

# THE EFFECTS OF SPINA BIFIDA

Not all spina bifida patients are seriously affected. The majority, however, are born with the nerves supplying the legs and bladder unformed or damaged, causing a variable degree of paralysis.

One problem is incontinence, which interferes with the child's education and social life. There is also the danger of renal (kidney) damage and this is now the chief cause of death in patients who survive the peri-natal period.

In about 75 per cent of cases, spina bifida prevents free circulation of fluid round the brain; the fluid collects under pressure causing enlargement of the skull and brain damage (hydrocephalus or "water on the brain"). There was no reliable remedy for this until 1956, when an American engineer, John Holker (himself a father of a hydrocephalic child) invented a plastic valve that can be inserted in the head and left there indefinitely. These valves, which drain excess fluid from the brain into the jugular vein, have revolutionised the outlook for the spina bifida baby.

## The Association

for Spina Bifida & Hydrocephalus Ltd. sprang out of various local associations of parents and was incorporated in 1966. Its constitution allows it to maintain clinics, schools, homes, employment centres; to improve facilities for the treatment and welfare of sufferers; to raise funds for research, equipment or any other means to the end of helping victims. As this leaflet goes to press, detailed research is being carried out to determine future needs and establish priorities.

Most important of all, perhaps, membership of ASBAH provides social contact and comfort for those affected, especially new parents, who often have no idea of what the future holds or how to cope with their new problems. Many local associations also have adult victims among their members.

Donations and/or offers of help will be gratefully received by the Hon. Secretary.

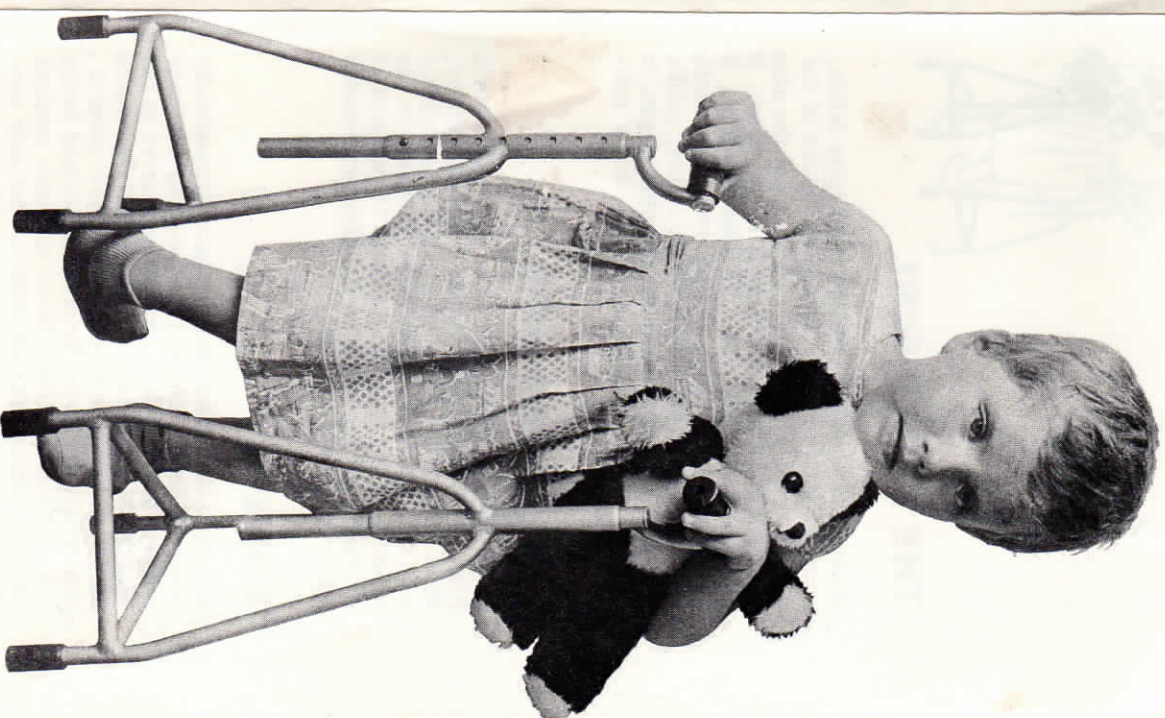


## Association for Spina Bifida & Hydrocephalus Ltd

Benjamin Franklin House 36 Craven Street  
London W C 2 Telephone: 01-930 6856

Hon. Secretary: F. G. Armour, FCA  
Instituted by Guarantee Charity Registration No. 249838

Medical science has given her life



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A LIFE WORTH LIVING

## THE LITTLE GIRL



In our picture, Carol, suffers from spina bifida, a congenital deformity caused by failure of the nerves of the spine to sink below the skin during a baby's development in the womb. If you have never heard of this condition, it is probably because it was, until recently, usually fatal. When the survival rate is low, public knowledge of a condition remains slight. In fact, it is one of the commonest major malformations.

## TEN YEARS AGO

about 80% of children born with spina bifida (literally "a spine split in two") died in infancy. Most of them died as a result of the associated condition of hydrocephalus ("water on the brain"), which occurs in about 75 per cent of all cases and for which no satisfactory remedy was available at the time.

## TODAY

advances in medical science have dramatically reversed the situation; the majority of these children now survive. Implanting a valve in the head makes it possible to siphon off the excess fluid and keep hydrocephalus under control. Nearly all survivors have normal-sized heads and a normal intellect. Given adequate medical care throughout life, patients can not only survive but can make a useful contribution to society and expect a full life-span (even if their legs are completely paralysed). Surgery can often strengthen limbs and correct deformities where these occur.

# HERE LIES THE CHALLENGE

Research indicates that each year, now, well over 2,000 spina bifida children are being born. An increasing number require education, welfare facilities and eventually training and employment.

## Medical Care

Owing to the decrease in polio, TB and other infections, children's hospitals have so far been able to find room for the additional spina bifida patients. A few special, long-term units have been built with the help of children's charities. More will be required in future.

## Education

Some local authorities have built special schools for the disabled, often with facilities for physiotherapy. Some normal schools have adopted classrooms or started a special class. A few day and residential units have been opened by voluntary societies.

## Research

Spina Bifida presents many problems, most of them not common to other diseases. The Society for Research in Hydrocephalus and Spina Bifida has been active in this country since 1957. It is not a fund-raising body but encourages and coordinates work and publishes results. Activity in this field must be stepped up.

## Housing

Most parents are able to take their spina bifida children home. Some of the children have no home to go to because of illegitimacy or other social deprivation. A few of these are adopted or fostered, but they are not easy to place; most are taken by voluntary children's homes. While these institutions give excellent care, there is a great need for accommodation with a more home-like atmosphere. If abandoned spina bifida infants are deprived of home care, they will grow up mentally and emotionally stunted and will be unable to make the difficult adjustment necessary for life in the community. Suitable houses are needed, close to a treatment centre, where small groups of patients can be brought up by experienced staff.