ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

What is Spina Bifida?

Spina Bifida, which literally means 'split spine', is a condition with which some 2,000 babies are born every year in this Country. It arises in the very early stages of pregnancy and its causes are not yet known.

The spine does not join as it should and so the spinal cord remains exposed. Left untreated, it is liable to damage and infection. In the majority of cases an operation is carried out as soon as possible after birth to close the spinal column.

Not only has the spine not developed normally, but the spinal cord which it protects is often malformed or is incompletely developed and so the nerves have already suffered damage and there is paralysis; its degree varies from baby to baby. There is resultant loss of feeling and malformation of the legs. In many cases lack of control of the bladder and bowels is a further consequence.

The medical profession is actively following a progressive programme in relation to treatment and management to help with walking and to deal with the many other problems. Many of these children have a number of operations in their early years. They can be provided with special aids such as baby trolleys, crawlers and wheelchairs; with the aid of calipers many are able to walk. About one-fifth of all patients will walk normally or near normally without aids.

Hydrocephalus – sometimes called 'water on the brain' – is often associated with spina bifida, though it also occurs in children without spina bifida. Fluid accumulates in the brain in abnormal quantities and if untreated this leads to brain damage.

Although there have been several attempts to treat hydrocephalus by 'medical' means, that is by using drugs, no reliable method has yet been found which will give satisfactory results over a long period of time. However, surgical treatment became possible about ten years ago, by the insertion of a shunt, incorporating a valve such as the one designed and developed by Mr. Holter of Philadelphia. This method has led to a revolutionary improvement in the results, although every child is different and not all will need this treatment.

The Association and the Trust

The impact of the birth of a Spina Bifida baby is immediate and severe. There are decisions to be taken and then the question : 'What will the future hold ?' Doctors and Social Workers are at hand to give skilled help, but then parents want to be in touch with others who share their difficulties, and they want to talk to lay people who can spare time to listen. To meet this need, groups of parents formed round the principal treatment centres during the early 1960's, and in 1966 they came together to found the Association For Spina Bifida and Hydrocephalus (ASBAH). Today the Association is at the service of seventy-five Local Associations in England, Wales and Northern Ireland and works closely with the Scottish Spina Bifida Association ; there is also a growing network of two-way communication with Associations overseas.

Local Associations, largely comprising parents of children with spina bifida, and some adults, but with a growing number of other members from all walks of life, provide mutual support, welfare services, equipment and grants. They help to make known the problems of spina bifida and hydrocephalus and promote understanding in the community, which is so important. Local Associations also make their needs known to ASBAH, to Local Authorities and elsewhere. In recent years many have acquired holiday bungalows or caravans for their members' use and all help to raise money to combat the manifold problems which such multiple handicap presents.

ASBAH provides a link between Local Associations, answers innumerable queries about welfare, education and other problems, and represents their needs at a national level. Its quarterly magazine, *Link,* has a circulation of 8,000 and this is increasing all the time. ASBAH is active in seeking urgently needed funds for welfare and research : to ensure sound management and the impartial allocation of resources, funds raised by ASBAH are managed by the Spina Bifida Trust, an independent charitable Trust whose Trustees work in close co-operation with ASBAH.

PLEASE HELP US MEET THESE NEEDS

The present work of the Association is mainly directed to children and their parents, because relatively few born with spina bifida and hydrocephalus have hitherto survived to adult life. Improved medical treatment now means that several hundred babies survive every year to grow up as spina bifida children.

In the first place the Association acts as an information centre, assisting the parents to understand medical details and problems of nursing management. The Association is responsible for organising help in many other ways.

SPECIAL EQUIPMENT

For children who are paralysed, special apparatus and aids to mobility – even special toys – are essential. Prototypes need to be made and tested, and successful equipment given or lent to the children. A purpose-built baby-walker costs £6; a hand-operated tricycle, which has been proved a valuable aid to mobility, can cost up to £20.

Extra aids are needed to learn to walk

Some can go to their local school

EDUCATION

Pre-School Centres

The play-group or nursery school for under fives is particularly important for physically handicapped children. This is officially recognised, but Local Authority pre-school provision falls sadly short of what is needed. Several Local Associations have taken the initiative and started their own groups with excellent results. The Association knows of other areas where there is need of a similar project. The overall cost will not be less than £30,000.

Schooling

Provided their physical handicaps can be catered for, there is no reason why many spina bifida children should not attend their local school ; others will do better at special schools for handicapped children. Attention is being directed to their special requirements and as will be seen in the section on research expenditure, a grant of £1,020 has been made to the Welsh School of Architecture towards their study of the problems. Some schools and centres, even for the physically handicapped, cannot accept all the spina bifida children needing to attend them unless extra money is spent to adapt them and staff them. The Trust must be in a position to offer grants for such extensions. Estimated cost is £10,000 per unit.

TRAINING AND EMPLOYMENT

It seems certain that present facilities for training and employment will prove inadequate ; the handicapped school leaver should be able to expect specialised training and suitable work, preferably near his family. For some, even employment in a sheltered situation may not prove possible and for them there must be residential provision. In co-operation with other statutory and voluntary bodies the Association is seeking to increase the number of training establishments and work centres.

HELPING THE FAMILY

Because of its complexity, spina bifida and hydrocephalus make big demands on families where there is a child with this handicap. The Welfare Scheme outlined on page 7 (opposite) will be a great support to these families. Frequently the child has to spend further periods in hospital, and both National and Local Associations help with travelling grants for hospital visiting.

Holiday Chalets

For families living with these stresses, holidays are doubly important; suitably equipped holiday accommodation is proving a boon to families who are unable to find places which are able, or willing, to meet their special requirements. The Devon and Cornwall Association has purchased a holiday bungalow for £2,250 with the help of Trust funds and 8 Local Associations have bought caravans for £1,500 each.

Suitably equipped holiday accommodation is proving a boon to families

EDUCATING THE PUBLIC

The Association is a twin source of information. It answers parents' questions and also promotes greater public awareness of the problems of spina bifida and hydrocephalus; only as public understanding grows can ostracism, caused by fear of the unknown, be eliminated and the handicapped thus integrated in society.

Note: A resumé of research projects sponsored by the Spina Bifida Trust appears on page 11

Proposed Scheme for Welfare Workers

The special help which parents of Spina Bifida children require has become increasingly identified since the formation of the National Association.

PILOT SURVEYS

A series of pilot surveys in differing types of district has been carried out to study the nature of the stresses imposed on the family of a Spina Bifida child. Amongst the findings, it was clearly shown that a need exists for social workers with a specialised knowledge and experience in this field of handicap, as many families find themselves facing great problems of adjustment, as well as the practicalities, and feel unsupported.

APPOINTMENT OF SOCIAL WORKERS

Social workers are therefore being appointed who will use home visits as the basis of their work, so that they have the full picture of the situation. They will work closely with those concerned with the medical, educational, employment and financial needs of the handicapped and support the family in times of strain and anxiety.

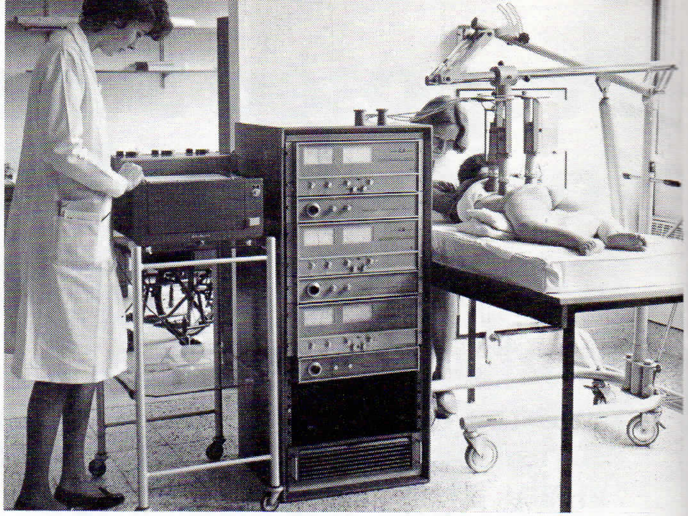
CAN WE EXTEND THE SCHEME ?

This is an exciting development to meet a deep need, but it will be costly. To cover the five areas of the pilot scheme for the first two years will require £25,000; other areas want this help but it can only be extended to them if financial support is assured.

One child every four hours is born with Spina Bifida

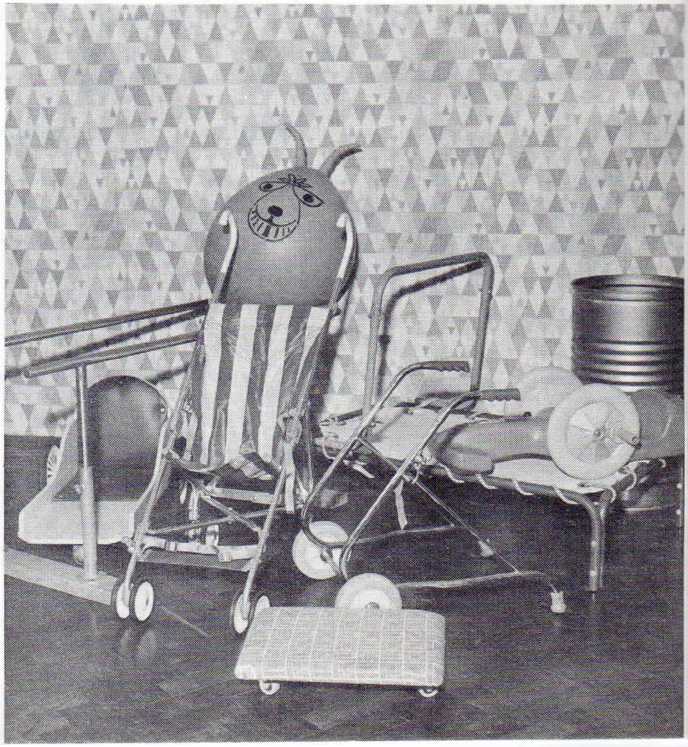
£190,000 is needed now, to meet existing needs, and our task is growing every four hours. The programme outlined on page 13 is urgent. Please give us your support.

Action is needed NOW!



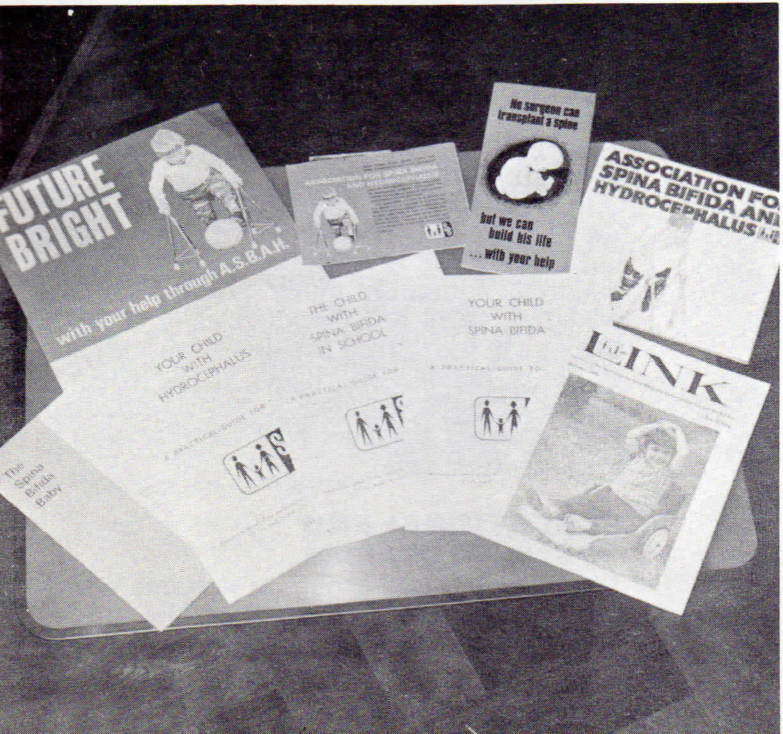
WE NEED . . . £32,000 to continue existing research projects and £50,000 for further research

THEY NEED . . . special equipment



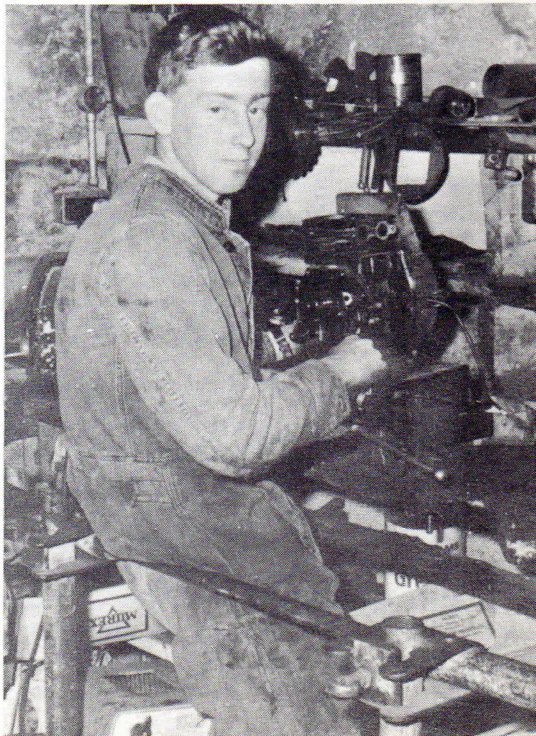
WE NEED . . . £30,000 for the provision of pre-school centres

WE NEED . . . to present our case and supply information



WE NEED . . . £50,000 for grants to adapt educational centres

WE NEED . . . to increase training opportunities and work centres (photo Jersey Evening Post)



Research

Research into spina bifida comes under three main headings. Firstly we have those research programmes which study the patients with spina bifida to assess the severity of the condition and the best plan of treatment and the methods of avoiding complications.

ASSESSMENT AND TREATMENT

Further study is still needed to determine what degree of hydrocephalus is best treated according to current methods of surgery and which cases will be better without operation. Research continues for methods of controlling hydrocephalus by means of drugs without operation and extensive investigation will be needed to see whether the drugs at present available offer a reasonable alternative to surgery.

Lack of bladder control and poor kidney function are not only a serious inconvenience but a grave risk to health and to life in older children. Although much research in the past five years has detected early signs of damage to the urinary system, more intensive study is needed to detect those children whose kidneys will deteriorate if untreated, and to select the best type of operation in the individual case.

EDUCATIONAL AND SOCIAL PROBLEMS

The second broad aspect of research which has been started, is a study on the educational problems of children with spina bifida, not only during the normal range of school life but the more extended education and vocational training which will be needed to fit them for some occupation. There is a considerable general interest and concern in this aspect of research into spina bifida and it is a field in which more intensive study would reap great benefits for these children.

FUNDAMENTAL RESEARCH

No plan of research into a serious condition like spina bifida could be complete without a study of the causation of this congenital abnormality, which involves experimental pathology, family and population studies, genetics and other fields of research. Systematic studies must be supplemented by being on the alert for an unexpected clue or chance observation which may then direct systematic research in new directions. Although we know much about the family incidence of these disorders, we are far from solving the main issues of cause and prevention and prediction of risk to an individual couple. If we can pick out the mechanisms which are responsible for the breakdown in normal development of the spine, we may have taken a most important step towards eliminating these adverse factors and towards preventing the condition.

FUTURE NEEDS AND EXISTING PROJECTS

These three aspects of research – the assessment of the disease and its appropriate treatment, the educational and social problems and, finally, the fundamental study into the cause and prevention of spina bifida – these three main lines of research can only be maintained and intensified if more research funds are available. An additional £50,000 invested in research over the next two years alone could well show considerable benefits.

The Spina Bifida Trust is already supporting the following projects and £32,000 is required for their continuation.

(i) A study of the electrical activities of the brain in children with hydrocephalus.

(ii) A study into the cause of valve infection in these systems used in the treatment of hydrocephalus.

(iii) Assistance is being given to work in the Pathology Section at the Sheffield Congenital Anomalies Research Unit.

(iv) Research into aptitudes in children with spina bifida and hydrocephalus.

(v) Case study examination of the use of accommodation and physical facilities at a special school for the physically handicapped to assess their effectiveness in use and to formulate further research proposals.

The Finances of the Spina Bifida Campaign

The combined Income and Expenditure of the Spina Bifida Trust and the Association for Spina Bifida and Hydrocephalus Limited, extracted from the latest annual accounts, was as follows:

INCOME

	£
Membership and affiliation fees	240
Donations and sundry receipts	47,324
Interest on Bank deposit and Investments	1,721
Link Magazine – surplus for the year	308
Total Income	£49,593

EXPENDITURE

Grants for Research approved by the Trustees during the period			
Westminster Children's Hospital	£5,000		
University of Sheffield	6,500		
Queen Mary's Hospital, Carshalton	2,400		
Children's Hospital, Sheffield	1,500		
The Welsh School of Architecture re use of accommodation and facilities at Special School for Handicapped children	1,020		
		£16,420	
Film 'What Is Spina Bifida'		2,623	
Welfare and other Expenditure:		£18,354	
			37,397
Balance			£12,196

NOTE: The under-mentioned grants have subsequently been allocated:

Towards the adaptation and equipment of a Day Centre for Spina Bifida children in Liverpool	£5,000
Towards the establishment of pre-school play groups by the North Hampshire, West Surrey and South Berkshire Associations	£3,000
Loan for the purchase of a holiday bungalow in Cornwall for families with Spina Bifida children	£1,250

The secretary will be pleased to supply copies of the audited accounts on request.

The Association needs now

	£25,000	for the appointment of urgently required Welfare Workers.
	£30,000	for the provision of further Pre-School Centres.
	£50,000	grants for the adaptation and extension of educational centres to meet the needs of the physically handicapped.
	£32,000	to continue existing research projects.
	£50,000	to initiate further research.
	£ 3,000	for the production of a film dealing with educational opportunities.
TOTAL	**£190,000**	

Please help us to undertake this work which is prevented only by a lack of money. If we could put all this into practice at once we would still be just beginning to tackle the problem, for there is so much to be done to ensure that the best facilities and opportunities are available to those who have already been born with Spina Bifida and/or Hydrocephalus, and also to explore every avenue in an endeavour to find and prevent the causes.

DONATION FORM

To the Appeals Secretary, Spina Bifida Trust
112 CITY ROAD, LONDON EC1V 2ND

NAME______________________________
Please insert Mr., Mrs., etc.

ADDRESS______________________________

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* I have pleasure in enclosing £......

* Please send me bankers order form

* Please send me Deed of Covenant and Bankers order form

Note: Please make cheques etc for your donation payable to the Spina Bifida Trust.

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