

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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History and Scope of Activities

Treatment for hydrocephalus was revolutionised by the development of shunt surgery (often referred to as insertion of a valve). From 1958 onwards this technique was more and more used, so that babies who would have died lived - and as a consequence, operative surgery to close the spinal lesion was undertaken. Among the centres treating children were Sheffield, London (several hospitals), Bristol and Liverpool. Parents began to meet each other in out-patient departments and even ambulances, and realised what a lot of help and support they got by talking to each other and sharing experiences. Paediatricians and surgeons saw this too, and arranged meetings to tell families more about the two conditions. From these early beginnings Local Associations were formed.

It was not long before the need to share experiences more widely and represent the needs at government and central level was recognised, and so the National Association was set up in 1966 - at first with voluntary officers and later with a small professional staff. It is still a very small staff for the enormous and growing task before it. In a long, hard battle, but obviously of maximum importance.

The Local Associations are independent bodies which have constitutions in line with National recommendations, and they affiliate to the National body. Association which is linked closely to us.

Most Local Associations include in their service some visiting of families, grants to help with the cost of hospital visiting, an equipment loan service and the organisation of meetings, with parties and outings for the young members. Quite a large number have specially adapted caravans or chalets for holiday use, as many families find these easier with a disabled child than commercial provision. Listing facilities can be misleading, as it could appear to limit scope, whereas we hope that we can give or get help for most of the problems which confront the families.

Some areas have social workers who can give specialised support, which the statutory services cannot always render in full owing to lack of experience in depth of this multiply-handicapping condition and through their heavy case loads.

The National Association is concerned with assisting the Local Associations, helping the many individual families who ask for assistance direct, advising and helping social workers with placements and other problems. Consultation at Government level with both the Department of Health & Social Security and the Department of Education & Science is important in helping with the development of improved services.

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The Association's publications have met a great need and new ones are added from time to time. The magazine "Link", at present published bi-monthly, does a great deal to help families not to feel isolated with their problems, as well as being a source of interest and information.

There is an Appliance Department, and its Officer and her Committee arranges to test new aids, to encourage new designs, and indicates suitability of things from socks to mobility equipment.

Education, Training and Employment are also matters receiving much attention, and help is given to those needing advice or assistance. There is much more to be done as the numbers reaching adolescence increase as the result of a higher survival rate.

The Association has contacts with many other countries, and the British publications are in great demand. Some have been translated into other languages.

The Appeal Department raises money for welfare and the development of the work and for research into both treatment and causes. Such projects may take the form of assisting with a scheme covering a period of years or the provision of special apparatus. The search for the causes is a long, hard battle, but obviously of maximum importance.

There are about 5,000 members in England & Wales and Northern Ireland. Scotland has its own Association which is linked closely to us.

Not all families want to join the Association. The reasons are varied but all understandable, and freedom in this matter is, of course, essential. Service is given regardless of whether families belong or not.