

## Welfare

Once their spina bifida child leaves hospital, most parents receive very little help or guidance. Visits from trained social workers would help enormously and would also be a source of reliable information for research purposes. A comprehensive information service for parents is needed, also a Samaritan Fund to alleviate cases of financial hardship.

## Homes

If spina bifida children are rejected or abandoned by their parents, they are not easy to place for adoption or fostering. Some are taken by Children's Homes but as numbers increase there will be a pressing need for houses or bungalows, close to a treatment centre, where small groups can be brought up by experienced staff.

## Training and Jobs

Many spina bifida children will be quite capable of earning a living (already there are a few adult survivors) but they will need special training and employment opportunities.

The sponsors of the Spina Bifida Campaign are grateful for what some voluntary organisations are already doing for some sufferers and we intend to collaborate with these bodies wherever possible. The Campaign does not seek to supplant or duplicate their work but to generate publicity and greater resources so that no child is forgotten.

### THE SPINA BIFIDA TRUST

has been formed to hold and allocate funds raised by the Spina Bifida Campaign. The initial trustees are:—

*Mr. Ambrose Appelbe, MA, LL B*  
*Mr. John C. Bayley, FCA*  
*Mr. Oliver J. Colman*  
*Mr. Ernest W. Gaman*  
*Sir Herbert Seddon, CMG,*  
*DM, FRCS*  
*Mr. Richard I. Stubbs*  
*Mr. Robert B. Zachary, FRCS*

## THE ASSOCIATION

for Spina Bifida & Hydrocephalus Ltd. (ASBAH) sprang out of various local groups of parents and was incorporated in 1966. It is a registered charity, No. 249338. In over 60 local groups, parents can meet others with similar problems and learn how to cope with their children's needs. They benefit from talks by doctors, teachers, physiotherapists, etc. The Association seeks to tackle the problems on a national scale and is the sponsor of the Spina Bifida Campaign.

## WHAT TO DO

Money is urgently needed. So is neighbourly help for the children and their parents. Every local group is delighted to hear from men and women who are less tied and who can spare an hour or two occasionally. If you would like to assist in this way, please ask for the address of your nearest group.

## DONATIONS

Please make cheques, etc., payable to 'Spina Bifida Trust' and send to:

**Spina Bifida Trust,**  
**112 City Road,**  
**London E.C.1.**

Telephone: 01-253 2735



**SPINA  
BIFIDA  
CAMPAIGN**

*Your nearest Association's address is*

# No surgeon can transplant a spine



# but we can build his life ... with your help



- Andrew (5) missed a vital operation and has lost valuable movement which existed in the limbs at birth.
- Sarah (3) after nine operations now leads a lively normal life.
- Mark (6) was not expected to walk but can now *run* with the aid of calipers.

These extracts from our case-book give you some idea of what it can mean to be born with spina bifida (literally "a split spine"). Spina bifida is the defect which results when the bones of the spine, and the spinal cord which they protect, are not properly formed during a baby's development in the womb. Until recently, about 90% of these children died in infancy, often as a result of the associated condition hydrocephalus (water on the brain).

Recent advances in surgery and medicine have dramatically changed this situation. Today, given proper care, over 50% of the children born alive with spina bifida can survive the critical first year and most of these can grow up to live happy and useful lives.

Most survivors are mentally normal. They have full use of their body above the waist, including their arms, so they have considerable potential.

No-one knows exactly what causes spina bifida. Anybody's child can be born this way. After a pregnancy that may have appeared quite normal, the baby is born with a raw "lump" in the middle of its back. The spinal cord and nerves are usually involved and there will be varying degrees of paralysis in the lower part of the body. The legs, and bladder and bowel control, are likely to be affected.

Estimates based on material supplied by the Registrar General show that this tragedy occurs over 2,000 times a year in the United Kingdom—about once every four hours. In addition, some 500 babies are born with hydrocephalus but without associated spina bifida.

**It is estimated that at least 8,000 of these children—probably more—are alive in Britain today.**

**The annual increase in the number of patients, allowing for deaths, is about 900—nine hundred more children whose future will be in jeopardy unless there is more action now.**

# The Spina Bifida Campaign

has been launched to make the problem known to the public and to raise funds for two main purposes:—

- (1) Financing *research* into the causes of spina bifida and hydrocephalus and into various problems arising from these conditions.
- (2) Ensuring that the *needs of sufferers* are more adequately met.

## WHAT IS NEEDED

### Medical Care

It is urgently necessary for present NHS facilities to be supplemented. There are today only some half-dozen centres in England and Wales which are anything like adequately equipped to treat these patients. Some children have to travel scores of miles, at frequent intervals, to get treatment. There are growing waiting lists for orthopaedic and other operations. A few special long-term units have been built but more will be required as the number of survivors increases (by some 900 a year in the UK).

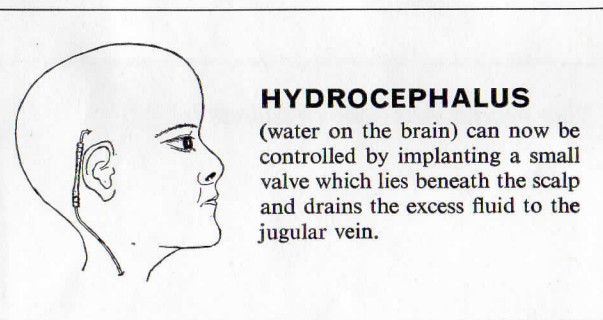
### Education

Many areas are without suitable educational facilities for spina bifida children. Some are fit enough to go to ordinary schools; others could if there were class-rooms adapted to their needs.

Many others, however, will need to spend all or part of their school career in special schools. Too little research has been done into the educational needs of multiple-handicap children.

### Research

As spina bifida affects several parts of the body, surgical and medical research must be wide-ranging. The hunt for clues to the causes of the condition must be stepped up. ▶



### HYDROCEPHALUS

(water on the brain) can now be controlled by implanting a small valve which lies beneath the scalp and drains the excess fluid to the jugular vein.



Five-year-old Ian has spina bifida and hydrocephalus. Our picture shows how lively such a child can now become, given proper care.