ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

What is Spina Bifida?

Spina Bifida is a deformity of the spine through which the spinal cord is exposed and liable to damage and infection. Often the spinal cord is malformed and the nerve system damaged. Paralysis in varying degrees results.

Hydrocephalus is often associated with Spina Bifida though it also occurs independently. Excess fluid accumulates in the brain and if untreated may lead to brain damage.

These two defects are the commonest malformations detected at birth; on average there are six babies born every day in the UK who are affected by them to some degree. Until comparatively recently 95% of these babies died, but with modern treatment and surgery about three quarters of them now survive and many grow up intelligent, lively and with a good future, given extra care.

The Association

The Association for Spina Bifida and Hydrocephalus is determined to enable these children to lead happy and fulfilled lives; to integrate them wherever possible into normal schools, living with their families, following the pursuits of normal childhood, and training for a worthwhile job, as far as their disability allows. To achieve this, the child and the family need understanding from the public, and medical, educational and social support. The Association exists to inform public opinion, to promote research into treatment, causes, and prevention, and to give help and support to those born with Spina Bifida and Hydrocephalus.

ASBAH was founded seven years ago and is growing and expanding – with the need for its existence becoming more apparent all the time.

Parents of Spina Bifida and Hydrocephalic children formed Local Associations so that they could support and help each other, and these were soon followed by the setting up of a National body in order to co-ordinate the work.

This body, ASBAH, has now spread its work into a variety of channels; by helping the individual families in every way possible; by helping on the welfare side; by appointing, in areas where appropriate, specialist welfare officers in cooperation with local authorities; and by funding research projects.

A great deal of research is needed into the causes and effects of these conditions and it has been decided to create in 1973 a Research Fellowship – starting at £60,000. This is where we are asking for your help.

Only by finding the causes of these defects can we stop the tragedy of one of these children being born every four hours somewhere in Britain. Imagine the traumatic effects it has on a family. It can happen to anyone, and it could be your family.

Please be generous and help.

Masham of Ilton

Grants already made as part of the Association's Research Programme

Research into Causes

		£
Manchester University	Cell structure of the central nervous system	3,494
Sheffield University	Towards work in the Pathology Department	3,700
	Quantimet electronic scanner for the Congenital Anomalies Research Unit *This equipment will enable existing work to be carried out fifty times as fast*	14,500

Research into Hydrocephalus

Queen Mary's Hospital, Carshalton	Research into the colonisation of the valve	2,400
Westminster Children's Hospital	Electrical impulses of the brain	5,000
Royal Infirmary, Hull	High frequency recording apparatus *Mr N Guthkelch FRCS writes: "we are delighted with the magnificent and scientifically advanced apparatus, the value of which is already becoming manifest. . . ."*	4,300

Pre-Natal Diagnosis of Spina Bifida & Anencephaly

University of Edinburgh	Chemical analysis of amniotic fluid	4,500

Research into Social & Intellectual Consequences of Spina Bifida & Hydrocephalus

Sheffield Department of Child Health	Study into the care of the spina bifida child and support of the family	2,240
Welsh School of Architecture	Suitability of schools for the physically handicapped	1,070
Sheffield University	Aptitudes of school leavers with spina bifida cystica/hydrocephalus	7,000
	This work is now being continued as a service to adolescent patients	10,000
Hospital for Sick Children, Great Ormond Street	Correlation of spina bifida and hydrocephalus with ocular abnormalities	500

We need £60,000 for a Research Fellowship

On average, six babies with Spina Bifida are born each day in the U.K. alone and the causes are not yet known. It is likely that they are complex and include both genetic and environmental factors. We do know that this heavy toll in human suffering is hideously expensive in terms of family well-being, medical and community care and the country's economy.

In order to make possible a long-term study into the detection of causes and the means of preventing these abnormal births, **the Association is appealing for £60,000 to fund a Spina Bifida Research Fellowship.** This is only part of a programme to increase the resources available in this specific field of research. Please will you help us to discover the root of the problem so that this recurring tragedy can be ended?

" . . . No one ever tells you how little it matters to have Spina Bifida and a wooden leg."

Angela Dowson is 27. She is gay, pretty and independent. She has worked in the Civil Service, as a grape picker in France, as a handbag maker in Spain, and she dreams of becoming a teacher.

She was born in Stockton-on-Tees and her parents were told it was unlikely she could live. She was partially paralysed from the waist down, and as a child every two or three years she had an operation on her legs or feet. At 13 she had to have a wheelchair.

The many operations, the lack of schooling and Angela's physical disabilities should, on paper, have given her every psychological problem in the book. In fact it seems insulting to mention her normality – because she is so utterly normal. Like most adolescent girls, she left home because she did not get on very well with her mother; she is surrounded by friends; she confidently expects to get married and have children.

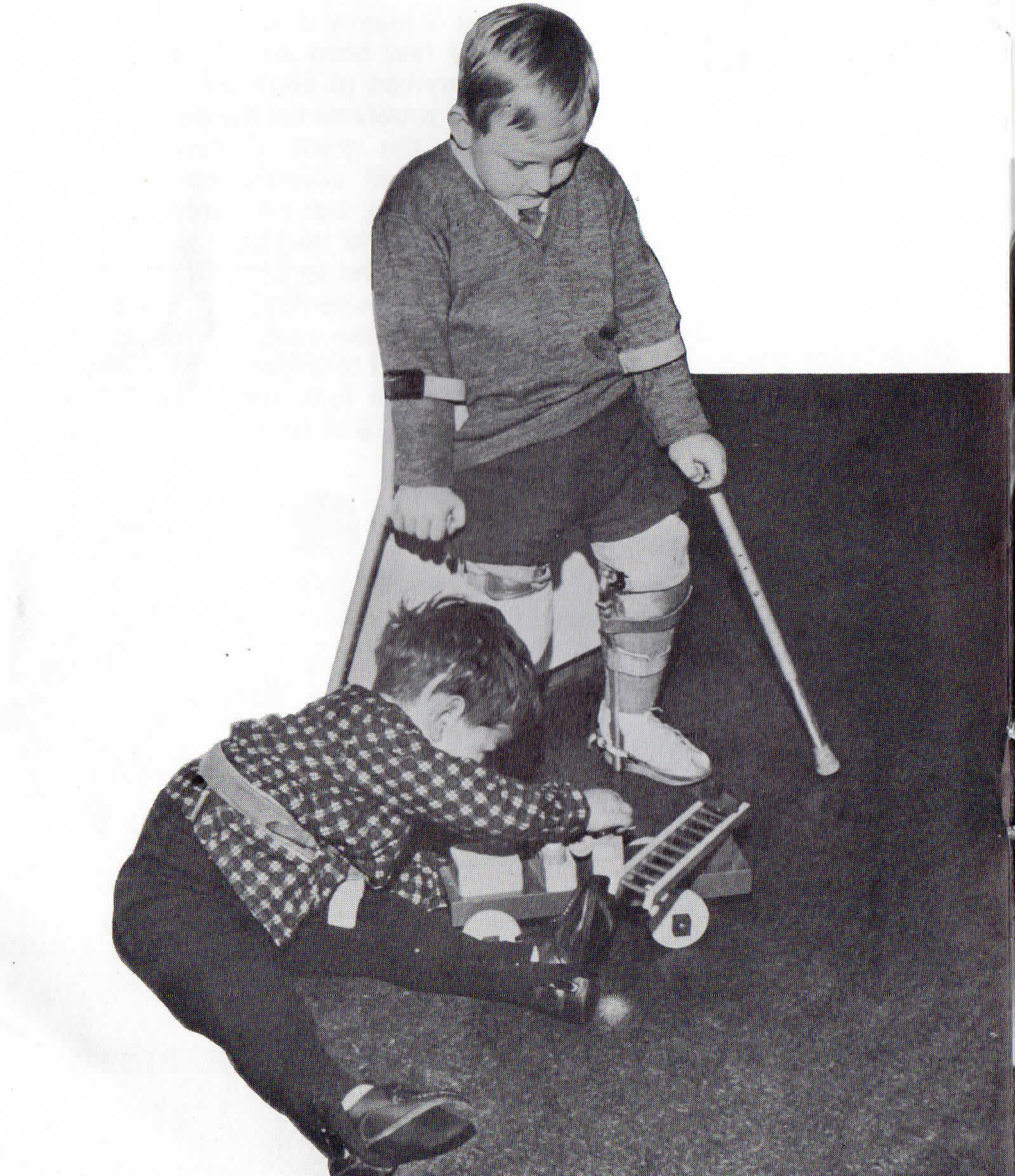
Reprinted from an article by Victoria Brittain in 'The Times'.

Help for the Family

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. The birth of a Spina Bifida child creates special problems for the parents and family; this has been recognised in the grant of three million pounds to the new Family Fund for all severely congenitally disabled children. This is a welcome step, but can only make a small impact on the problem in view of the numbers of children involved. Personal support is important, and in conjunction with Local Associations social workers with experience of handicap have been appointed, and their regular home visits are invaluable to the family in a time of stress. It is hoped to expand this scheme substantially. These social workers cannot fulfil their task unless the children's special needs can be met.

Grants from the Samaritan fund to facilitate hospital visiting, assist with footwear, transport, holidays and many other individual needs are called for and funds must be readily available to give this support on an adequate scale.

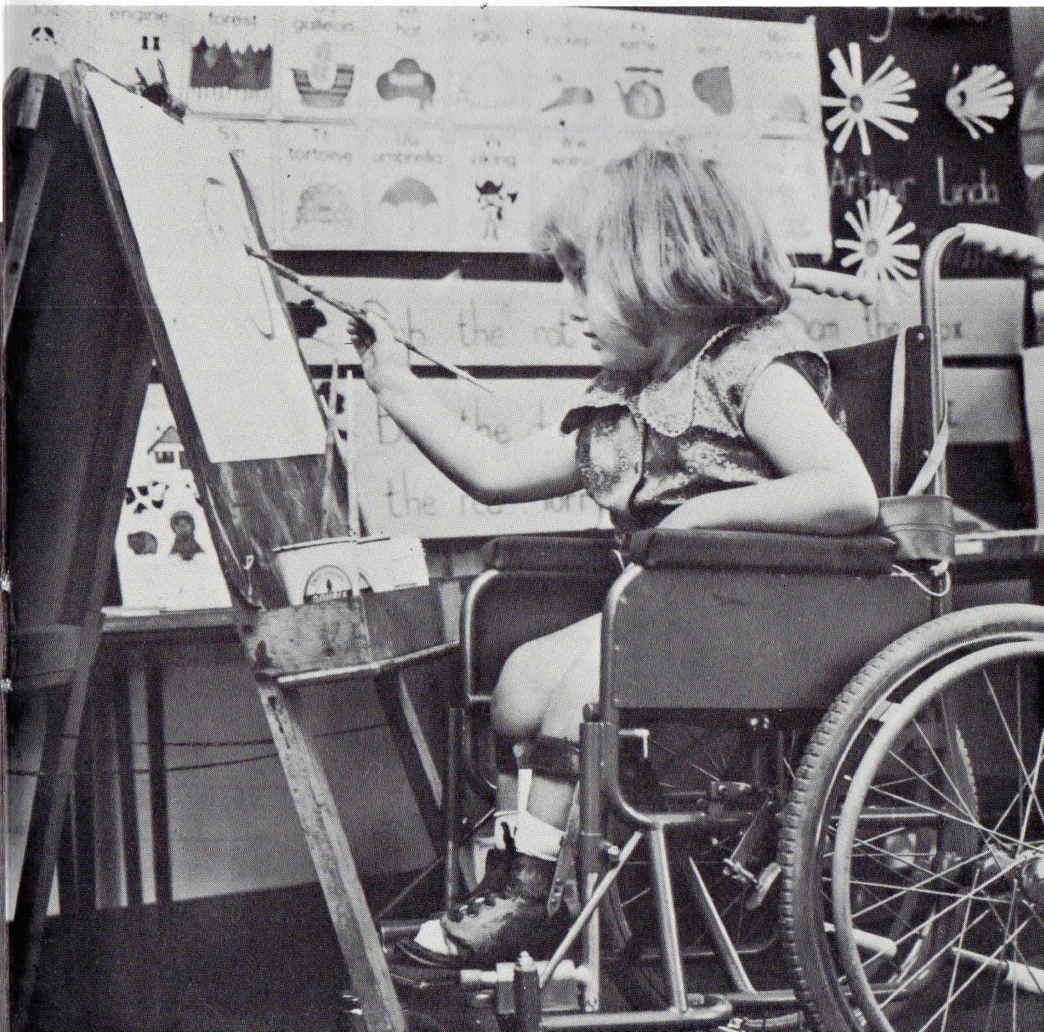
Special equipment is needed by children with multiple handicaps. Aids to mobility, toys to develop potential and special clothing help to make life easier. Prototypes need to be tested, and equipment given or lent to the children.



Education of children with Spina Bifida and especially with Hydrocephalus is a complex matter. An increasing number is being accepted into ordinary infant and junior schools, though for others a special school for handicapped children may be more suitable.

Play groups or nursery schools for under fives are particularly important for the physically handicapped, and several Local Associations run their own groups, sometimes with assistance from their Education Authority.

It seems certain that present facilities for the training and employment of handicapped school-leavers will be inadequate and the Association is actively trying to promote improved training facilities and employment prospects.



DONATION FORM

To the Appeals Secretary
ASBAH
30 Devonshire Street
London W1N 2EB

Date ....

I have pleasure in enclosing £ ....

as a donation
*for the Research Fellowship Fund
*for the general work of ASBAH

NAME ....
Mr/Mrs/Title

ADDRESS ....

....

**delete as appropriate*
Please make cheques or postal orders payable to ASBAH

FORM OF BEQUEST

Legacies form an important part of our resources and if in your

WILL

you would help our handicapped children who have the

WILL

to live, the attached form of bequest may be helpful.

I BEQUEATH to the Association for Spina Bifida and Hydrocephalus the sum of £.., free of duty, to be applied for the purpose of such Association, and I declare that the receipt of the TREASURER or other proper officer for the time being of such Association shall be a sufficient discharge for the same.

FORM OF COVENANT

ASSOCIATION FOR SPINA BIFIDA & HYDROCEPHALUS
(LIMITED BY GUARANTEE)

I, ...
(*Block letters, and full names please*)

of ....
(*Home Address*)

HEREBY COVENANT with the Honorary Treasurer, of the Association for Spina Bifida and Hydrocephalus, 30 Devonshire Street, London W1N 2EB, that for a period of seven years

from this date (A) ....
or during my lifetime, whichever period shall be shorter, I will pay annually to the said ASSOCIATION or its Treasurer for the time being such a sum as will, after deduction of tax at the Basic Rate for the time being in force, leave in the hands of the ASSOCIATION a

net sum of £ p (..

....)
(*Amount of words*)
such a sum to be paid from my General Fund of Taxed Income, so that I shall receive no personal benefit in either of the said periods from the above mentioned annual sum, or any part thereof.
IN WITNESS whereof I hereunto set my hand and seal this

(B) ....day of 19
Please note that the date at (A) *should be later than the date at* (B)
SIGNED, SEALED AND DELIVERED

by the said ....
(*Signature of Subscriber*)

in the presence of

Witness to the Signature of Subscriber
Signature ....
Address ....
....
Occupation ....

BANKER'S ORDER

To the Manager .... Bank
.... Branch

Please pay Lloyds Bank Ltd., South Bank Branch, Code No. 30-18-25, for the credit of ASBAH Ltd, A/c No. 0598682 on the .... day of ....
each year until further notice from me, the sum of

£ ....

(*in words*) ....
charging such payments to my account with you, and continue to pay this amount annually on the same day until this Order is cancelled by me in writing.

To Bank .... Branch ....
Name .... Signed ....
Address .... Date ....
....

When completed, this Order should be sent to:
ASBAH Ltd, Devonshire Street House, 30 Devonshire Street, London W1N 2EB.
Please do NOT send it direct to your bank.

The Association for Spina Bifida and Hydrocephalus
Devonshire Street House, 30 Devonshire Street
London W1N 2EB
01-486 6100 and 01-935 9060

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