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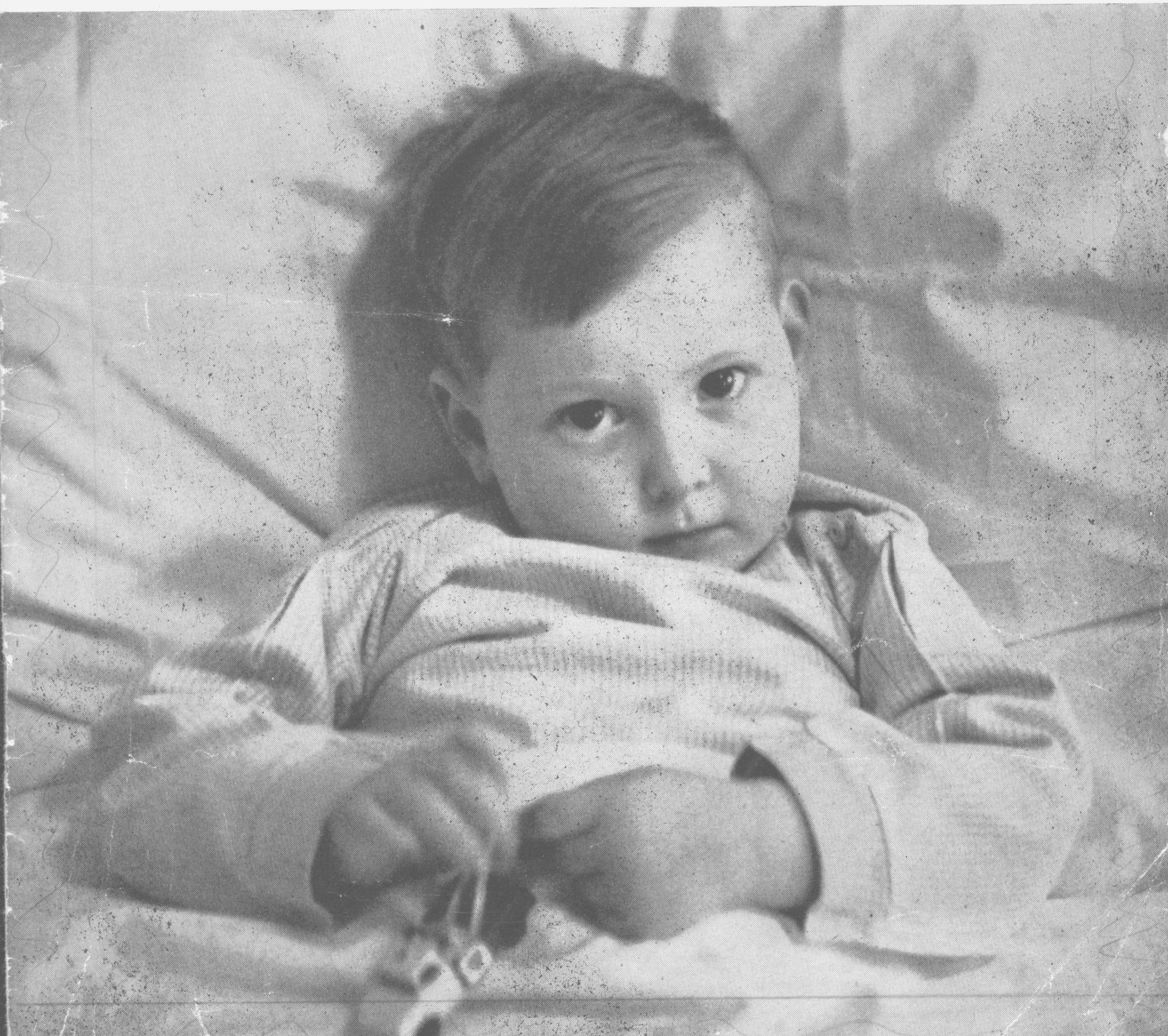
LINK

The Journal of **The Association for Spina Bifida and Hydrocephalus Limited (A.S.B.A.H.)**

Spring 1966 **One Shilling**



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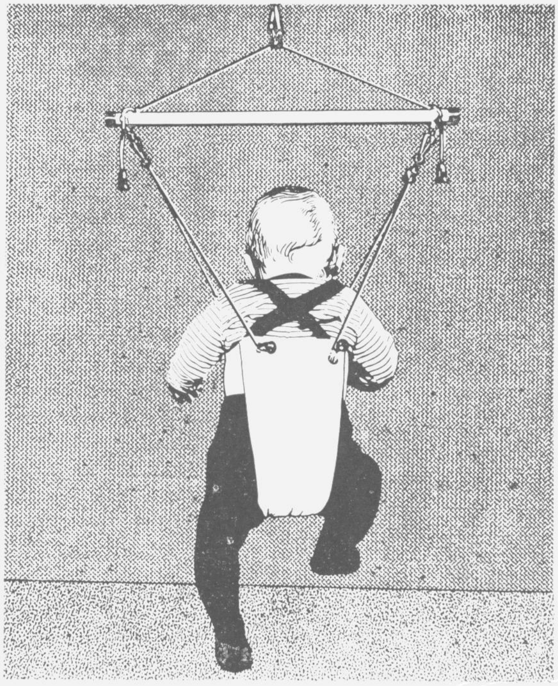

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LINK

SPRING Vol. 1 No. 1

The Journal of the ASBAH

Chairman : Mr. R. B. Zachary, West Lawn, 54 Clarendon Road, Sheffield, 10.

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Advertisement Manager : Mr. D. Miles 3 Gordondale Road, Mansfield, Notts.

Contents

Our cover was designed by John Perry of Manchester and the pictures of young Peter Whitehead of Rainham, Essex, taken by Alan Doxon.

Editorial: The task is urgent

After many months of work and much delay, here is our first fully national journal. I will start by thanking all those who have helped with the production of this edition. The magazine will be an instrument of our Association, to be used in the service of our members, in fact to fulfil the aims of the Association as completely as possible.

The contents of the magazine will have variety, and at all times the aim will be to maintain high quality.

This first edition of "Link" is our first means of national publicity. A fully national publicity campaign will be organised in the near future. Through "Link" and the campaign to follow, all members will have the opportunity of bringing the tremendous problems of the scourge of spina bifida and hydrocephalus out into the open. There are the problems of treatment unobtainable for some, years delayed for many performed by a few overworked doctors, who have the vision and the faith to know that their positive treatments are the right ones, but who are frustrated by lack of funds, skilled staff and hospital beds, and see an ever-increasing number of patients, awaiting their life--giving services.

While at all times we will try not to offend, we will not be afraid to be controversial. We will be ambitious. Ambitious for the Association. The tasks which face us to provide the care for ALL those who need it, to make available the follow-up treatment for those who require it, to research into the immense outstanding problems are all urgent.

The lives of thousands of patients now, and many more in the future, depend on the action which we initiate.

So much can be done, but so few people know how to do it. There are so many patients, but so few beds. This is something which many people of this country are unaware of. They and the authorities MUST remain ignorant no longer. We as an Association must educate them, and bring our needs to the highest authorities in the land.

This magazine will work for the Association, for the ordinary things and for the most important things. **THE TASK IS URGENT, PLEASE HELP US TO FULFIL IT.**

Our chairman says . . .

The Association for Spina Bifida and Hydrocephalus has now been founded on a national basis.

This follows the excellent work of local associations and groups, where so much has been done to bring together the parents of children with spina bifida or hydrocephalus, to provide lectures and discussions, and to arouse interest and support in the community in which they live.

Local associations will be represented on the national body in proportion to their membership. This will enable each active area in the country to express the views of its members and contribute to the aims of the Association as a whole, which we hope will soon bear the name "National," to which its widespread support entitles it.

I am delighted that the establishment of the national Association coincides with the publication of the first number of the national journal. This journal will play a vital part in advancing the aims of the Association — "For the care, welfare, interests, treatment, education and advancement of persons suffering from spina bifida or hydrocephalus."

Those of us who are physically active and who really know from first hand (parents, doctors, nurses, social workers, teachers and others in direct contact) the disabilities of these children, have a serious obligation to promote their interest in every way. If WE do not do so who will?

Vigorous support and publicity for the journal will be one of the first steps in our campaign to help in every possible way, those who have the burden of this handicap from birth.

R. B. Zachary.

Ideas please !

There will be a meeting at Birmingham Children's Hospital on Sunday May 22, starting at 11 a.m. to which representatives from all active groups, or potential groups, in all areas are invited.

This has been specially arranged to give all branches the opportunity to bring their questions and ideas to the National Committee. Such ideas as fund raising for national projects, how the National Association can help local branches and vice versa, or anything else of importance. No holds barred. Please come.

WHAT'S IN A NAME ?

In the case of this magazine, we consider it vital. For some considerable time we have been searching for a title which will convey the purposes and aims not only of the magazine, but the national Association whose voice it is.

We have also been faced with the difficulties that many titles that might be appropriate are already used — some many times over — or have become meaningless with over usage.

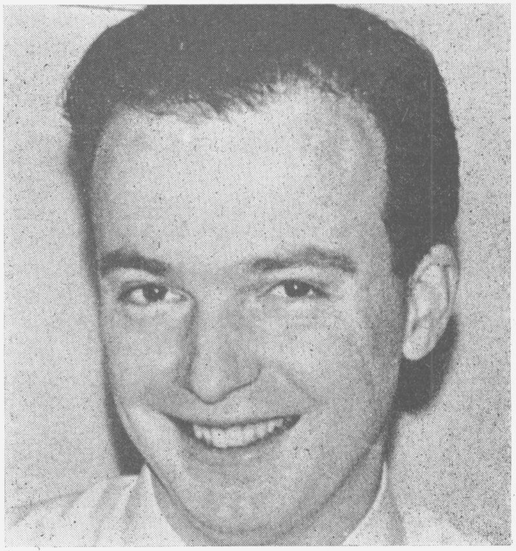
So we decided on "Link".

What does it mean as far as we are concerned?

We hope that this magazine will Link member to member, member to doctor, doctor to member, and doctor to doctor.

We also hope that it will help the national Association to provide a link with the outside world.

Please help to keep the Link going.



Editor Stephen Hinchliffe

National Secretary Mr. Tudor Williams at Central North London Group's children's party with his two daughters.
Picture by Westminster and Pimlico News.

Films are fun - sometimes

We owe it to ourselves — and to our children — to get out and enjoy ourselves occasionally. Ann Pacey, film critic of the "Sun" newspaper, will be talking in future about films you might like to see. Here, she discusses her job.

We who stalk the labyrinths of show business are constantly being told by people who stalk some place else what exciting lives we lead.

We must be exposed, they say, to the endless snap, crackle and pop of champagne corks and bitchy conversation; of premieres and press receptions.

Well, of course, up to a point they're right.

Basically, though, our function is to assemble in pale and shivery little groups early on a Monday morning for the first film of the week and, perhaps, work our way through five others before Tuesday night has fallen.

What is being presented can be marvellous, good, run-of-the mill or plain awful.

The trickiest moments come when a "plain awful" is followed by an official film company lunch, into which the stars and film makers have been press--ganged.

In order to negotiate a "plain awful" successfully you must ensure that you are not left sharing the cloakroom with the female star, who is nervously powdering her nose and waiting for you to say something while you are powdering your nose and thinking of something to say, apart from how nice her mink looks.

Once into the reception, it is important to find a large and wide somebody behind whom you can hide from the press officer who wants you to meet the film director.

After all, tomorrow your verdict will be in print — and tomorrow is always soon enough

On a location visit, you have to remember during shooting to keep out of the way of the camera, the director, the technicians and the tea-trolley.

In Monte Carlo a few weeks ago, I listened to Warren Beatty playing the piano, and talked to Susannah York as she warmed herself in front of a log fire, and joined with them and the director in praying for a higher sun, or a brighter sun, or a warmer sun, or a less hazy sun, or whatever it was that was holding everything up.

Filming is often a slow and hazardous, costly and hysterical business.

Criticism of the result requires impartiality, detachment, a good supply of non-tipped cigarettes and a reliable alarm clock.

"Don't you get bored, seeing all those films?" is the question I'm most often asked,

The answer is, quite simply, no,

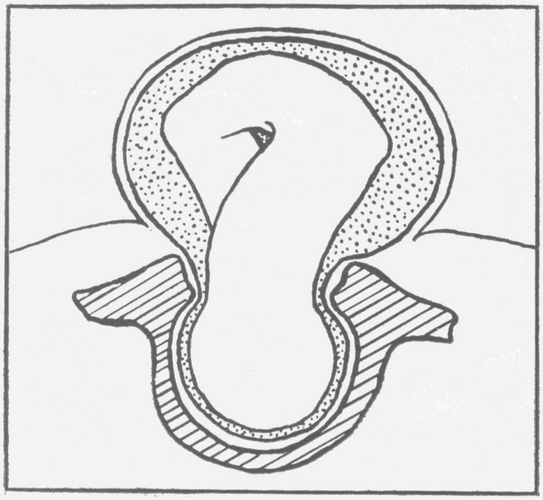
What is spina bifida?

Dr. John Lorber, Reader in Child Health, explains the problems that face parents and doctors when a child is born with spina bifida. He emphasises that with treatment, the majority of these children will eventually be able to lead full, useful lives. Next issue, another expert will deal with hydrocephalus.

The spinal cord is the nerve centre of the arms, the legs and the bladder. In people who are formed normally the spinal cord is safely surrounded by membranes and by the backbone, or spine. These coverings protect the cord against injury and infection.

During development, before the baby is born, the spinal cord lies on the surface, and is gradually surrounded by the developing bone, until two prongs in the back around it unite. In babies with spina bifida these prongs do not unite so the spine remains bifid or split in two, which is the origin of the name, spina bifida. In these babies, the spinal cord usually lies on the surface, in a large fluid containing sac.

Often the spinal cord itself is also abnormal, so that it does not have the usual number of nerve cells, which could control the activities of the muscles. The spine is usually split at the lower half of the back, so that the legs and the bladder are mainly affected.



A simplified drawing of a cross-section of the spina bifida, shown looking from head to feet. The spinal cord can be seen looping out of the back-bone, surrounded by fluid (dotted area). Both drawings by Trevor Nash.

Less often, the spina bifida affects any other part of the back, the neck, or the base of the skull. If it is the last variety, the condition is called encephalocoele.

Much additional damage can be caused if the membranes surrounding the spinal cord burst, which can easily happen either during birth or later due to friction, or if infection gets to the cord and the nerves coming from it. In such cases the paralysis may become much more extensive and there is a great risk of meningitis.

It is for this reason that more and more surgeons like to operate on these babies as soon as possible, often within hours of birth. This may not be possible in every case, and much may depend on the baby's condition when it reaches hospital.

Healing

When the surgeon operates on the spina bifida in order to cover the spinal cord with its membranes and then draw the skin together, the wound may heal very quickly, but healing may be delayed for several weeks because the condition of the skin is poor or it has had to be brought together very tightly in order to close the gap. This is why some babies' backs are healed within ten days and others take three or four weeks. It is during this period that the risk of meningitis is the greatest.

In some children the nerves are not involved in the spina bifida, and these are very fortunate because they have no paralysis. In others, the spina bifida is so low down on the back, that only the centres dealing with bladder function are involved. These children have no feeling in

A spin bifida baby before operation.

their bladder and cannot voluntarily empty it, but their legs are good and they will walk normally.

But in most children the lesion is more extensive and affects centres higher up and often over a longer stretch. These children will have weak or paralysed legs as well as bladder muscles. Nevertheless, the amount of damage varies a great deal from child to child, and every one is an individual problem.

Because of the weakness of the legs, unequal pull of partly paralysed muscles or immobility before birth, babies' legs are also often deformed.

Fortunately, the amount of paralysis can be greatly diminished by very early operation at the right centres. Later, with the help of skilled orthopaedic operations most of the deformities can be eliminated and the remaining muscles can be put to the most possible use.

When the spina bifida is higher up on the back or is at the back of neck, there is usually no paralysis or bladder problem. In cases where lesion is at the base of the brain, different problems arise. In these the posterior part of the brain may be involved in the swelling or may be malformed. This may result in defective vision and problems of intellectual development.

In a very large proportion of children with spina bifida about four-fifths, there is also an obstruction to the circulation of the fluid. This fluid is normally present within the brain and also surrounds the brain and spinal cord. Normally this fluid acts as a cushion and protects the brain from injury. But with an obstruction present, the fluid-containing spaces within the brain get distended, resulting in hydrocephalus or "water on the brain".

Hydrocephalus rarely shows itself when the baby is born, but investigations can show it quite early on. An early diagnosis is important, because treatment of the associated hydrocephalus can be planned and undertaken before there is irrevocable brain damage. Not every baby with hydrocephalus requires operative treatment : it all depends on its degree and on its rate of progress.

Bladder

Finally, there is the bladder problem.

Babies who have no voluntary power in their bladder may appear to the lay person to be normal because they are always wet. Unfortunately, they cannot ever fully empty their bladder. This makes them liable to infection of the bladder and kidneys, which can be prevented or postponed by frequent bladder expression. These problems need a fuller description in another article.

There are, therefore, many serious problems. With effective modern treatment most of them can be overcome. These babies will be able to walk, often with the help of orthopaedic appliances. The most important thing is that the large majority should be mentally normal.

Spina bifida children also face the illnesses every normal child has to contend with. In a series of articles, a specialist tells parents how to guard their children against these.

HANDICAPPED CHILDREN NEED PROTECTION, TOO

Children born with spina bifida present many special problems in upbringing. Their life is interrupted for hospital treatment for their condition. But is must be the aim of every parent and every doctor to ensure as far as possible that these children enjoy the privileges and pleasures of normal infancy and childhood. They should also be protected against all those diseases against which children born normally are protected.

Although these babies often have serious physical handicaps, it does not mean that they are ill. As long as they are in good health, immunisation should begin at about the third month of life, with 3 injections of the triple antigen against diphtheria, whooping cough and tetanus, given at about monthly intervals.

It is important to complete this course by the time baby is about 6 months of age, because whooping cough can be contracted very early in life and it is then that it is at its most dangerous stage.

Vaccination against poliomeylitis is usually given by mouth, starting at round 6 months. Again, three doses are usually given at monthly intervals. There is no harmful or painful effects from this. Booster doses are necessary against all these diseases at about 18 months to 2 years of age, and can be conveniently given on the same day.

The need for smallpox vaccination in our country is much less, and I would advise that it should not be performed on these children, unless there is a risk of a local epidemic, or if they have to travel to countries where smallpox still occurs.

Vaccination with BCG against tuberculosis should be done if there is anyone in the family, or among friends, who suffers from tuberculosis.

Measles is another illness which can be minimised or prevented by an injection of gamma globulin, if your child has been in contact with measles.

Among other health measures, which apply to these children alone, the most important is the prevention of bladder infection, if the child has no bladder control. This object may be achieved either by continuous drug therapy, or by intermittent treatment with the most appropriate drugs.

Regular expression of the bladder, every 3 hours or so, from early infancy onwards, is at least as important as drug treatment. It is essential that all parents should be familiar with the technique, and if they are not, they should ask for instruction.

To detect bladder infections, and to treat them effectively, we have to have freshly expressed urine for examination, which we obtain at clinic attendances. Parents should watch the doctor obtaining the sample, to check that their own method of expression is correct.

Some children with spina bifida have weak abdominal or chest muscles, which means that they can more easily acquire chest infections, such as bronchitis, and have more difficulty in getting rid of such infections. So if your child is only a little chesty, do not hesitate to get your doctor's advice early, to prevent more serious trouble.

Naturally, you will ask for medical advice if your child is ill in any way, but you need not be unduly concerned that the frequency of such illnesses will be greater than in children born without defects.

Next issue, the specialists will talk about the emotional side of upbringing.

Reader's Problem

Mrs. Evelyn Saunders, of 46, Maeshendre, Waun Fawr, Aberystwyth, asks for help with this problem :—

"Our son, aged 3, is paralysed from the waist. He has recently been fitted with an ambulating frame. He is becoming accustomed to wearing the frame, stands holding onto furniture, 'walks' when we 'steer' him. Can any parent advise us how to encouarge him?"

Courageous Anne shows how to enjoy a full life

She is as brave as she is bonny and there is pride in the voices of Scots who know, and can speak about, Anne Ross.

Anne was born 21 years ago before science had made any strides towards helping babies with spina bifida. Operations were unheard of, but luckily her spinal defect was covered by skin and Anne was able to survive without surgery.

She was fortunate, too, in being born to a mother who was as staunch as the Scottish Highlands where she lived. It was Mrs. Ross's determination and devotion which kept the premature babe alive.

And when Anne's legs showed signs of movement when she was three her mother, aided by a dedicated family doctor, urged her to make the fullest possible use of the muscles.

Today, Anne is a young woman who typifies the qualities which all parents hope for their children.

Charming

She is independent, outgoing, charming, considerate and posseses an appealing sense of humour.

She successfully holds down a secretarial job in the highly competitive business world. She leads a full and active social life with a wide circle of friends and often finds that she has little time left for the swimming, stamp collecting and reading she enjoys.

Anne is able to walk, but a chronic condition of the heel caused by a nail in her shoe means that she has to revert to crutches sometimes. She is also able to get around in her small car.

The last 12 months have demanded all Anne's reserves of courage. The mother who helped her to overcome the handicap died last year and her father suffered a stroke.

She is now helping her father to uproot from their familiar farmhouse in Ross-shire to move to a bungalow in the nearby town of Tain.

Anne Ross, pictured in her wheel-chair

She was allowed to leave hospital in Edinburgh, where she has been receiving treatment for her foot, to supervise the removal. But when she has seen her father settled in she must return to the hospital for more treatment.

Anne is naturally a modest person. But she has agreed to overcome her self-reticence to help parents of younger spina bifida patients. In the next few issues she will answer questions which every parent finds cropping up at some stage in his child's development.

Mr. Norman Kjelgaard, regional editor for the Scottish section of the Association, has asked the questions with the complete understanding of a parent of a spina bifida child.

Anne will answer them with the honesty and humour which have made her rather special to her Scottish friends.

A specialist guides parents on the aids and benefits that can be obtained to make their childrens lives easier.

Make the most of the Health Service

There is much uncertainty among patients, and even doctors, as to the benefits that can be obtained for the ill and handicapped. Since the prescription charges were removed a year ago, the situation has been easier but there are three separate sources of benefits, and the patient with spina bifida, who may be seen by a number of different doctors, often misses out by falling between stools.

The general practitioner, who usually has the day to day care of the patient, will prescribe medicines, dressings, bandages, etc. free on a prescription. He will often also order simple appliances, such as trusses and elastic stockings.

The hospital service usually bears the responsibility of supplying more sophisticated drugs, as well as appliances needed for treatment while the patient is under hospital care. Of course, in a disorder such as spina bifida, the patient will usually be under the care of one or more hospital consultants for many years, and so the hospital will order such things as calipers, crutches, and so on.

Articles which have been specially made and fitted to the patient, such as calipers, will be given to the patient, who will be responsible for bringing them back to be repaired as necessary. Items like crutches, which may be needed only for a short time, will only usually be loaned by the hospital, to be returned for use by other patients.

Footwear is in a category of its own, and different patients have quite different needs. Many patients have feet which though paralysed, are of normal shape and so they are able to buy ordinary shoes or boots in the shop. Sometimes calipers or other additions such as stiffening can be applied to these. In these cases it is reasonable that the patient should pay for the footwear. The hospital bears the cost of the modifications.

Other patients with slightly deformed feet can be fitted into shoes of slightly unusual commercial make. Many hospitals keep a stock of these, and can fit patients with the more suitable footwear. Where one leg is more severely paralysed than the other, the feet will often be of different sizes. It should be possible to purchase in the larger stores shoes of odd sizes at slightly added cost.

Many patients have reported difficulty, and some have complained of exorbitant charges. Some hospitals have a list of retailers in the district who offer this service. In cases of difficulty, application should be made to The British Footwear Manufacturers Association, 22, Gilbert Street, London W.1. (Tel. Mayfair 2843).

Where the feet are severely deformed and it is not possible to fit normal shoes, it is necessary for special boots or shoes to be made. Such surgical footwear is extremely expensive and usually takes a long time to be delivered. The cost is borne by the hospital service, but whereever possible it is desirable that normal shoes should be obtained.

Housing

In the case of patients not under the direct care of the hospital, the local authority takes over and will provide appliances for walking, and often pays for modifications to the home, such as ramps to overcome steps, modifications to the toilet and hand rails. The council also is responsible of course for housing lists, and many councils give high priority to families who have a handicapped member.

Whereas the hospital and general practitioner services have an obligation to provide benefits, in the case of the local authority they are permitted to help, but are not compelled to do so. The result is that there are very wide differences in the amount of help obtained from different local authorities.

For those patients unable to walk, or whose walking is not adequate for full activity, wheel chairs are provided. These can be obtained either from the hospital consultant or the local authority. The Ministry of Health permits, and even encourages, patients to have two chairs for home and school or work, if this avoids much transporting of the chairs. Obviously for children, hand-propelled chairs are provided, and many modifications may be made to these to suit the individual. Adults are provided with motorised chairs in suitable cases.

So far, we have dealt with items essential to the treatment and mobilisation of the patient. The National Health funds and the local authorities should not be expected to provide anything other than a fairly limited range of standard items. There are many other useful devices, such as bonny bouncers and spider chairs, which will help young patients. These are sometimes provided by individual hospitals who buy them from charity funds which they hold for the well-being of patients.

There is a further sub-division; the class of items which are just toys or recreational devices, i.e. tricycles, motor cars, etc. Often these will need modification before they can be used by the paralysed child. Some hospitals are building up a stock of these devices, but in the last two fields local groups of the A.S.B.A.H could well begin forming collections for loan to patients.

HERE'S HELP JUST FOR THE ASKING

In each issue a senior consultant from one of the main treatment centres will be answering your problems or questions. If something is troubling you, don't hestitate — write!

Mrs. Seager of Coventry says :—

I am particularly interested in any tips for preventing abrasions over the spinal bones. Paul is 22 months old and "swimming" along the floor, but tends to turn on to his back a lot. Also, the skin rubs off very easily if he sits in a canvas chair or cardboard box while playing.

There is an advertisement in the 'Nursing Mirror' for some kind of bed pad, which provides "comfort, relief and cure for pressure sores." I wonder if anybody has used one and if they are suitable and easily worn? My neighbour has suggested a thin sheet of foam rubber between shirt and vest, and I think I will try this first.

The other problem is keeping his legs warm. Does this matter? At the moment he wears corduroy trousers over wool and nylon tights, but is not really warm.

Also, at what age should we attempt to teach a seriously paralysed child to swim, always supposing he is willing?

Our doctor replies :—

The best way to keep limbs warm is to have the heat come from inside, that is from the circulation. If the child does not have much muscle power in the legs, there is very little pumping action along the blood vessels and the circulation is sluggish, It is for this reason that the legs are cold.

Circulation

If the legs are persistently cold, the skin is not in such a good state to withstand injury or friction, and it is certainly better if they can be kept warm. This does NOT mean that they should be warmed. Not only is the circulation poor, but also the nerve supply to the skin is poor, and the skin may be burned without the child knowing.

Can anything be done? Two things — keep the limbs well covered by soft materials, but nothing tight. Secondly, one can try to substitute a little for the ordinary active movement which is missing. Gentle movement of the legs by the mother with light stroking movements upwards on the skin, may help the circulation and these can be done about three times a day in a warm room, and the legs then covered.

I think it an excellent idea to teach paralysed children to swim in warm water, but there is the problem of bladder and bowel control. Provided these can be coped with. the idea is excellent.

★If anyone has any helpful advice on the problem of abrasions, please let us know. Mrs. Seager also asks if there is any possibility of having further children with spina bifida.

This is a very big question, which many people are asking, and will be covered fully in a future edition of the journal.

Advice on forming branches

While any group of people can be said to be an association, there are certain minimum requirements which are necessary before such a group can become an organisation accepted and trusted by the local community and by the national Association.

Here are a few details of what you should do :—

1. A general meeting of the local association should be called for the purposes of :—
   - (a) Adopting the rules (suggested form of rules can be obtained from the Secretary, Mr. Williams.)
   - (b) Appointing the trustees
   - (c) Appointing the other officers
2. A Deed of Declaration (form also obtainable from Mr. Williams) should then be engrossed for execution by the Trustees . After signature it should be presented at the local stamp office for stamping with a 10s. Deed Stamp.
3. Application should then be made to the Charity Commissioners for registration of the association as a charity. A form of application together with explanatory notes can be obtained either from your local authority or from the Secretary, Charity Commission, 14 Ryder Street, London S.W.1. With the form of application you should send the original Deed of Declaration and a copy of the rules.
4. The form of application is quite short and there should be little difficulty in completing it with the aid of the explanatory notes. The objects can be stated quite shortly on the form as : "Welfare of persons suffering from spina Bifida or hydrocephalus or allied or related disorders."
5. Local association will be asked in due course to affiliate to the national association by signing an affiliation agreement and paying a prescribed fee. The purpose of affiliation is to ensure that close contact is maintained between all associations and to carry out through the national Association projects which could not be achieved by local associations separately.

Now a few hints for those starting from scratch on how to become known and how to contact other members :

(1) Use your local newspapers, tell them about your meetings and activities, and in most cases they will be only too willing to help, so long as you can show that this is in the interests of local people.

(2) Aim to promote some kind of relationship with the local authorities, health and education departments and hospitals. Generally they will be only too willing to meet you and discuss your problems. They may provide you with names and addresses of potential members, but this can not be guaranteed.

(3) Many people will not be interested, but do not be disheartened. Carry on with those who are, set up a happy group until your organisation is strong, when you can re-approach those who turned you down in the first place.

(4) Ask for and accept help from a nearby group who may be well established. Good luck with your efforts.

CHILDREN'S CORNER

13, Cowlersley Lane,
Cowlersley, Huddersfield.

Dear Boys and Girls,

I am sorry your corner is such a small one, but I hope there will be more room for you in the next magazine. Just how much depends on you because I want this to be your very own spot in "Link."

So I would like you to write to tell me what you would like to see. And I would like you to send me your own stories, rhymes and puzzles so that all the other readers can share them.

Regards, UNCLE ED.

Uncle Ed would like you to paint your favourite doctor or nurse for him. If you don't have a paint box, use your crayons instead

Prizes will be sent to the best entries in two groups : Those aged seven and under and those aged between eight and 15. Age will be taken into consideration. Only entries accompanied by a stamped addressed envelope will be returned.

News from the Groups

N. Hants, S. Berks. and W. Surrey

This group was formed in May, 1965. The chairman is Mr. Pat Gould and the secretary Mr. Ivor Davies. Membership is now approaching 50, and activities have included a vigorous search for new members, talks by various medical personalities, and a visit to Chailey Heritage and several fund-raising activities.

Mr. and Mrs. Gardiner raised £25 at a jumble sale, and there was a generous donation of £50 from the Farnborough Rag Committee. Another donation of £25 was received from the Bonhomie Organisation of Southampton.

An approach has been made to the Principal School Medical Officer for the area regarding schooling for the children.

Mr. Davies, has been able to make available some interesting leaflets for information of members.

North Western

The North-western Group was formed early last year, and has now about 200 members. In the past year, the steering committee ran a newsletter, organised three official meetings with guest speakers and numerous small group meetings.

The first annual meeting was held in Manchester on February 19th at which a committee for the coming year was elected and a formal constitution was adopted. At present, the committee consists of five members, and it is hoped to co-opt three further members so that the committee can be brought up to full strength. The treasurer announced that there was a balance of £31 19s. 9d. at the end of the year, and appealed to all members whose subscriptions were due to renew them as soon as possible.

The committee has organised a programme for this year, and is especially anxious to encourage the formation of new groups and to recruit new members. Experience is showing that members always welcome opportunities to meet each other for informal discussion, and in rural areas are prepared to travel considerable distances to attend meetings.

Scotland

The Scottish Spina Bifida Association started in June, 1965, with a dozen interested parents. Articles in national newspapers increased membership, and notification of the existence to all Medical Officers of Health and major hospitals in Scotland also helped in this direction.

Membership, from the Orkneys to the English border, has now passed the 120 mark. Distance makes newsletters of vital imporance, and the group is delighted that, with the formation of the national association, it will be able to offer Scottish members four national newsletters a year. In the meantime, two Scottish newsletters a year, with a circulation of around 500, will be issued to keep members up to date with more local affairs.

Meetings are held at about three monthly intervals, and such is the interest that members have travelled great distances to attend. A system is being introduced whereby these members will be able to stay overnight with members in the Glasgow area.

The Scottish Association has a separate finance committee which has the responsibility of raising funds. These amount to £200.

Already the group realise that it has a vital role to play as a social service. It is finding that hospitals are referring cases to the group, as they can appreciate that the best thereapy for parents facing what may seem in the early days to be insurmountable problems, is to meet other parents, or to meet spina bifida cases, and hear at first hand how they have overcome their handicap.

It is early days for the fledgling Scottish branch, but they are exciting days, and the prospect of working along with others all over Britain in the development of ways and means of ensuring that spina bifida cases receive the very best available care and treatment, is a most challenging situation.

Sheffield

This group was formed in spring, 1964. The chairman is Mr. F. Burgin and the secretary Mrs. M. Foster. The group has had up to 300 members from many parts of the country, but as other groups have been formed, many of these members had their membership transferred.

There are quarterly meetings addressed by surgeons, doctors, and the Director of Education for Sheffiield. Fund raising activities during the past year have included a dance, which raised £45, and a "toy fayre" which raised £90. The group does a lot of work to help the Richard Fund — Research into Congenital Hydrocephalus and other Radical Deformities — which is based in Sheffield.

Because of the large area covered by the Sheffield group, it was decided to split it into smaller branches, with localized activities at :—

Doncaster : A group is in the process of formation.

Huddersfield : There are about 30 members. They have supported general meetings at Sheffield, and have held local meetings addressed by doctors and education officers. Fund-raising activities have included coffee evenings, jumble sales and raffles, and funds to date total approximately £85. The group held the first children's party in January. Members are agitating for better local medical and educational services for their children, and have been greatly helped in their efforts by the local M.P., Mr. K. Lomas.

Leicester : Leicester is the centre of fund-raising activities for the Richard Fund by Mrs. P. Keeling, who is a member of the Sheffield Area Committee. A total of £283 was raised at the home of Mrs. Collier, at a coffee morning and raffle. The raffle was drawn by a seven year old Spina Bifida patient, Stephen Lacey.

A Further £100 was raised by Mrs. Keeling at a rummage sale.

The Ladies Section of the Leicester and District Butchers' Association is working for the next six months for the Richard Fund, encouraged by Mrs. Keeling. Mr. Keeling organises an annual Golf Competition in aid of the Richard Fund.

It will be held this year on May 14 at Lutterworth, Leicestershire.

Nottingham : From the influence of Mrs. Keeling, Mrs. Angelides in Nottingham has started activities in that area. She raised £80 for the Richard Fund at a sale of toys, etc.

Mansfield : £40 was raised at a concert in the Town Hall, arranged by Mr. D. Miles, a member of the Sheffield Area Committee.

North Lincolnshire

The group was formed, as a subdivision of the Sheffield Branch, in summer, 1965. The chairman is Mr. A. L. P. Carter, Treasurer Mr. Keeble, and secretary Mr. Wright. Membership is now about 50. The group has held several meetings addressed by specialists, including a doctor from Sheffield and the Grimsby Medical Officer of Health. Fund-raising activities have included a concert which raised £38. Raffles and apron-making by Mrs. Dunster raised £17, and a raffle by Mrs. Keeble raised £3 10s.

South Hants.

Membership of this group is around 50. It covers a large area, with members in Dorset and Wiltshire, as well as Portsmouth and Southampton. The group is affiliated to the Southampton Federation of Clubs for the Disabled, which have been a great help. Financial assistance has been given by the Bonhomie Society, and funds have been raised from several jumble sales.

At Christmas, the South Hants. Group was 'adopted' by Brune Park County High School Gosport. The school held a "Spina Bifida and Hydrocephalus Fortnight." The pupils put collecting boxes in classrooms, held raffles, socials, dances, a carol service, sold calendars and asked for presents for a Christmas Party. Over £100 was raised, to be used to form a pool of equipment, baby bouncers, trolleys, etc., which will give aid to younger children.

The chairman Mr. C. W. Salter, treasurer Mr. C. R. J. Hibberd and secretary Mrs. J. A. Rae.

Potteries, W. Midlands

This group has been meeting for a year. There have been various fund--raising activities, and the monthly meetings have been addressed by such speakers as the headmaster of a nearby special school, the head of a rehabilitation centre and a welfare officer. Many of the 20 families travel long distances to these meetings. The Chrismas Party was very successful.

Despite one or two early difficulties, the group is now gaining strength, and recently has been very encouraged by a donation of £50 from the nearby firm of Rubery Owen & Co. Ltd., from their penny-a-week charity fund. Secretary is Mrs. M. Powell.

Surrey

The group has a committee of three : Chairman Mr. M. Batt, secretary and treasurer Mr. Ian Couper and activties member Mr. Colin Maclean.

Activities to raise funds during 1965 included a coffee morning, three productions staged by "The Entertainers" — a group of talented performers who put on shows to raise money for deserving organisations — and a bazaar. This was held in December in Croydon, and was well attended. It was opened by Mrs. Roy Hudd, wife of the T.V. personality, and raised £100.

Meetings of the group are held bi-monthly : There was a visit by a number of members to Queen Elizabeth's Training College, Leatherhead, and to Chailey Heritage, Sussex.

The group donated £100 towards the cost of a machine required for research into paralysis of the bowels and bladder.

Sussex

The Chairman is Mr. D. W. Bushby and secretary Mr. F. G. Armour.

This group has published a news sheet to keep members informed of the progress to date. Fifty members visited Chailey Heritage. There have been several group meetings, one addressed by a handicapped service officer, when members were given practical demonstrations of many kinds of equipment available through the welfare services.

In collaboration with the Hampshire Group, an attempt has been made to obtain publicity on Southern ITV, and hopes are still high that something will come of this.

The secretary has a price list of waterproof playwear suitable for children of various ages, available on request.

Liverpool

This group was formed in August 1965. It has taken the name of Liverpool Association for Spina Bifida (Myelomeningocele and Hydrocephalus.) The group has monthly meetings at which medical and educational experts have been able to speak to the parents. There have been various outings for the children, including a Christmas party.

The group has established a 1966 six-berth caravan at a holiday camp in North Wales. This is for the use of its own members in the first instance, but the group hopes to be able to offer it for the use of members of other branches at a later date.

Cardiff

Under the patronage of the Lord Mayor, an appeal in aid of Tenovus Spina Bifida Fund has launched for a spina bifida unit at been Cardiff Royal Infirmary. The unit will cost about £15,000, and it is hoped to announce the success of the appeal in a later edition of Link.

Central North London

Central North London branch is approaching a membership of 100. Rules have been submitted to the Charity Commission for registration.

On April 4 about fifty members gathered at the branches's Westminster, London, meeting hall for a film show and talk by the headmaster of Coney Heath, Britain's only school devoted to spina bifida children. They saw young pupils taking their Duke of Edinburgh award challenges.

"LINK" is the journal of the Association, and we can only make it a success with the help and co-operation of members. We want your views, stories.

Each branch will have an opportunity to have its local news in the journal, so secretaries please send your news along, and we will print as much as possible. We would suggest that for information about more local affairs, a simple news-sheet of your own could be duplicated and sent out to your members along with Link.

A column about gadgets to make life happier

This column will contain news of gadgets aimed at making life happier and easier for our children and ourselves. It can be successful only if you help us to help you by sending in descriptions of your own ideas.

We want adaptations for toys and games to enable our children to have pleasure from them, also labour saving ideas and devices. Our list is already impressive and we will supply plans and instruction for making any of the following :

1 Conversion of a tricycle so that it can be be manually operated.

2 Oiled silk cover to prevent urine spoiling the leather back piece of a divaricator.

3 Conversion of a pram to accommodate a divaricator by adding "blisters".

4 Home-made chair with saddle to accommodate a child with a divaricator.

5 Conversion of a "push-along" truck by fitting castors to replace front wheels.

6 Home-made steel toe-caps for protecting toes of boots when child does a lot of crawling.

7 "Heel-skis" to strap on full-length plaster so that child can shuffle without wearing plaster out.

8 Tricycle pedal adaptors to enable child's foot to be strapped to pedal.

Walking

9 Straps to prevent shoe coming off in walking when child has ill-shaped feet.

If you would like further details of any of the above, or have any ideas yourself which you feel would be of value to other members, please write, enclosing a stamped addressed envelope, to Alistair Wood, 7 Garthwen, Llanfairfechan, Caernarvonshire.

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HOW THE ASSOCIATION WORKS

After months of long negotiations, the Association is now formed and registered on a fully national basis.

The constitution is a most comprehensive document, and covers the Association for just about every conceivable future project.

The Association will operate as follows:— Each group or branch will be able to have representation in the national Association according to the number of branch members. There will be one representative for a minimum of 30 members and under 100, increasing thereafter at the rate of one per 100 to a maximum of 5. This means a branch of 150 members would have one representative, whilst a branch of 350 members would have 3 representatives. The Association will meet once a year at an annual general meeting, or at a general meeting called for a special purpose.

The Executive Committee of the Association, consisting of 12 members, will be elected at annual general meetings, by a vote by the members of the Association. The Executive Committee, will meet several times a year, and deal with the general running of the Association.

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