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LINK

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

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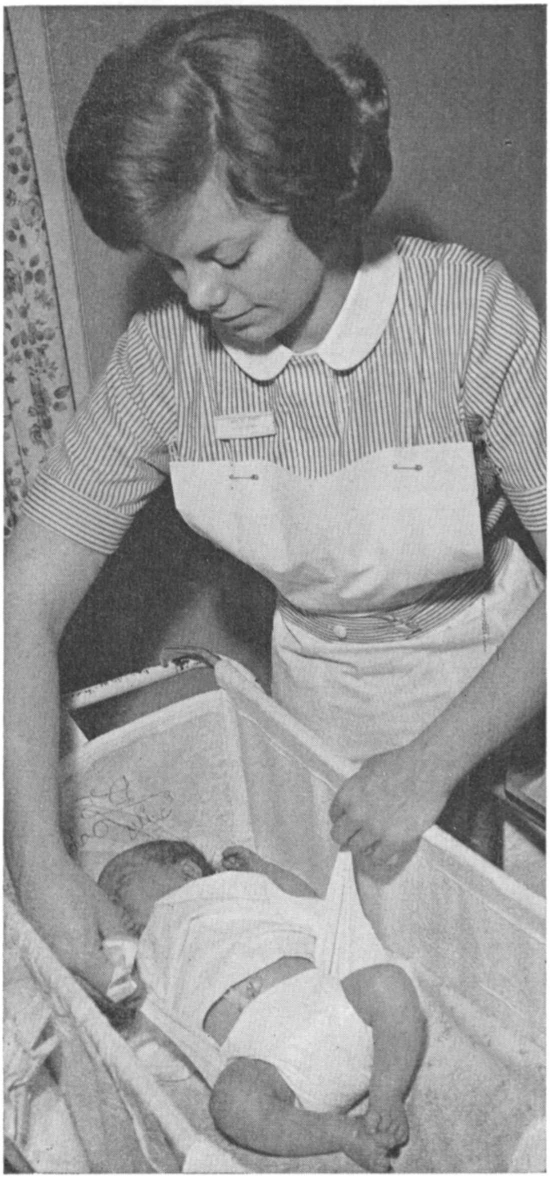

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LINK

CHRISTMAS Vol. 1 No. 13

Contents

Our Cover

Our cover shows Sarah Cotsford who has hydrocephalus controlled by a valve. Sarah is a happy outgoing child despite 11 operations.

EDITORIAL

A happy Christmas to all readers of LINK! This is the third issue of the magazine I have produced and already I am greatly encouraged by the many letters I have received in appreciation of my small efforts.

In addition, readers have helped by responding to my appeal for letters of personal experiences, quite a few of which appear in the following pages. These, I am sure, give hope and comfort to others who are going through trying times.

There are lighter moments which can be kept in the mind and remembered on a darker day.

Just recently, I went down to our local hospital to see a Spina Bifida boy of five who was in—just for a change—with a broken leg. This was being treated by traction and whilst I was in the Ward he laughed so much he fell out of bed and hung suspended by the weight and pulley!

No damage was done and as the nurses helped him back he kept on laughing. This boy will have a happy Christmas and many more I am sure.

SOME COMPLICATIONS OF HYDROCEPHALUS

By D. M. FORREST, F.R.C.S.

In his article in LINK (Summer 1966) Mr. Zachary described causes and treatment of Hydrocephalus, but in a short article could not hope to do more than sketch in the main features of a notoriously complicated condition.

Twelve years ago, when valve drainage became a practical method of treatment, we were for the first time able to drain Hydrocephalus with a good chance of success. We hoped to control pressure inside the skull and thus prevent brain damage and undue growth of the head until such time as the patient's own body became able to deal with the excess fluid and make the valve redundant, perhaps after a year or two. In many cases this hope was realised and there are today hundreds of children growing up whose valve perhaps is no longer being used.

Unfortunately, though, not all children reach this state of "natural arrest" but remain dependent on the drain indefinitely. This, of course, introduces difficulties because it means that blockage or other complications of the valve will need to be watched for throughout life. No valve system will work forever, though the valve itself very rarely fails. Manufacture and testing are rigorously controlled. (This is the main reason why valves are expensive). As the child grows, the tube leading down into the heart becomes too short and finally may block. This may happen from one to seven years after the original insertion, or even later.

The other common cause of blockage is obstruction of the upper tube lying within the cavities (ventricles) of the brain. Sometimes these ventricles are very much enlarged, in which case drainage is easy, but more often nowadays with early treatment they are quite small and may shrink back to normal size, little more than slits deep within the brain. Then the situation is like the village fire brigade trying to pump water out of a well. Shallow water permits only an intermittent flow and debris may block the pump completely.

The amount of fluid which a valve is called upon to dispose of varies enormously from one case to another. The block in the brain may be almost complete so that the whole output of fluid must be drained off, perhaps a pint or more each day. In other patients, the formation of fluid only slightly exceeds the body's ability to remove it, so that the valve is called upon to shunt only a tiny amount. We know that production of fluid varies from time to time and that, for instance, more is formed when the patient is feverish. In a few cases the valve is not needed except on such occasions.

Thus symptoms of blockage vary greatly in different patients according to work load of the valve. If a valve is being used only slightly, or if it becomes partially blocked, then there may be little to show for it except perhaps some lack of energy or appetite, irritability or drowsiness. An older child may complain of headache. This may go on quietly for days or weeks. When, however, a much-needed valve blocks completely the symptoms are much more dramatic and serious. There may be vomiting, screaming with pain, drowsiness and then unconsciousness. If nothing is done to relieve the pressure, the heart and respirations will slow and stop.

Obviously, this is a state of emergency and in such circumstances the patient must be rushed to hospital without delay. Luckily, the usual onset is much more gradual and there is plenty of time. On the other hand, minor symptoms can very rapidly become severe, so it is always safest when a hydrocephalus patient becomes unwell, to suspect the valve first of all. Fortunately, it is usual for each individual to show the same symptoms each time a block occurs, so parents quickly learn to recognise trouble in their own child.

HOW CAN WE TELL WHEN PRESSURE IS TOO HIGH?

In an infant who still has a soft spot (fontanelle) there is not much difficulty. When the child is sitting up quietly the fontanelle should normally be flat and pulsating. When a valve is working well there is often a hollow. Of course if the baby cries or is laid flat, the fontanelle will normally bulge. If the fontanelle is tense and bulging even with the infant sitting up quietly, then pressure inside the skull must be too high, and something must be done about it.

Unfortunately, this useful pressure-gauge is lost during the second year of life when the fontanelle closes and we then have no direct means of learning about the state of affairs inside the skull. To overcome this lack, we sometimes deliberately fashion a permanent false fontanelle so that parents can tell whether or not their child's symptoms are due to raised pressure.

IS IT POSSIBLE TO TEST FOR BLOCKAGE BY PUMPING THE VALVE?

In theory, yes, but in practice there are many pitfalls. A blocked upper tube prevents the valve from refilling after it has been compressed with the finger. There are, in fact, many valves which refill very sluggishly because they are partly blocked, yet function perfectly adequately for the body's needs. This sign should therefore only be taken as indicating blockage if the valve remains completely flat for some hours after squeezing.

When the lower tube is blocked the valve should, in theory, be impossible to compress. In practice, it is usually the vein and not the tube which obstructs, so that it is almost always possible to go on pumping before the valve becomes stiff to squeeze. Sometimes, when a vein is beginning to block, sufficient fluid can be pumped away to relieve symptoms temporarily, a useful test in cases of doubt.

Should the valve be pumped every day?

Some surgeons recommend daily pumping to prevent blockage from developing. This should not be necessary, and there is slight danger of damage to the valve by over-enthusiastic pumping. You should ask your surgeon to demonstrate the correct method of pumping and remember that it takes some time to remove any quantity of fluid—a hundred squeezes deliver a desertspoonful.

In conclusion, it must be said that valve blockage may be a serious matter, and parents who suspect it should take prompt action.

VALVE INFECTION

The tissues of the body have a wonderful ability to destroy invading bacteria, so that normally the interior of the body remains sterile and healthy. Unfortunately, the body's defences are hampered by the presence of any foreign material so that, for example, a finger with a splinter in it will continue to fester until the offending sliver of wood is removed.

This applies, too, to foreign bodies deliberately implanted by surgeons, and the valve is no exception. In this case there are two reasons for concern: firstly, the brain has rather poor capacity to throw off infection, and secondly, infective material inside the valve is dripped continuously into the blood-stream where it overwhelms the body's defences. For this reason, normally harmless germs can become the cause of chronic ill-health.

Infection can get into a valve in one of two ways; during operation for insertion or revision, when it is virtually impossible to guarantee absolute sterility, or later, from stray bacteria entering the blood stream and colonising the valve.

When infection has become established, the patient will develop symptoms which may be slight or severe. He may be grizzly, listless, sweating and feverish. The diagnosis must be confirmed by growing bacteria from a blood sample, often a tricky procedure. The infection can seldom be eradicated by antibiotic treatment alone as usually the whole valve system is removed. It is sometimes possible to put a new valve in straight away but often a period of intensive treatment is necessary to kill all germs before the shunt can be re-established. Meanwhile, pressure must be controlled by temporary means.

(*Continued on page 6*)

Sarah Cotsford has hydrocephalus controlled by a valve. Aged two when our cover picture was taken, she is now five and this is the first photograph taken at the ordinary infants school which she now attends.

PROJECTS AND GRANTS

Spina Bifida Trust

These are the projects which have recently been approved and awarded grants by the Spina Bifida Trust.

Other grants are held up in the pipeline through lack of funds, but our trustees are determined to give the go-ahead for more schemes which will help our children to lead fuller, happier lives, at the earliest opportunity.

One scheme which deserves priority when the money is available is a study of the physical and social problems of adolescents with spina bifida in relation to opportunities for employment and recreation. This project will cost £5,000.

Any groups who are considering making a donation might like to consider this as an extremely worthy fund-raising cause.

Grants Authorised by Spina Bifida Trust

1. Study of the electrical activities of the brain in children with hydrocephalus.
   Sponsor Mr. D. Forrest, Westminster Children's Hospital.
   Cost £5,000.
2. Research in aptitudes in children with spina bifida and hydrocephalus.
   Sponsor Dr. J. Lorber, University of Sheffield.
   Cost £6,500
3. Study of the causes of infection of valve systems used in the treatment of hydrocephalus.
   Sponsor Dr. R. L. Newman, Queen Mary's Hospital, Carshalton.
   Cost £2,400.
4. Part-time secretarial assistance for Pathology section of Congenital Anomalies Research Unit.
   Sponsor Dr. J. L. Emery, Children's Hospital, Sheffield.
   Cost £1,500.
5. Case study examination of the use of accommodation and physical facilities at a Local Education Authority Special School for physically handicapped pupils to assess their effectiveness in use and to formulate further research proposals.
   Sponsor Mr. Alan Lipman. The Welsh School of Architecture, Cardiff.
   Cost £1,020.

The Plan

The Liverpool Association has been seeking a site suitable to give adequate facilities for the special care, education, employment and general welfare of Spina Bifida children in the Liverpool area.

A suitable site has been offered in Gate acre now known as the Tudor House. The total cost of the property will be £35,000 which includes alterations, extensions, furnishing, etc.

A very successful Liverpool Festival for Spina Bifida was held from October 6th-11th and although total receipts are not yet known, sufficient has been raised to pay the deposit on Tudor House.

The Festival included many fund-raising attractions including a Fashion Show, Animal Show, etc. Demonstrations of Judo and Karate, mobile Zoo, Concerts, Dances, Donkey Derby and many other features.

Cont. from page 5.

FITS

Epileptic fits are caused by a part of the brain becoming irritable and setting off a chain of impulses causing loss of consciousness and uncontrolled movements of the body. Even slight injury to the brain may be responsible, so it is not surprising that a percentage of children with Hydrocephalus have convulsions at one time or another. Some are severe and endanger life but the majority are brief and easily prevented by prolonged drug treatment. They are more likely to occur when the patient is feverish or otherwise unwell, so often it is sufficient to give a dose of medicine at such times. Severe, prolonged fits need urgent treatment to prevent obstruction to breathing and tongue biting and hospital admission for vigorous treatment in order to prevent further brain damage.

HEAD INJURIES

Parents often enquire whether or not it is safe to allow their child to play normally with other children, since they fear that a blow on the valve may damage it. In practice, while the possibility exists, it is too remote to justify any restriction of activity, which itself would be likely to harm the child's general development. The only exception to this rule is a child with a very large rigid skull. In this case a fairly mild jolt can set off bleeding within the skull, so it is wise for a padded helmet to be worn.

OUR READERS WRITE

Dear Editor,

My son, Julian, was born a little over six years ago, at home, and because the G.P. who attended us knew exactly what to do, he was taken straight away to Gt. Ormond St. Hospital where his back was operated on the same day.

It was not necessary for him to have a valve and seven weeks later he came home.

From that day on he has not looked back. He has over the years had three orthopaedic operations and as a result of these and the skill of a good physiotherapist, his legs are now extremely strong.

Julian got to his feet himself when about 18 months old and moved around the furniture, he has calipers but is well able to walk without them, and we are considering just short calipers to support his weak ankles.

Julian attends normal Primary School and is very happy there, he is a lively, intelligent child and gets on well with his classmates, who treat him as one of themselves.

Maybe our experience may help parents of young spina-bifida babies, who I know from experience may be completely bewildered and have probably never heard of spina-bifida until now, and are wondering if there is any hope of a normal family life for their child.

There is often a great deal to be salvaged from an apparent tragedy and with skilled help their child will probably grow up like mine, and others, I know. Well able to cope with life and as near normal as possible.

We all have our defects; after all it is only a question of degree.

EILEEN FORDHAM (Mrs.),
"Pantiles",
Rickling Green,
Saffron Walden.

The following letter was received by Mr. K. Fletcher, Secretary of Staffordshire Association. It is reproduced here unedited and unabridged! (Ed.)

Dear Mr. Fletcher: We are all nine years old and attend Norton County Primary School, Stoke-on-Trent.

Ruth Turner, Anthea's sister is six and for the past two years she has joined our class on Friday afternoons. Ruth is a Spina Bifida.

We decided that it would be a good idea to have a sale for Spina Bifida children. We asked Mr. Mars our teacher and Mr. Bailes our Headmaster what he thought about it.

He thought it was a good idea so he gave permission. The Sale took place on July 31st.

We decided to get some more money by holding a Raffle. There were two cushions for prizes. The first was gold on one side and the second was green velvet. We sold the tickets at a penny each and we had so much money that Karen bought a money bank and we kept the money in there.

To raise some more money we had a refreshment stall we sold cakes and biscuits and drinks of orange squash.

We enclose a cheque for £5 12s. 6d. Will you please forward it to the Stoke-on-Trent branch of the Spina Bifida Association. We are Anthea Turner, Elma Palmer, Nicola Astbury, Karen Bradshaw.

Dear Editor,

As a result of the Nottingham & District's Association Newsletter giving details of a caravan owned by the Sussex Association, I can report that my wife and I along with our daughters had one of the most enjoyable holidays ever.

We have spent several past holidays in caravan's but they were nothing to compare with this particular one.

It did lead us to think what a good investment it would be if our Association were to purchase one and make it available to our members. Based on a site with facilities similar to the Sussex one, it would enable many of us, with our particular problems, to still look forward each year to a holiday, without worrying about any difficulties which could possibly arise with a handicapped child in an hotel or boarding house.

To elaborate more fully on the Sussex caravan, it really consists of two units bolted together which give a living area 22 ft. long and 16 ft. wide. The interior was fully furnished and lacked nothing.

Perhaps the most important point was the fully equipped bathroom, with hot and cold running water, also the flush toilet, this alone made the difference between other vans and this particular one.

Double doors at the front of the van, with a well constructed ramp to the ground made it easy for a wheelchair to move in and out of the van without any bother.

Cont. on page 8

OUR READERS WRITE—contd.

Electricity was connected and the lighting in the van was very pleasant, with twin wall light fittings in the lounge and both bedrooms. All doors were the sliding type. The kitchen was roomy with plenty of working space and an electric refrigerator was included.

Charges for hire were on a sliding scale from £5 per week in April up to a maximum of £15 per week during July and August and then down to £5 again up to October.

To conclude, the holiday left me in no doubt that the answer to any future holidays was to buy a van of my own and I am investigating all the in's and out's of the venture with real enthusiasm.

E. FREEMAN (Mrs.),
Secretary, Notts & District Association.

Any More for the Island?

On Sunday the 7th September the SHASBAH Group waved gaily from the Isle of Wight Ferry as it sailed from Portsmouth. On shore, the Treasurer, with the group's sailing ticket in his pocket, waved gaily back.

Such a start would seem to herald a disastrous outing to the Isle of Wight but like all treasurer's ours proved no exception and with quick thinking and a fast get-a-way passed the ferry in mid Solent by hovercraft to greet his charges on the Island shore.

A Southern Vectis coach driver met us for a tour and after much permutation the wheelchairs were stowed and we set off for Carisbrooke Castle. However, perhaps the custodians had heard that we were coming and we found the gates closed, portcullis raised until the afternoon so we set off for lunch at Godshill. Here we enjoyed excellent amenities followed by visits to the famous attractions of this lovely village.

On, after lunch to the Blackgang Chine where once again we were made very welcome and every attention afforded to us to make access as easy as possible.

From the crazy mirrors we went to Sandown Beach for picnic teas and a quick swim and then back to the Ryde ferry which was successfully boarded by the treasurer escorted by a squad of modern Boadiceas.

We had a wonderful day with a laugh a minute—and the children enjoyed themselves too. At each of our stopping points the people of the island went out of their way to make us welcome and ensure that the children thoroughly enjoyed themselves.

Dear Editor,

In reply to the letter from reader Mrs. Price in the Autumn issue of *Link*, I have a son of 11 years who is a Spina Bifida child. He is the third of four children, my other three children are perfectly healthy.

When my son was born, ASBAH had not begun and so I had no way of asking for advice from people who knew what it was all about; fortunately we had a very good family doctor (we also looked upon him as a friend).

It was to him we turned for advice. I had always tried to bring Steven up as a normal child. With three more children watching everything I did I could not afford to do anything else. If he needed a smack for doing wrong he got one. If he did something that pleased, then he was rewarded the same as the others. To my husband and I Steven is not a cripple. To look at he is, with calipers and crutches.

Our doctor agreed with the way we brought him up, but he said we could go a step further. I give my children jobs round the house, these tasks include washing up after a meal, carrying coal, running errands, peeling potatoes and dusting. This summer Steven has been helping his father repair the car, even unscrewing nuts can become interesting if tackled in the right spirit.

Once interest and enthusiasm for a particular task are established his natural instinct to sit and mope are soon overcome.

I offer the above information in the hope that by my experience others may in some way benefit.

MRS. M. LEACH,
90 Bondgate,
Pontefract, Yorks.

Dear Editor,

I have a nine-year-old daughter with Spina Bifida and enjoy your magazine so much. I would like to correspond with a mother of a daughter near my daughter's age.

She is in fourth grade, is going to school this year, previously has been on homebound programme due to broken bones. Keep up the good work. Several of us mothers in Mobile look forward to each copy.

MRS. W. E. LANGLEY,
2806 Bellmead Drive,
Whistler, Alabama 36612.

OUR READERS WRITE—contd.

Dear Editor,

When we got over the first shock of having a Spina Bifida child born to us, we coped as best we knew. We love the child very deeply, and we do all we can for him, but as the years roll on, and we have to make the visits to the hospital more times than we care to remember, we seem to live from day to day, hoping that someone will make a wonderful discovery which will make our child as perfect as possible —I know I did.

But as the years go by the child is too heavy to hold, you find that you can't lift him so well and in the end it starts to drag you down, and as much as you love him you know in your heart that there must be a parting, to some form of school, in most cases it will be a residential school, and your heart feels as heavy as it did the day you gave birth to him.

You will face it; you have to, and you visit the child as often as possible. It is hard to bear, the child wants to come home, you want him home, but human endurance can only stand so much. So the child settles down and makes friends with other children, and you feel better. Life is not so much strain at home for the rest of the family and in any case the child is really enjoying life more, as he is not the "odd one out".

So the years roll by, and you still go on hoping for the best; to give up would be terrible, you dare not lose hope. Until one day you find your child has been lucky and reached the age of sixteen and will be on the point of leaving school, now comes the crunch, where is he to go? Try as you may, no one wants him. He can't remain at school forever, they need the beds for the little ones who are waiting to come in, so what do you do? You apply to the Invalid Aid Association; they can't help you, so you start to send letters to all the medical people you know, that have had dealings with your child in the early days. They can't help you, so you may be like me and get very cross and write to the M.O.H. but the letter never gets to the person you sent it to, the buck is always passed to a lesser person, so you get a letter back "on behalf of", and you then begin to feel really wild; you think of the unmarried mothers' clinics, drug addict clinics, to name only a few.

But there is never a mention of a place where we can take our young sons or daughters to be cared for during their adult years.

So what are we to do? Well let me tell you there is nothing you can do, no one will listen to one voice, I know I have tried it many times, and I have learnt for the first time in my life that we have many, many, homes up and down the country, in fact I was really surprised we had so many, the only way I found out was because I got so many doors slammed on my son.

Never did I think I would have to go begging for a place that my son could live his life out, in the comfort he should have as his right. I am not alone in this struggle, there are many others who have the same problem, and there will be more to come up against this worry in future years. We must rally now, unless you also want your child put in an old people's home, while the M.O.H. are trying to find a place for him, as this happened to one mother I know, and God knows how many more will suffer the same fate in the near future.

We must get together to sort this out, it is up to us to do something about it while the child is still young, and being cared for. Don't wait until he, or she, is on the point of leaving school, then start to worry where they are going to. The crush will come along in the next few years, as the children are surviving more now, and unless we are heard now it will be years before anything is done. If you want a rally, or a march then let me or your group know, and we will see if we can get one, but please, we need to have your names so send them into me, or to your group.

You are not doing this for yourselves, or for me, you are doing this for children who have only you to speak for them.

MRS. B. GODFREY,
50 Barrow Lane, Cheshunt, Herts.

Dear Editor,

Our son, Stephen, was born last November 11th. It was a shock to learn that he had spina bifida.

My only knowledge of this came from the fact that my mother-in-law had lost 3 because of it and my husband's paternal aunt had lost 2.

I think we owe it to our son to learn as much as we can about spina bifida. I have been corresponding with the head of the Spina Bifida Study Group at New York University. It was he who sent me a copy of *Link*.

I would like to correspond with one or two mothers of children with spina bifida.

Sincerely, MRS. SHARON ROBINSON,
R.R. 1 Carfield, Ontario, Canada.

Derek Barnes (who suffers from Spina Bifida) playing football in boots specially designed for him by Remploy.

Letters to the Editor (contd.)

Dear Editor,

I read with interest the letter you published from Mrs. Price of Llanrumney, Cardiff. We are sorry Mrs. Price has stopped coming to our meetings as at least two of us have girls older than Yvonne.

My own daughter is fourteen. We are hoping to have a psychiatrist to talk to us shortly on behaviour traits of handicapped children and how we, as parents, should cope. But unless all group members make a real effort to be present on such occasions, my committee feel reluctant to ask these busy people to give up their valuable time to come and talk to us.

I wonder if Mrs. Price has considered Yvonne joining a Guide Pack? Leaders of Guide and Ranger groups are usually delighted to have a handicapped child as it helps the other girls to face up to their social responsibilities.

My daughter who is a hydrocephalic, joined the Rangers last year and it is a great help to her. Our Ranger leader is most kind, and we were able to get a large hat especially made for Jenny. She is trying for her Duke of Edinburgh Bronze award and this gives her a real interest.

Mrs. Price's daughter is no doubt becoming increasingly aware of her handicap, and will have to adjust to this fact. I have found that warm understanding (not pity) helps a lot, and a good-humoured tolerance of passing moods. All adolescents are moody at times and handicapped children may well be more so.

I should say that Jenny attended a school for physically handicapped children until she was eleven, but now goes to an ordinary school, but has to have a taxi as she cannot yet manage public transport.

I hope this letter may be a help to other Mums with older children.

Yours very sincerely, MRS. JOY HILL,
Chairman, Cardiff Branch.

NEWS FROM THE GROUPS

Jersey Association

A scheme has been arranged between two groups of ASBAH, the Staines, Hounslow & Districts Group and the Jersey Group. Many of the Jersey members are obliged to travel to London for hospital treatment for their children, and found the journey quite troublesome with a handicapped child and perhaps another toddler to cope with.

The Staines Group offered to arrange to meet any such families at the Airport and drive them to the Hospital, and this service has been really appreciated by several Jersey Members already.

Photograph shows Tony Bassett, Secretary of the Staines Group, meeting Mrs. Betty Testori and her son Anthony, at London Airport recently.

Sussex Association

Two money-raising events have been organised by individual members recently. The grandmother of one of SASBAH's children organised a Bring and Buy Sale and as a result nearly £150 was sent to the Spina Bifida Trust. The father of another child, who belongs to a team on a Darts' League put in a word to Tournament organisers. SASBAH's Chairman presented the Spina Bifida Cup to the winning team and received a cheque for over £100, being the amount collected for the Association throughout the tournament.

The holiday caravan was sited in April after 2 years' search. Who would have anticipated the difficulty in this South Coast county? We were not ultra fussy; no one wanted us! It has been occupied throughout the season except for one cancellation due to hospitalisation. A notice about bookings for 1970 appears elsewhere.

As SASBAH's contribution to publicising Spina Bifida a child's badge has been produced. This is 1¼″ in diameter and incorporates the S. B. symbol and the words Spina Bifida Children in black on a green background. All local secretaries should have received a sample and terms, badges are available through the local groups. They should sell well: they are of good quality and can be sold to the general public as well as to members.

The three families who live in Hastings decided to form their own Hastings and District Branch of SASBAH as group meetings were not convenient for them to attend. The Branch hopes to become autonomous later.

South Berks. & West Surrey

The Group has decided to undertake its most ambitious project so far and set up several play groups for Spina Bifida children in the local area. Miss Dorothy Hodges, B.A., a very experienced psychiatric social worker, has been employed by the Group in the position of Playgroups Project Director with the brief to set up and run the groups and form an effective liaison with the childrens' parents, with local medical and educational authorities and with possible sources of finance.

The first step has been to take over the responsibility for operating the Woking Playgroup, previously run by the Invalid Childrens' Aid Association, and set up an office in Guildford. Plans for a second play group have been drawn up and this will start early in January 1970. Finance for the initial stages of the Project will be provided from money collected from The Great Walk and applications have been made to a trust fund to cover the long term costs.

The Group has started its own newsletter called *Interlink*. This provides news at local level in the same way that *Link* gives news at national level. *Interlink* goes to all Group members plus all local people who have shown an interest in our children. Members are encouraged to write for the newsletter and articles are included on forthcoming events and various aspects of the operation of the Group.

Members who attended the Group meeting on September 26 heard a most informative and helpful talk given by Mr. Forrest, F.R.C.S. Consultant Paediatric Surgeon (Queen Mary's Hospital for Children and Westminster Children's Hospital).

We are looking forward to our next meeting on October 31 when Tom Ravensdale, the ASBAH Appeals Director, will give a talk and show the new ASBAH documentary film "What is Spina Bifida?".

Leeds & District Association

This group is at present 'linked' with the York Group on a joint project and recently joined forces with the local Christian Aid Committee to organise Leeds Marathon 1969, a very successful sponsored walk, which has already brought in £2,800 to be shared between the two Charities.

£50 was given towards the cost of the Publicity film, £100 to Sheffield University for research, £100 to Leeds General Infirmary for the provision of a Spina Bifida library and £25 to Leeds Welfare Services Committee to help in the provision of facilities for handicapped people.

A very successful Autumn Bazaar held in the City for one week raised the splendid sum of £720.

Over 3,000 ball pens advertising Spina Bifida have been sold and members have held Coffee Mornings and arranged Club Concerts, all helping to swell funds.

Mr. T. Lawrence of Leeds Welfare Services Dept. attended the last meeting and gave an interesting talk and answered questions concerning the services available for Spina Bifida children.

THE DAY THE INFANT SCHOOL BROKE UP

By MISS B. GREEN

Former Head Teacher, Rawthorpe Infants School, Huddersfield

Every Infant School is a busy place, and one of the busiest days in every year is the day the school breaks up for the Christmas holidays.

At about noon on the last day of term, in December, 1965, the whole school was assembled for the purpose of making its annual presentation to the canteen staff.

Parties and festivities were almost over. Some decorations had already been taken down, and piles of brightly coloured garlands lay about in corners.

Two hundred wildly excited children were kept in some sort of order by smiling understanding teachers, whilst I made my little speech and chosen boys and girls proudly carried round the presents.

In the midst of the ceremony, the door opened and in walked the bulky figure of our Deputy Chief Education Officer.

What could he want on this day of all days? Nothing to add to the day's burdens, please heaven!

He does not waste time, nor beat about the bush. Would I be willing to take into my school a few handicapped children, who suffered from a defect called spina-bifida? They would probably use wheel-chairs—some of them were paralysed. The Education Authority was responsible for their education. Children with their handicaps had not usually lived long enough to attain school age up to now.

A nursing assistant would be appointed and a special toilet provided.

We quickly walked through the school and I indicated a cloakroom that could be spared. Ten minutes later the gentleman had gone, and I was left, somewhat shaken, to rejoin the festivities; wondering as I re-tuned my mind to the business in hand—what is spina bifida? I had said "Yes".

During the school holidays I went to the local library to see if there were any books dealing with the education of spina-bifida children. There were none.

I wrote to Her Majesty's Stationery Office to ask for books or pamphlets. An answer came—no such books or pamphlets were available.

Eventually, one of the school doctors came up and described the condition, but could tell me nothing about the educational possibilities.

Later, through the School Health service I heard that the Oakes Park School for Handicapped Children in Sheffield had a few spina-bifida children, and obtained permission to spend a day there.

A school doctor, Health Visitor, Physiotherapist, a teacher and I went in turns, and were given a great deal of help and advice for which we were most grateful.

The Head Mistress also gave us a copy of an American pamphlet, "The Child with Spina Bifida" which was most useful.

The Education Authority advertised in the appropriate journals, for a teacher with special qualifications for teaching handicapped children.

No applications at all were received. Later, I understood that it was an unheard of thing to have severely handicapped children taught with normal children in school, and that any likely candidates would be cautious about applying.

Our local Building Department Manager came to see me about a proposed special toilet, and to ask what was required.

I did not really know, but with the help of our School Health Department, we decided on the basic things. These were added to later.

A nursing assistant was appointed—a lady with some nursing qualifications, and long experience in Children's "Homes".

By now, the whole scheme was held up for want of a teacher, and eventually I approached a former colleague of mine, who had given up teaching, and persuaded her to come back to start this class. I must point out that at this time, there was an acute shortage of teachers in this area and all the existing teachers in the school had large classes.

At length, we were given the names and addresses of our proposed little pupils and the nursing assistant visited their homes.

We learned more from the parents than from anyone else. Some copies of LINK were given to us containing very helpful articles.

In the meantime we had prepared a sunny class-room with bright new toys and equipment, and were ready to begin.

It had been thought that wheel-chairs must be provided at school in case taxi-drivers should object to carrying them. Two wheel-chairs were delivered, but they were adult size, and useless. They had to be returned.

Our taxi-drivers, anyway, never objected to the wheel-chairs, or anything else. They were invariably kind and helpful and altogether good.

At last—ten months after that busy breaking-up day at school—at nine o'clock in the morning of October 17, 1966, a taxi turned in at the school gates.

Our experiment begins

In the class-room—a vast room built for forty children—four frightened little faces looked at an almost equally frightened teacher.

After a few days the teacher came to me in despair. "It won't do", she said. "I can't go on like this—they don't know what to do—they don't know how children behave."

It was true. These little ones had spent so much time in hospital and more or less confined at home, that they lacked the experiences normal children have and they did not know how to play.

After deep thought and discussion we decided to introduce into the class about a dozen normal, healthy, bright, reasonably well-behaved children about the same age as the handicapped ones.

We went round the classes, explained the position to the five- and six-year old children there, and asked who would like to be in the new class to help the "poorly" children.

Volunteers

Lots of children volunteered, and we chose those who seemed most suitable.

The teacher set out the toys the other children had just stared at—the Wendy House, the dolls and prams, furniture, engines and cars, the sand-tray, the jig-saws, the paints and everything else.

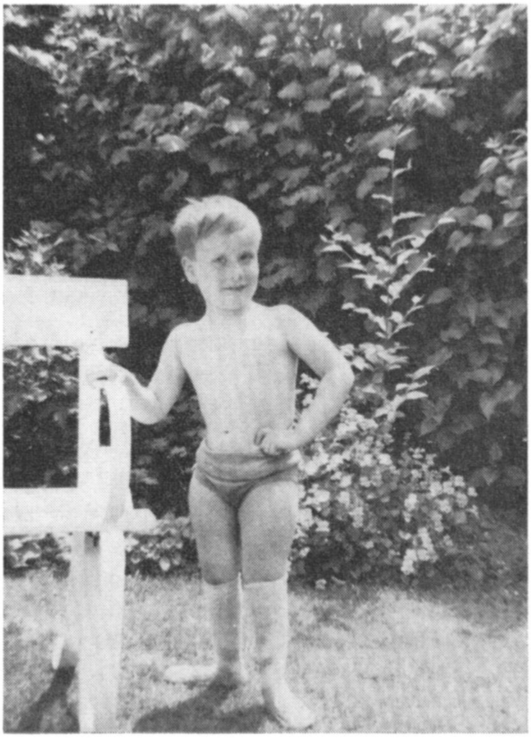
The new children were brought in, saw the bright new toys and fell upon them with whoops of joy.

In a very short time they had drawn in the other children and the first steps towards the success of the experiment had been taken.

The normal children soon forgot that the others were different and one could often look in at the door and not know which was which.

The whole school meets for prayers every morning, for school dinners, for community singing and festivities of every kind.

(*Cont. overleaf.*)



"Julian Fordham, whose mother is a contributor to our letters column."

We do not feel that the paralysed children are quite ready yet to transfer, but already plans are being made, and alteration to premises are in hand. The children will move on as soon as it is felt they are ready.

After much discussion it has been decided to invite spina-bifida children under school age to spend perhaps one day or half a day weekly at school so that they can mix with other children and share experiences with them.

Now the time has come for me to hand over responsibility to others, for I have reached retirement age.

I should like to offer thanks to many people for their help in starting this new venture.

First, the entire staff of this school, who have all helped in every conceivable way—in discussion—pooling ideas and suggestions—giving a helping hand and taking over from time to time to relieve the teacher. This has never been a class shut off in its own room.

Second, all departments of the Local Education Authority, but especially the School Health Department.

Lastly, the parents, who have taught us so much.

I should like to end with a declaration of faith—

I believe that, given certain requirements of school premises—level ground and one storey—it is perfectly feasible for spina-bifida children to be educated with normal children.

TO ALL BRANCH SECRETARIES

I am getting a little short of News from the Groups. Will Branch Secretaries please let me have details of any points of interest within their own Groups.

H. L. PARSONS, Editor.

THE SHASBAH TROLLEY FOR HANDICAPPED CHILDREN

PATENT APPLIED FOR IN
U.K., Commonwealth Countries, U.S.A., Canada.

This Trolley was designed by Mr. Ken Charrett of Southampton for his daughter who was born with Spina Bifida. It was soon found that here was a chair that would enable a child paralysed from the waist down, to become mobile.

The Trolley weighing only 14lb. is strongly constructed completely manoeuvreable and easily propelled by the child. Due to the low centre of gravity and rear castor action it is virtually impossible to be overturned.

The Trolley is finished with foam upholstered durable vinyl and comes in a wide range of attractive colours, this is to give the child the impression it has a toy. The child soon learns to use the Trolley, and adds much happiness to the child's life.

Is suitable for children from one to five years old. Cost £6 10s. plus postage approx. 9/- in United Kingdom, prices on application overseas.

Produced by the

Southampton and District Spina Bifida and Hydrocephalus Association

We should like to acknowledge the help of Tatchbury Mount Hospital, and voluntary work of the members of Southampton and District Spina Bifida and Hydrocephalus Association to make this Trolley.

All enquiries to:—Mrs. K. Charrett, 2 Marchwood Road, SOUTHAMPTON. Telephone enquiries TOTTON 3365 (Mr. Mortimer)

D.I.Y. – IF YOU CAN

A hand operated, front wheel drive 'Go-cart'

The idea of this hand-propelled toy car or 'go-kart' came to me when my sister asked if I could convert a go-kart for her eight year old girl Sharon. I thought about this for some time. In the end I came to the conclusion that the easiest way to solve the problem of propelling and steering a vehicle by hand, would be to start from scratch and make a three wheeler, with hand pedals driving the front wheel and rudder type steering.

As I was not too sure if the idea would work I did not want to spend too much money on it, so I set about collecting secondhand materials which I thought would be useful. The list of things which I used consisted of angle iron from an iron bedstead, two pram wheels, one pushchair wheel, part of a small tricycle, two bicycle chains, three bicycle hand grips, four assorted gear wheels and lengths of conduit piping! The only bought things were: one sheet of 24 gauge tin for the body, foam for the seat to support the back and legs, one second-hand seat belt and the paint.

I was lucky to be able to use the equipment at Jesmond Garage where I work to build it. A number of additions and adjustments had to be made to the original idea, including the hand brake which works on the two rear wheels and altering the gear ratios so Sharon would be able to use it on the lawn, but it was finally finished in time for my niece's birthday.

The price of the car I built was about £5 but with new parts?

Sharon drives the Go-Cart made by Mr. R. R. WASS, 2 Northfields, Gt. Bardfield, Braintree, Essex.

NEW PUBLICATIONS

Parents, doctors and specialists will welcome "The Spina Bifida Baby" by Olwen Nettles, a new booklet recently published by the Scottish Spina Bifida Association.

The authoress has drawn on her experience as a physiotherapist to provide a really useful handbook, written in non-technical terms, to help parents over the first hurdle of realising that their child has spina bifida.

Her close contact with parents has given her an insight into their deepest problems and this is reflected in a booklet which anticipates all the early questions, provides the answers, and adds practical suggestions to help a child to progress at his own rate.

This is a booklet which no new parent should be without and which parents will refer to again and again. Price 2s. a copy; £2 5s. for 25 copies; £4 5s. for 50 and £8 for 100; it is a worthwhile Investment for any group.

Parents whose children have just started, or are about to start school, might like to hand the teacher a copy of "The Child with Spina Bifida in School".

This booklet has been written for ASBAH by Mr. D. H. Lee, headmaster of the W. J. Sanderson Hospital School, Newcastle upon Tyne, to explain spina bifida to teachers and students at training colleges.

Mr. Lee has outlined the causes of spina bifida and hydrocephalus and has included a comprehensive guide to help teachers to cope with the problems with which parents are so familiar.

It is a booklet which teachers will find useful and which branches might like to present to schools in their areas.

Dear Editor,

My attention has been drawn to a letter in your Summer, 1969, issue, from Mrs. Brayley of Hillside Avenue, Southampton.

I would like to add that we regard Annette's membership of our school as a privilege. We have all learned from her courage and cheerfulness under difficulty.

Yours truly,
J. H. MASTERS, B.Sc.,
Headmaster,
Bitterne Park Secondary School,
Southampton.

A.S.B.A.H. area officials

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