



The Spina Bifida Campaign

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FOR RELEASE at 12 noon Wednesday,
13th March 1968

CAMPAIGN IS LAUNCHED TO HELP 'SPLIT-SPINE' CHILDREN

A national campaign to help an estimated 8,000 handicapped children in the U.K. was launched today at a press conference in London chaired by Harry Secombe.

The 8,000 are sufferers from spina bifida (split spine) and/or hydrocephalus (water on the brain) -- two conditions, present at birth and often found in the same child, which used to be fatal in four out of five cases. As a result of medical advances, these children are now surviving in increasing numbers.

"Spina bifida children have not had a square deal, mainly because the size of the problem has not been realised," said Mr. R. B. Zachary, a consultant surgeon, at today's press conference at the Royal College of Surgeons.

"Even in well-established centres", said Mr. Zachary, "facilities are inadequate to give every child the treatment he needs at the time he needs it, so that a child may develop paralysed muscles while waiting for operations."

The Spina Bifida Campaign is concerned not only with fund-raising but also with educating the public and inspiring more action at all levels towards meeting the medical, educational and welfare needs of these children. The Association for Spina Bifida & Hydrocephalus, sponsor of the Campaign, is anxious to locate all the parents of affected children -- many do not know what help is available to them. There is no central register of spina bifida or hydrocephalic patients.

Sponsored by the Association for Spina Bifida & Hydrocephalus Ltd.

more

Patron: Rt. Hon. Horace King, MP
Chairman: R. B. Zachary, FRCS

Charity Registration No. 249338

Supporters include: Sir Robin Darwin, Lord Grenfell, Peter Hall, Richard Hearne, Bernard Miles, Dame Marie Rambert, Harry Secombe, Joan Sims, Rt. Hon. Sir Geoffrey Shakespeare, Sir Charles Wheeler, Rev. Austen Williams

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Although they suffer from varying degrees of paralysis in the lower half of the body, spina bifida children are usually strong from the waist up and of normal intelligence. Given suitable education, they can live near-normal lives in society and be gainfully employed upon reaching working age.

Education is a major problem. While some of these children are able to attend ordinary day-schools, they can only do so at the head teacher's discretion. Others need special care and there are too few places available in special schools.

Mr. Allen Field, headmaster of a special school, suggested that the ideal pattern might be for the child to attend a pre-school play-group or nursery and then go through the normal State system where this was possible without harm, or alternatively to go to a school which specialises in the treatment and education of children who are incontinent from physical causes, until such time as the child is ready for transfer to the normal system. This would call for the establishment of many more special schools.

"Incontinence is one of the heavy burdens which many parents of spina bifida children have to bear," said Mrs. Mavis Cotsford, who represented parents at the press conference. "It is a problem which an embarrassed public has difficulty in understanding. It is socially acceptable to complain of a headache, but taboo to discuss constipation. These mothers have to cope with nappies long after the toddler stage and have the added anxiety that their child may be socially unacceptable or may suffer from kidney damage."

Donations to the Campaign may be addressed to the Spina Bifida Trust, 112 City Road, London, E.C.1. Telephone 01-253 2735.

PRESS INFORMATION from the Spina Bifida Campaign,
112 City Road, London E.C.1.

Inquiries : 01-730 2229
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EMBARGO : No part of the following script
should be published before 12 noon
on Wednesday, 13th March, 1968, please.

EXTRACTS from a speech to be delivered by Mr. R.B.Zachary, FRCS, at the
Press Conference launching the Spina Bifida Campaign on
Wednesday, 13th March, 1968 (11.00 a.m.).
Mr. Zachary is Chairman of the Association for Spina Bifida
and Hydrocephalus.

Few children with spina bifida and hydrocephalus could walk into this room as we have done today. Many would be using calipers and elbow-crutches but others would not be on their feet at all, because their paralysis was so severe or because they were waiting for an operation. This is the most obvious form of spina bifida - paralysis of some or even all of the muscles of the legs. The split in the spinal arch (the bifid spine) causes nervous tissue to lie exposed on the surface of the back at birth. Some of the nerve cells in the spinal cord have not developed properly so that there is no control over the muscles they serve and this includes the bladder as well as the legs.

Some children with spina bifida have excessive fluid within the brain (hydrocephalus), very often in such quantity and at such a high pressure that it will damage the brain unless treated. It was the development by John Holter of a valve system for treating hydrocephalus that made the treatment of the rest of the disability worthwhile. It would have been useless to operate on the feet if the hydrocephalus was so bad that the child could not even sit up, or had caused such brain damage that he could not know how to use his legs. With modern treatment, most children will have normal intelligence and a normal-sized head.

It was the primary importance of the control of hydrocephalus which prompted our Association to include in its care and concern those children who have hydrocephalus alone without spina bifida, and there are about 500 infants of this group born alive each year.

The live births of children with spina bifida amount to more than 1,500 each year in the U.K. At least another 500 are still-born but with steadily-improving obstetric care tending to reduce the proportion of stillbirths, our chief concern is with those now born alive. These are the children who need our help if they are to develop to the maximum and this should be our aim.

Our Association is concerned with three aspects of the problem:-

1. Treatment and research
 2. Welfare
 3. Education and vocational training
1. Even in well-established centres, facilities are inadequate to give every child the treatment he needs at the time he needs it, so that the child may develop paralysed muscles while waiting for operations.
The parents of our children are worried about the provision of adequate treatment but they are also very anxious that intensive research be undertaken: research into new methods of treatment and new appliances; research into the causes of spina bifida and hydrocephalus and its possible prevention.
 2. The welfare of the spina bifida child in the environment of the family is our immediate concern. The family of the spina bifida child has had a shattering experience and they have a burden to bear far greater than anything we know.
I mean not only the care and attention the handicapped child needs, not only the extra physical and financial burden, but the great emotional and psychological stress and strain.
If we are to help these children to develop their potentialities to the full we must support the families in their vital role.
 3. I will say very little about the case for education and vocational training except to emphasize that these children's education provides the chief outlet, if not the sole outlet, for their full development. They have to rely on education for their future and for the contribution which they can and should make to society no matter how severely disabled they are.

Spina bifida children have not had a square deal, mainly because the size of the problem has not been realised, but there are tremendous possibilities for the fuller development of these children. It is time we put this right and the opening of this Campaign is the first step in that direction.

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TEXT of a speech to be made by Mr. Allen Field, L.C.P., at the Press
Conference launching the Spina Bifida Campaign on Wednesday,
13th March, 1968. Mr. Field is Headmaster of Coney Hill School,
Hayes, Kent.

Are we wasting our time and money educating spina bifida children?
To refute this question ten years ago would have required more faith than
fact. Although faith is still needed, the facts available show that
educating spina bifida children can be justified on economic as well as
moral grounds. The Shaftesbury Society's pioneer experiment at Coney
Hill has shown that it is a sound social investment.

The experiment started nine years ago with a small boarding school
for thirty children who, because of spinal disorders, were incontinent.
This work has subsequently been extended to cater for sixty-five children,
a mere drop in the ocean.

The School, which is supported by a team of medical officers eminent
in this field under the leadership of Mr. D.G. Ellison Nash F.R.C.S., has
a broad educational philosophy. Anything that increases confidence and
the ability to enjoy life is grist to the mill. Recent surgical advances
and refined techniques, with the emphasis on early salvage, increased
mobility, and the prevention of brain damage, have made education a very
worthwhile prospect so the general curriculum is quite wide and includes
not only the basic three R's, but the humanities, current affairs, Human
Anatomy & Biology, French, light crafts, sewing, typing, music, cooking,
swimming and driving. Training in incontinence management and physio-
therapy is woven into the everyday pattern of activities. Trained and
confident in themselves, the scholars mix freely with other children, play
local schools at football and cricket, stage dramatic performances, attend
concerts, shop in the High Street, borrow books from the public library,
take selective and secondary exams, swim in the public baths, visit homes
of friends, go camping in Britain and abroad, and have produced from their
number the first disabled gold medallist of the Duke of Edinburgh's Award
Scheme.

Coney Hill Old Scholars are showing that it is possible for them to take up their birthright and are entering into twentieth-century life with zest. They are doing full time work, attending evening institutes and day release classes, entering competitive sport, getting married, leading protest marches, and emigrating.

Looking at the picture nationally, a variety of things can happen to an incontinent child when he reaches the age of five years.

He can :-

1. have home tuition;
2. go to a primary school;
3. go into a special unit attached to a state school;
4. go to a Special School for children with mixed physical handicaps as a day child, a weekly boarder, or a full boarder;
5. go to a special school catering exclusively for children who are incontinent because of spinal disorders.

Home tuition could be an answer to the education problem. It certainly has the advantage of individual attention for the pupil and sometimes a child can start (say) reading early. However, there are some grave disadvantages. Rarely is the teaching full-time. Education is narrow in that it tends to exclude physiotherapy and incontinence training. Also, it tends to make the child socially backward, and he misses the stimulus of living and learning with other children.

If the child's incontinence is such that he can manage with not too frequent visits to the toilet, then the normal primary school could be an answer, although kidney infection and lack of physiotherapy can be deleterious. It sometimes happens that a child can have a traumatic experience because he 'disgraces' himself and becomes wet, dirty and smelly. This is dangerous because it can affect the child's attitude to education, which may take a considerable time to overcome, and it can inhibit his personality development.

Special Units composed of several spina bifida children within a local school might be an answer. However the age range as well as the ability range of such a unit would probably present a formidable teaching problem.

Education within a special school for mixed physical handicaps might be an answer. This can have its drawbacks. Incontinence does not appear to command the same instant sympathy and understanding as say cerebral palsy or polio. The incontinent child feels a sense of shame and cases of scooping up faeces and hiding it in lockers are not unknown.

Education within a school which caters exclusively for spina bifida children has many advantages. A higher degree of specialisation is possible, an expertise in incontinence management can be built up. It is easier for the child to learn his individual bowel cycle and the most suitable aids to keep him regular: besides knowing how to express his urine he can establish the habit of constant liquid intake; he can learn to avoid pressure sores and burns. Children talk freely about their disabilities and can build up a positive attitude towards them. Having mastered these techniques, the spina bifida child can become independent and can then move on to taking full-time work in his own locality, or go to a local school.

What then would be an ideal educational programme for a spina bifida child? In my view it might be something like this :-

1. Attendance at a pre-school or nursery, where he could learn to mix and play with others, get the feeling of materials and shapes, and relieve the pressure on Mum;
2. Progress through the normal state system of education where this is possible without deleterious effects; or
3. Attend a school which specialises in the all-round treatment and education of children who are incontinent from physical causes, until such a time as he can safely be transferred to the normal state system. This would probably call for the establishment of many more schools like Coney Hill.

If our Society is to live up to its responsibilities, then it ought to provide the proper facilities for all spina bifida children to 'have life and have it in abundance'. Besides being the right thing to do, it would free unexpected talents for the Society, and save us money in the long run.

DEFINITIONS

SPINA BIFIDA is a deformity of the bones of the spine,, usually (but not always) in the small of the back. The coverings of the spinal cord are inadequately supported and may protrude to form a soft, thin-walled sac. The nerves of the spinal cord are thus very vulnerable and there is often partial or complete paralysis below the level of the defect; this may affect not only limbs but also bladder and bowel control, making the patient incontinent.

HYDROCEPHALUS (water on the brain) occurs in most cases of spina bifida; it can also occur on its own. The spinal fluid which is normally formed near the centre of the brain is unable to get to the surface because the narrow channels are blocked. Pressure builds up and if untreated will cause enlargement of the head and compression of the brain.

CAUSES

It is known that there are many factors which together can give rise to spina bifida, but much more research will have to be done before causes are clearly identified.

INCIDENCE

Ignoring still-births (of which there are a considerable number), medical authorities estimate that over 1,500 babies are born alive annually, in the United Kingdom, with spina bifida. About three-quarters of these will also have hydrocephalus. In addition, some 500 babies are live-born annually who have hydrocephalus WITHOUT spina bifida.

It is estimated that, after allowing for deaths, about 600 spina bifida children are being added to the population each year and another 300 with hydrocephalus only, making a total increase of about 900 with one or both conditions.

Combined figures provided by the Registrar-General's department indicate that the average incidence of spina bifida and/or hydrocephalus in Britain is about 2.5 per thousand births, but this incidence is not evenly distributed. In parts of Wales, for example, the rate is over twice the average.

TOTAL IN THE POPULATION

Because there is no compulsory notification and no central register of patients, the exact number of survivors is not known. An estimate can, however, be arrived at by assuming that the number of births is constant year by year and deducting the DEATHS notified over the period since these children began to survive in appreciable numbers. On this basis, it has been estimated that there are about 8,000 children under the age of 16, with spina bifida and/or hydrocephalus, alive in the United Kingdom today.

THE ASSOCIATION FOR SPINA BIFIDA & HYDROCEPHALUS LTD.

This national association, known for short as ASBAH, sprang out of various local groups of parents and was incorporated in 1966. It is limited by guarantee and a registered charity. The Association is primarily concerned with helping directly spina bifida and hydrocephalic children and their parents. It is the Sponsor of the Spina Bifida Campaign.

THE SPINA BIFIDA TRUST

The Spina Bifida Trust was formed early in 1968 to receive and allocate funds contributed in response to the Spina Bifida Campaign. Its objects are :-

"to promote the care, welfare, treatment, interest, education and advancement of persons suffering from spina bifida or hydrocephalus and allied or related disorders, and especially to assist the Association for Spina Bifida and Hydrocephalus Ltd., insofar as that body is and remains charitable."

The initial trustees are :-

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

ADDRESS

Donations should be addressed to the Spina Bifida Trust, 112 City Road, London, E.C.1.
(Telephone 01-253 2735.

The parents' association (ASBAH) is at the same address.

SUMMARY OF KNOWN NEEDS

It is estimated that at least £350,000 is required to begin to cope with the spina bifida problem. The needs can be classified under the following headings:-

1. **MEDICAL**
A number of medical research projects have already been submitted to the sponsors of the Campaign. Clinics and special treatment units will have to be provided in certain areas.
2. **SOCIAL SERVICE,
EDUCATION AND
WELFARE**
Research into social needs. Urgent provision of educational facilities (primary, secondary and advanced) where lacking. Scholarships, tuition etc. Case workers to make domiciliary visits. Information and advisory service for parents via literature, film, lectures etc. Hardship grants.
3. **BUILDING**
Cost or part cost of buildings urgently needed for medical purposes (see above). Grants to voluntary residential schools and organisations caring for rejected infants.
4. **GENERAL**
Public education. Statistical research. Advisory service for professional people ... medical lectures, symposia, etc. Premises, equipment and running costs for the co-ordinating organisation.