be they physical or emotional we are moving closer to a time when young people with spina bifida and/or hydrocephalus can grow up on equal terms.

ASBAH is a registered charity. More than 95% of its work is financed by voluntary contributions. The Appeals Department works in many different ways to raise money.

There are almost 80 autonomous local Associations in most parts of the country. These receive advice and support from the National Association and most are affiliated to it. Local Associations work in differing ways, some have started accommodation schemes for young adults, others have holiday accommodation and some function as small groups or meet for fund raising. Most local Associations are run by parents and/or young people with spina bifida and/or hydrocephalus.

DIRECT SUPPORT AND FRIENDSHIP

ASBAH has a team of professional, trained Fieldworkers who know the particular problems relating to spina bifida and/or hydrocephalus. They support new parents, families and people with spina bifida and/or hydrocephalus giving advice and practical help. They work closely with the specialist advisors at the National Office. This service is being expanded continually.

HELP WITH DAILY LIVING

ASBAH's team of Disabled Living Advisors give advice on all practical problems of living with disability. The range of potential problems is huge and the range of expertise within the department has to match and reflect this. Problems of incontinence, mobility, clothing, equipment and treatment are dealt with daily. The advisors travel round the country when necessary, talking to individuals, families and to professionals.

EDUCATION, TRAINING AND EMPLOYMENT

ASBAH offers advice and help for children at school and to young people going on to further education or training or looking for a job. There are specific and, in the case of hydrocephalus, often hidden problems such as difficulties with learning and memory, spatial and perceptual problems and poor concentration. These can hinder progress if teachers, employers and colleagues are unaware of them. **ASBAH** provides information for teachers and employers to explain the problems and will visit schools, colleges and places of work to discuss specific difficulties. **ASBAH** helps some young people to find work by sponsoring them through the Sheltered Placement Scheme, others are helped by a work experience programme at the National office and some by receiving advice and information about the different sorts of employment possible, and more importantly the possibilities of rewarding and interesting pursuits for those young people who are not able to find work.

HOUSING

Disabled people are often prevented from leading an independent life because of poor housing choice. Housing that is wheelchair accessible is often difficult to find. **ASBAH** gives advice and information on the housing options available and works with local authorities and Housing Associations to encourage and support the setting up of new schemes.

INDEPENDENCE TRAINING COURSES

ASBAH pioneered the establishment of Independence Training Courses in 1977. Since that time they have become an important part of the Training Programme giving young people the opportunity to learn the skills necessary to cope on their own, or with the minimum of assistance. With **ASBAH's** help and support other organisations, such as schools and day centres have been able to introduce **ASBAH** type Independence Training Courses into their curricula.