

Spina Bifida, which literally means 'split spine' is a condition with which some babies

# ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS



are born and it arises in the very early stages of development, probably even before the mother knows she is going to have a baby, and its causes are not yet known.

The spine does not join as it should, so the spinal cord is exposed. If it is left like this, it is liable to damage and infection so, in most cases now, as soon as possible after birth, the baby is operated on to close the spinal column. The most usual trouble spot is the lower part of the back, but it may be higher up.



Because the spine has not developed normally, the nerves have already suffered damage and there is paralysis; this varies from baby to baby, but probably means there is loss of feeling and malformation of the legs, which lead to walking difficulties and often also lack of control of the bladder and bowels. Much is being done by the medical profession, both in treatment and research to help with walking and to deal with the other problems. Children have orthopaedic help, often involving operations. They have special aids, both baby trolleys and wheel-chairs, later with the aid of calipers many are able to walk and some eventually are able to do without the calipers.

Hydrocephalus—often called 'water on the brain'—is fairly often associated with spina bifida, though it also occurs independently. Fluid accumulates in the brain abnormally and if untreated this leads to brain damage and because the skull is soft it can be pushed out by pressure and could result in a large head. This condition is now usually treated by putting a tube into the child's head which pipes away the excess fluid down into the blood stream (there is a valve to stop blood flowing up the tube). This has been a wonderful discovery and has helped very much, though of course every child is different and sometimes there are complications.



These conditions are not new, but only in the past ten years has treatment been so improved that many babies and children who would once have died now live and grow up into happy teenagers and into adult life.

From what has been said you will see that these children have many disabilities to contend with and for their parents there is a lot of work and worry involved. They must give extra help to their children but also must not spoil them or over-protect them.

Some children go to normal schools, some are so handicapped that they need more help and so go to special schools, which may be residential. Some schools are for children with handicaps arising from a

number of different causes, others (so far there are two) have been specially designed for children with spina bifida: there is one in the south and one in the north.

There are booklets and leaflets giving more details written by doctors for parents, teachers and social workers.

As Spina Bifida became treatable and Hydrocephalus could be arrested parents wanted to get together to talk over what they found helpful and what their main difficulties were, and so local associations were formed. Just over 4 years ago, these associations came together to form the Association for Spina Bifida and Hydrocephalus, with a headquarters in London.



ASBAH is getting much more widely known and it links together the local associations, gives advice and help to parents and social workers and in areas where there is no local group, it publishes a magazine called 'Link'.

It is very important that there should be every help for families of a handicapped child, so that they may visit regularly when their baby is in hospital, have the right sort of equipment, including toys as well as medical and surgical things. Most local associations get supplies of trolleys (see illustration) and other aids, which families can have when needed and return when the child no longer needs them.

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Playgroups, suitable schools, vocational training and job opportunities must all be available, so that those with Hydrocephalus and Spina Bifida have the best possible life. This means too that they must have consideration from us all, not pity but opportunity through understanding. They want to be as independent as they can, so buildings and activities must be planned which do not exclude them and they must be made

welcome on equal terms with the rest of us, often they can do some things quite as well or better than those of us who have not had so many difficulties to overcome.

The Spina Bifida Trust looks after money raised to help with welfare, education and other needs and also promotes, and assists by grants, research into the causes of both Spina Bifida and Hydrocephalus and into medical and social aspects.