

Social Work

The stress caused by the birth of a very severely handicapped child is considerable. There are many hurdles in the lives of such a family, as the handicaps of a Spina Bifida child are multiple. The support of a specialist social worker, particularly in areas where the Social Services are under heavy pressure, does much to help families to cope with strain. The Association has already made eight such appointments, and more will follow.

Advice and Information

The need to understand these complex conditions is great. Families, young adults and professional workers now look to the Association for information and advice. In the pressure of a hospital visit many questions remain unanswered. A booklet read at leisure can often fill this gap.

School Leavers

The needs of school-leavers and young adults grow as the number who have received modern treatment increases. A few will work in open employment, others need to secure places in a sheltered workshop, and help and training is required. There is an Officer specially concerned with education, training and employment at the National Headquarters, but more facilities will be needed, preferably run as joint ventures with other organisations.

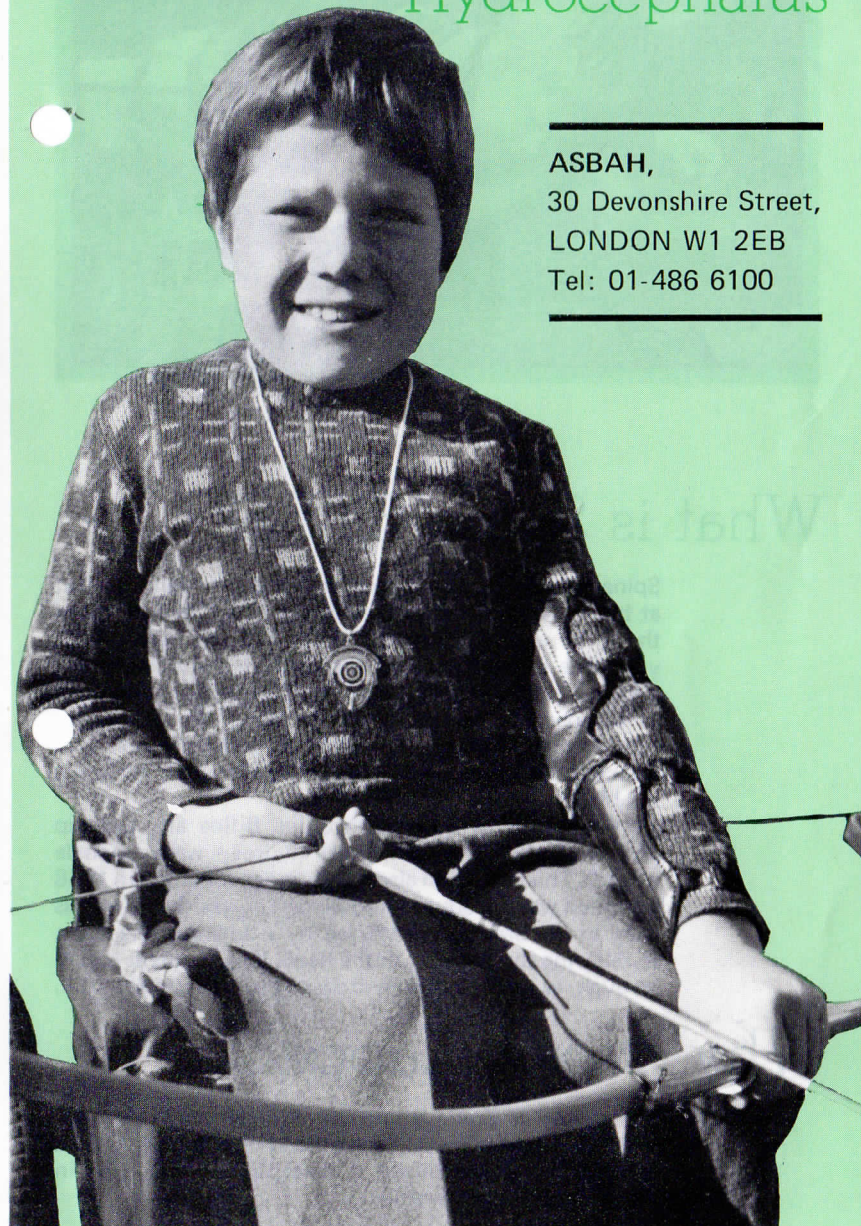
Resources

This work calls for large resources. Funds are raised locally and nationally to meet increasing demands on the Association's services. A grant from the Department of Health and Social Security assists, but 97 per cent of the Associations' work is financed voluntarily. The problems are immense and call for support on an increasing scale.



Association for Spina Bifida & Hydrocephalus

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What is Spina Bifida?

Spina Bifida is the commonest major abnormality present at birth. About 1,500 babies are born with this defect of the spine and of the spinal cord in Great Britain each year. The consequences of the malformation are usually paralysis of the legs and absence or weakness of control of bladder and bowels. Moderate cases can be successfully treated, and the children grow up to take a place in a society which is steadily becoming more helpful to the disabled.

Three-quarters of those with Spina Bifida also develop Hydrocephalus (from the Greek hydros = water, cephalo = head). This condition also occurs independently. In 1958 a method was introduced into Britain by which the excess fluid in the brain is transferred by a tube into the body, so relieving the pressure in the head. It was a great breakthrough, as prior to this Hydrocephalus was usually fatal.

Why does it happen?

The causes of Spina Bifida are not yet known, though many secondary factors have been recognised. It is a defect which is determined at conception or very early in pregnancy. It is irreversible.

What research is being done

Wide-ranging research is in progress in this country and in many parts of the world. Most recently it has been found possible to detect ante-natally severe Spina Bifida and a related condition, Anencephaly, where there is gross maldevelopment of the brain. This means that, if the parents wish, the pregnancy can be terminated. This relieves much anxiety among parents who want other children, but who would otherwise hesitate because those who have one Spina Bifida child run a higher risk than others that their subsequent children may have the same deformity.

This is obviously second best to prevention based on a knowledge of the causes, and the search for these must be extended.

The Association

The Association for Spina Bifida and Hydrocephalus was founded in 1966. Its aim is to give every help and support possible to those who, through no one's fault, are born with one or both of these disabilities, to their families and to those who care for them, and to promote research. Support for research schemes is an important part of the work. A large fund is necessary, so that if a grant for an important project is sought, the Association can help without delay. Many projects are currently being supported.

The National Office is in London, with departments specialising in various aspects: equipment and appliances, holidays, information, social work support, training and employment.

There are 80 Local Associations covering most of England, Wales and Northern Ireland (Scotland has its own Association). In each locality meetings are held for the exchange of information and to plan events and projects. Members receive practical and financial help and the Local Associations raise funds for these objects.

Short-term Care Home

A specially designed home for Spina Bifida children is urgently needed, to give families a break and to care for parentless children in their school holidays. This is to be provided in Yorkshire so that it will be accessible to many parts of the country, and will add to the existing but insufficient specialised centres run for these purposes.