

# LINK



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

**Spring 1967**

**One Shilling**



# Our cover girl gets mobile

For Diane Thomond, this issue's spina bifida "cover girl", the hand-propelled trike means mobility and access to all the exciting mischiefs which every 2½-year-old likes to get into.

And for three apprentices at the A.E.I. Training School in Manchester it meant an unusual and challenging project for their first-year course.

Diane, who lives in Bent Lane, Davyhulme, presented a problem when, like all rumbustious infants, she wanted to get around under her own steam.

Then Nurse Quayle, health visitor at Davyhulme, had a brainwave. She suggested that our Association might provide plans for converting a tricycle for the child and that A.E.I. might help in the conversion.

It seemed a small task for such a big firm, but A.E.I. chiefs were enthusiastic.

They chose three 16-year-old boys to do the job as part of their training: John Steinberg, of Fallowfield, an apprentice toolmaker; James

Mostyn, of Northenden, a budding fitter; and Eric Robinson, of Patricroft, a machinist.

The boys went to work with more than their usual verve. After finishing the trike, John and Eric posed with Diane for our photograph.

She hasn't quite mastered the knack of turning the handles yet.

But that shouldn't take her long.

And then, thanks to Nurse Quayle, A.E.I., and the three youngsters, Diane's horizons will be three wheels wider.

## ON SHOW

A little thought and a lot of enterprise gave the South Hants group an audience of 5,000 for free at last year's Southampton Show.

The group were allocated stand facilities in the marquee of the Southampton Federation for the Disabled.

Although South Hants were the "baby" of the show they gained a knowledge of showmanship and advertising from the experience.

By combining light and movement in their display they attracted many visitors to their stand. And an eager band of supporters ensured that the people who stopped to look were persuaded to listen too. Copies of the leaflet "What is Spina Bifida and Hydrocephalus?" were handed out liberally.

An illuminated house, complete with garden, pond and fountain, was the eye-piece of their display. And their invitation to "toss a coin and wish" was accepted to the tune of £7.

A selection of calipers and aids with the group's own children's trolleys were exhibited. Genuine lucky silvered horseshoes, novelties and sweets were sold. And a lucky dip was popular.

A doll, donated by a Southampton man, was raffled and Dr. Horace King, speaker of the House of Commons and Honorary President of the branch, made the draw.

South Hants recommend other groups to apply for stalls at similar shows and exhibitions. They are willing to make their pamphlets available to other branches and, with local facts and figures substituted, this would save money on having separate plates made.

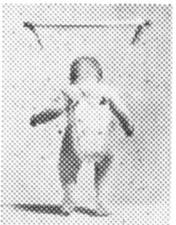


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## Editorial: Help us to grow

We are one year old. This is our fourth issue—our first anniversary. And this, we feel, is as good an opportunity as any to look back to see what we have achieved—and what we aim to achieve.

Our object, as we said in the first issue, has been two-fold. We wanted to be a link within the national Association—to bind parent to doctor, doctor to doctor and parent to parent. This, we believe, we are achieving.

We also wanted to be a link with the outside world—to do what we could to help make the words spina bifida and hydrocephalus the household names that spastic and thalidomide have become. This is a more difficult and frustrating task, and one in which it is difficult to be optimistic. But we think that, together with the efforts made by the Association itself, headway is now being made.

We have tried to give variety. There have been serious medical articles, human stories of both heartache and joy, and suggestions which we trust will make mother's work that much easier.

As for ourselves, our problems have been many. The first obstacle to surmount was to bring the journal into existence—a mammoth task in itself as any proprietor in the publishing industry will confirm.

The first issue came out of a system of trial and error. We wanted to produce a magazine of individuality and originality, and this was our prototype. Only when we had this could we see where our errors were and where improvements could be made.

There was also the question of finance. Our national resources were limited and it was necessary that the magazine should be self-supporting from the outset.

Thanks to the support from our members and branch secretaries, *Link* has paid its own way.

Now comes our next big obstacle. We want to expand. We want more pages so that we can print more articles. This is where YOU can help!

We need articles—whether they are medical, educational or domestic. We need stories of people—perhaps you have a story yourself in which *Link* readers would be interested. We need photographs of all descriptions. If you have only a tip that might be of interest to other parents, it will certainly be of interest to us.

We believe that *Link* has served a useful purpose in the past year. With your help it will provide a better service in the years to come.

# A blessing in disguise

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Twins, it is said, are a double blessing. But what if one is a perfectly normal boy and the other a spina bifida child? Mrs. Elsie Wilson, of the Scottish association, tells the story of her problem—and its happy ending.

“Once upon a time there was a child called Jon who was born with spina bifida. His fairy god-mother pondered on what would be the finest gift to give this little boy, and she finally decided on a twin brother.”

Now this sounds a pretty corny, unbelievable start to a story, and one which I would have laughed to scorn a few years ago.

But it is almost three years since a little spina bifida boy with just this name was born into our family, accompanied by a normal healthy, boisterous twin called Donald. At first it seemed to us a rather raw deal to have a twin who could sit up and walk at an early age, and who was certainly bonnier to look at than his brother.

There was Jon with his swollen head, ugly post-operative scars on his back and limbs locked in a jack-knife position. No one ever mistook one for the other then. But soon Jon's head assumed more normal proportions, his limbs began to open out and some movement was seen. The scar became less noticeable as he grew.

## Child's needs

We found means of encouraging the movement he had. Bonny-bouncers and walking aids were tried and Jon's Dad provided some home-made aids. We had wall-bars along the book-case in the living-room, so that he could “swim” along the floor and grasp the lower bars to raise himself.

All this time, his twin would be the one to demonstrate the use of the pieces of equipment. And both children had fun.

How does a very young child appreciate the needs of another? Yet, without prompting, we would find Donald retrieving objects out of Jon's range, or trying to give him a push up on to chairs.

I had assumed that the handicapped twin would be frustrated because he could not do the same things as his brother. Jon tries to copy his twin to the best of his ability, attempting feats of movement quite beyond him. The result is happy laughter.

At floor level Jon can hold his own. A poignant moment was when the twins faced up to each other for a game of fisticuffs—on their knees.

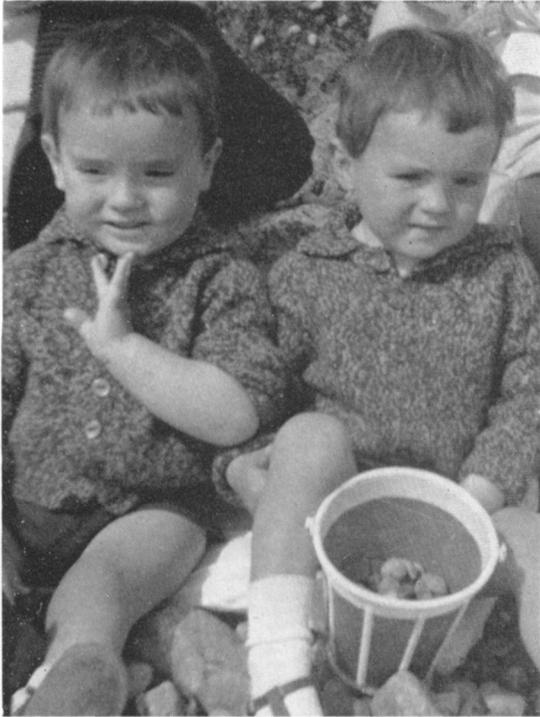
Right from the start we felt that the normal twin was ahead in most things. Donald spoke before Jon, but at this stage Jon was discovering for the first time that he could move around on the floor without assistance and therefore life was very exciting. And his progress rate seems to have remained constant.

## More independence

Twins have ensured that we do not over-indulge the spina bifida boy. It is impossible to spoil the one child while his active brother is making constant demands on our time and affection.

We felt that by providing Jon with a wheelchair for outside use at an early age we could give him more independence. He now goes “under his own steam” to places where previously we had to carry him, resulting in a rapid loss of energy for ourselves. Jon uses the wheelchair to go into shops, to propel himself round the library, museums and zoos. He is achieving a degree of mobility and independence at this early age which would have been denied him had I kept him in a pram.

Incidentally, we recognised that the wheelchair might have a great attraction for the normal twin. So, to prevent any resentment, we provided both boys with a tiny wheelchair (made from a child's



Which is the spina bifida brother? It's now almost impossible to tell as Jon (left) plays happily with his normally developing brother, Donald.

old desk seat and large pram wheels) for use in the house for a few weeks before the real wheelchair arrived. This had the desired effect, as Donald could see that his own two legs were the quickest way for him to get around and Jon realised that in the house his crawling had big advantages over the wheelchair.

Now, when we go out, Donald will sometimes stand up on the foot-rests of the wheelchair, facing Jon, and holding on to the arm-rests.

There are, of course, challenging and worrying situations ahead. One obvious one is that the handicapped child will require hospital treatment, but we intend to ensure that when this arises everything will be done to prevent damage to the present good relations between the two boys.

We do not intend that Donald should be slowed down in any way to the pace of his twin, but rather that we will be able to give Jon interests which, although of a less mobile nature, will allow him to keep alongside his brother.

We know now that if a 20th century Hans Andersen was to write this story he could give it a happy ending without any stretch of the imagination. For we have proved that Jon's fairy godmother was a very wise woman indeed.

## *And a sadder tale of another young boy*

# HAS ANYONE A HOME FOR STEPHEN?

Stephen, a boy born with hydrocephalus, needs a foster home. Foster homes for handicapped children are hard to find.

This is sad enough. But it is even sadder when one considers that Warwickshire County Council, who are caring for this unwanted five-year-old are willing to offer a special maintenance grant to a couple who will give Stephen the love and attention he needs.

Money cannot buy love. Nobody has answered the appeal made by Mr. A. E. Leeding, the council's children's officer.

The matron of the children's nursery where Stephen lives reports that, following a successful valve operation, Stephen is a very attractive, lively youngster who participates fully in nursery life. He is keenly interested in all that goes on; he enjoys painting and modelling and is full of self-confidence.

### Balance difficult

As a baby with a head circumference of 23 inches, he was a problem to hold for long periods. Learning to balance his head was difficult and his efforts to walk were thwarted.

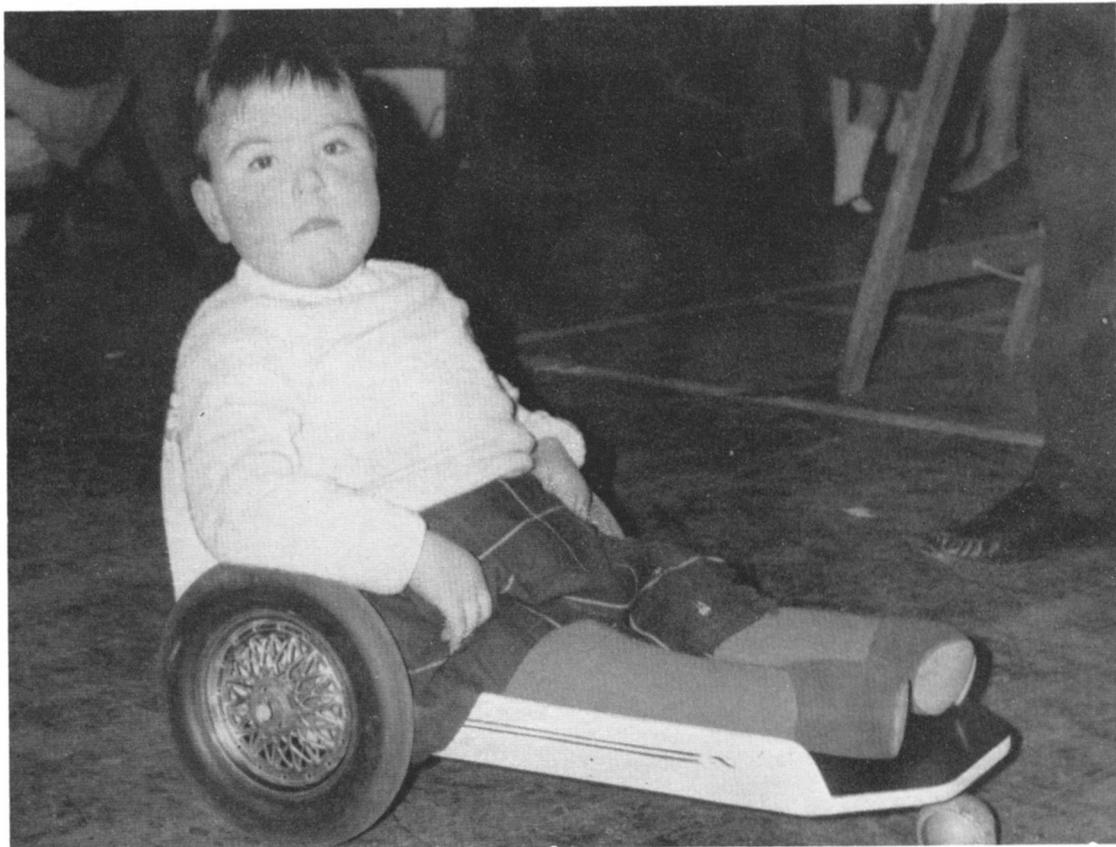
But growth has solved this problem for Stephen. He has grown in size and strength and his enlarged head circumference is barely noticeable.

He is just five years old—ready for the challenge of school.

His mother was very young when he was born. Youth on her part, possibly fear and ignorance on her parents' part, has meant that so far no interest at all has been shown in the child.

Stephen receives as much love as a busy staff with other unfortunate children to care for can spare.

It is surely not enough. Would any *Link* reader, we wonder, be interested in helping Stephen to help himself?



A visit to Chailey Heritage gave Mr. Ken Charret, of the South Hants Association, the idea for this trolley.

Mr. Charret saw children whizzing happily along on it at Chailey and decided to adapt it for his small daughter Debbie.

The story has two endings—one sad, one happy.

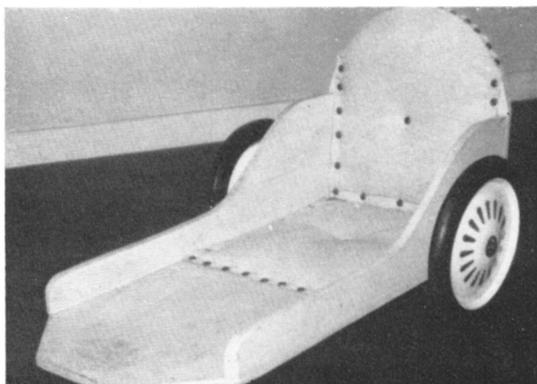
Debbie died just a few weeks before she could see this picture of herself printed in *Link*.

But her trolley was so successful that the South Hants Association have built over 50 copies.

Sales are so good that the branch has sub-contracted the work to a handicapped people's workshop. Orders are pouring in for the £5 10s. trolley.

So, tragic though the loss of Debbie Charret, happy are her father's memories of the pleasure she gained from this gadget.

It is a pleasure which lives on in the joy which copies of Debbie's favourite toy will bring to others.



### Send your stamps

The Richard Fund is wanting used or new postage stamps, British or Foreign to sell to dealers in large numbers. Used stamps should be on paper with ample margin.

Please send your stamps to: Richard Fund, Mrs. J. Lorber, 305 Ecclesall Road South, Sheffield 11.

# GIVING THE GIRLS A BREAK

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It was in 1908 that Sir William Purdie Treloar set up the Lord Mayor Treloar Trust. Its object was "to cure the suffering and then train the helpless cripples to become useful members of society."

For 40 years the boys' college and hospital, established under the Trust at Alton, Hampshire, worked in partnership—the one curing and the other training.

In 1948, the two parted company with the advent of the National Health Service. The hospital went under the control of the Ministry of Health, while the college went on with its work of making full and rewarding lives for youngsters who might otherwise be doomed to an existence of incapacity and boredom.

A few years later the college moved to new premises at Froyle, about four miles from Alton, and in 1956 took a big step forward in its development. It started to educate disabled boys aged between 11 and 20 as well as training them in their chosen trades.

Then the Trustees made their most ambitious decision. They decided that handicapped girls should have the same opportunities as the boys. So the Florence Treloar School was born.

## Waiting list

Although the boys' college has a waiting list, the girls' school has vacancies. Inquiries can be made to the headmistress Miss A. A. M. Wells.

The college and school are remarkable from two aspects. The first is the achievement in educational standards.

Since the boys began getting a grammar or secondary modern education in 1956, there have been 500 G.C.E. passes at 'O' level. Sixteen former pupils are now at university.

Nearly all the boys over 16—who take subjects ranging from tailoring to pig-keeping—find good jobs when they leave. Others continue their education at normal grammar schools.

The girls' school is unusual in that it allows the pupils to stay on to take the G.C.E. at 'A' level and to study specialist courses. In other schools for handicapped girls, the youngsters normally have to leave at 16.

As a measure of the girls' success, they have a pass-rate of 70% in 'O' levels in the first 18 months of the school's existence. One girl passed at 'A' level in both her subjects.

The second remarkable thing about the college and school is the variety of handicaps that can be accepted. Girls and boys with practically any form of disability—except the deaf, dumb and blind, and those whose main affliction is epilepsy—are taken from all over the country and the Commonwealth.

These are the numbers of pupils with the more usual conditions:

Boys: Spastic, 112; haemophilia, 35; anterior poliomyelitis, 34; spina bifida, 9; muscular dystrophy, 8; fragile bones, 5. The corresponding figures for the girls are: 9, nil, 17, 6, 3, 3.

## Special aids

The emphasis is on teaching these youngsters to become as independent as possible.

School life is kept as normal as possible. The boys have their cricket and football teams. The girls play badminton, rounders and other games. Archery, sailing and canoeing are all popular. In the heated swimming baths, the pupils can forget the restrictions of calipers, crutches and chairs.

The school, of course, has its special aids. Ramps take the place of steps, and showers and baths are designed so that they can be used without help. There is a trained nursing staff and physiotherapy treatment is given where necessary.

But perhaps the spirit of the school can best be illustrated by this true story.

Recently, a 16-year-old girl, whose legs have been paralysed for 10 years, was guiding a visitor around the school library. The visitor suggested the upper book-shelves were too high for girls in wheel-chairs.

"Oh, no!" the girl replied. "We cannot expect to have everything arranged for our convenience when we leave school. So we must learn how to deal with it while we are here."

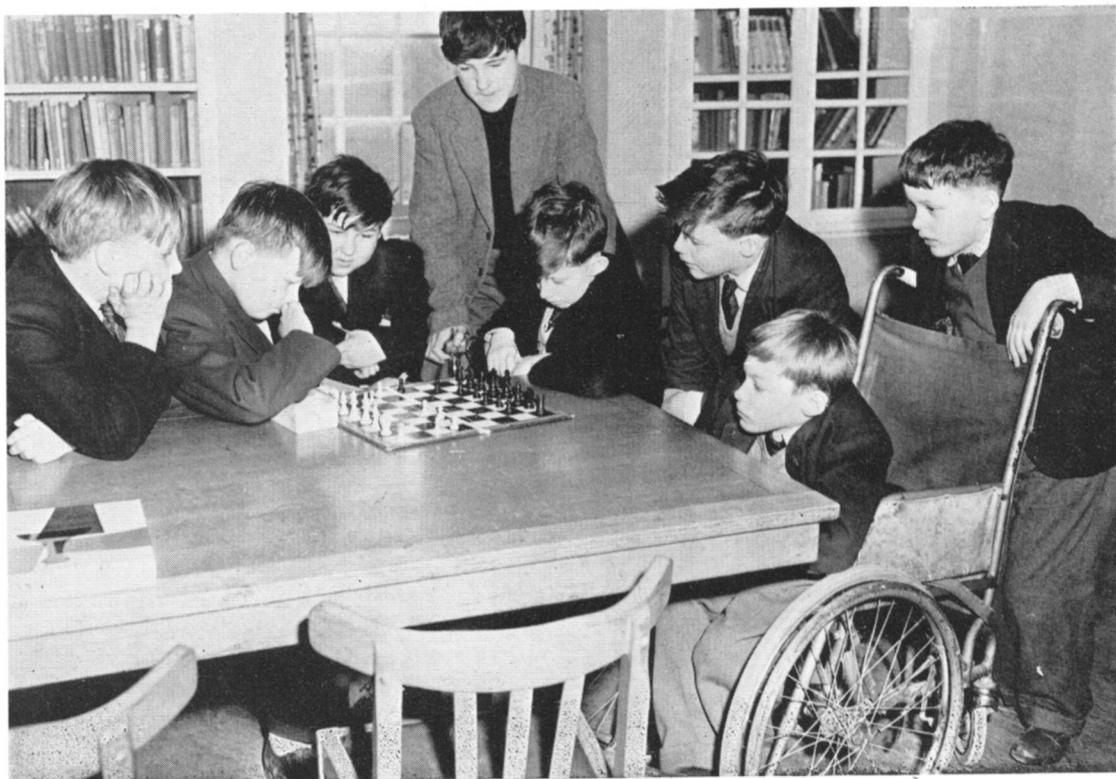
Independence! That was Sir William Treloar's aim for the handicapped in 1908. As far as this is concerned, nothing about the Trust has changed.

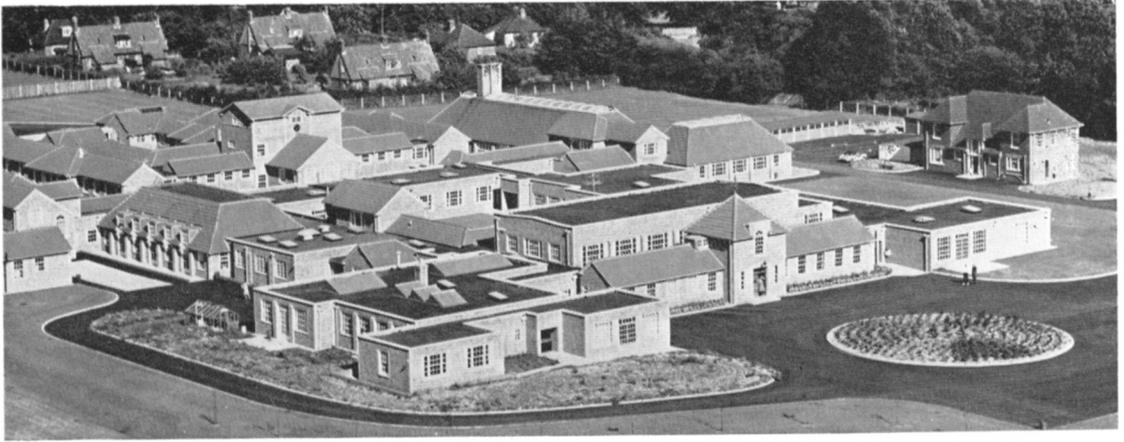
**See overleaf for pictures of the pupils at work and play.**

# At work and at play



Above: Boys of the Lord Mayor Treloar College give each other a helping hand as they go to their lessons. Below: Some younger pupils enjoy a game of chess. (Pictures by Bob Small.)





At work and at play, the pupils of the Lord Mayor Treloar College and the Florence Treloar School are kept happy and industrious. With these pictures we hope to show a little of the life of the boys and girls. Above: An aerial view of the modern building of the Florence Treloar School (Picture by R.A.F. Odiham). Right: A wheelchair does not spoil this girl's aim at archery as she proudly shows her playmates. Below: The girls concentrate on their teacher giving a French lesson (Picture by Nursing Mirror/Wilkie).



# Outlook... 'Continuing wet?'

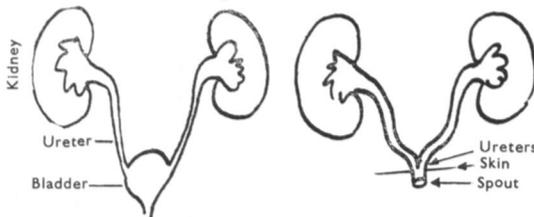
Many parents of spina bifida children must sometimes wonder if this is in fact a true forecast for their child. Will they ever be rid of nappies and wet clothes? In the past the answer was that it would be most unlikely. Now it is possible for nearly all to be so organised that they can live a life of normal schooling and social mixing without being "wet and smelly". To many this is a matter of regular assisted emptying of the bladder. To others it means an operation. This article is written about those who have operations.

Firstly an operation can be done to slacken the outlet to the bladder if this is too tight to allow proper emptying. Its shape is altered from:

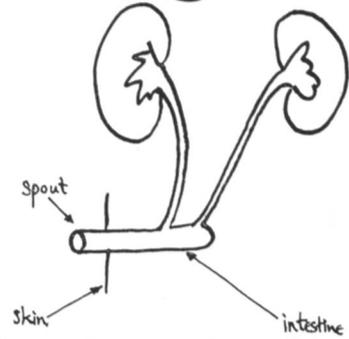


After this is done the bladder can be emptied more easily, infection can be more readily controlled and often the period of dryness between each expression of the bladder is longer than before. But sometimes it may mean that the water dribbles away all the time and the bladder never fills. This is very safe, ensuring that there is no back pressure to damage the kidneys, but is no good socially except in some of the boys who can be fitted with a collecting bag.

Other operations bring the urine directly to the surface on the front of the abdomen. The exact position it is brought out depends on where a collecting bag can be most easily fitted. Because of the different types and degree of deformity of the back and the legs there is no single standard place. Each is "tailor made" for the child. In some children the ureters can be brought out directly on to the skin surface to form a neat spout. In others a small separated piece of intestine has to be used to form the spout. Thus:



Unless there is a spout projecting for a short distance above the skin it is very difficult to fit an appliance that will keep the child really (and confidently) dry.

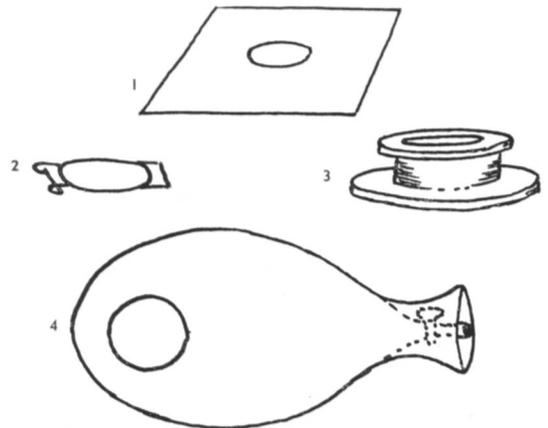


But why are these operations to bring the urine out on to the front done? There are two reasons, and both may be present, or only one. The first is that the child cannot be dry between expressions for any length of time (2 hours is probably the shortest reasonable period). This only applies to girls, who cannot be fitted with a collecting apparatus like the boys. The second reason is to treat or prevent back pressure on the kidneys which is sometimes present even in children who seem to have very good control and long periods of dryness. These back pressure changes are discovered only by doing special X-Rays.

Whatever the reason for bringing the urine out on to the front of the abdomen, it is now possible to keep dry and to get rid of the nappies. The child may not have full and conscious control of his bowels, but a well ordered routine (with perhaps occasional aperients and suppositories) should keep him organised and clean.

Often parents ask how good the appliances are. Do they really work? Surely the smell? How long does it take each day to look after them?

The appliance we usually supply is rather like the illustration:



It consists of:

1. A double sided sticky patch.
2. A metal ring for attaching adjustable belt.
3. The flange.
4. Bags (small size for daytime, large size for night time).

Also needed are:

Cotton wool or gauze.

A roll of waterproof plaster—"Chironplast".

A bottle of friars' balsam (Tinct. benzoin. co.) and perhaps a different cream or ointment in addition, if prescribed.

How to fit the appliance was undoubtedly demonstrated to you when it was supplied or when your child left the hospital after the operation. But I have met several parents who were so mesmerized (and even upset) by the sight of the spout that they did not really listen to anything that was told them. When you see it for the first time it may be a bit of a surprise, but don't be discouraged or frightened because even the most squeamish learn to manage it very easily and the best thing for the child is for him to learn to accept it as part of himself (which it is!) and to look after it for himself. So aim to teach him to deal with his appliance himself as soon as he is able to do so.

### Early morning

The best time to change the appliance is early in the morning when the flow of urine is least. Success depends entirely on getting the skin dry and this is easiest then.

First of all have everything within reach and prepare the appliance.

- (a) dry the flange thoroughly and wipe a little friars' balsam over its base.
- (b) remove one of the protective covers from a patch and stick the flange accurately over the hole in it. (Sometimes the hole will need to be enlarged with a pair of sharp scissors.)
- (c) loosen the other protective covering on the patch so that it is ready to be applied.
- (d) prepare 4 strips of Chironplast each about 3 ins. long.

Thoroughly clean and dry the skin around the spout, and holding the spout in a piece of gauze to prevent urine dripping on to the skin, wipe a little friars' balsam over the whole area of the skin where the patch will stick. Allow to dry.

Let go of the spout and before any urine has dripped over on to the skin put the sticky patch

and flange over it and press them firmly down so that it sticks without wrinkles. If the skin is at all moist the patch will not stick, urine will leak underneath giving wet clothes and sore skin.

Apply reinforcing strips of Chironplast over the edges of the square patch. Put bag on flange.

Put ring on flange (the bag can be threaded through it). Fit and adjust belt.

After a few weeks of practice you will find that it fits so well that it will stay on and keep the child dry for several days at a time and often for a whole week. He can even bath with the sticky square and flange in place but should bath and clean the skin under this thoroughly at least once a week.

**Daily Care.** The small daytime bags should be emptied frequently. If they overflow they will pull the patch off the skin. For the same reason a larger night time bag is recommended.

### Dry period

Each day, after use, the bags should be washed out using ordinary soap or detergent. They should be thoroughly rinsed and then turned inside out and left in an airy place. With this ordinary washing they should remain free from smell, but if this does develop, a teaspoonful of hibitane solution (1 : 1,000) can be put in the bag each time before it is fitted on. Your doctor will be able to prescribe this if necessary. On no account should strong disinfectants or abrasive cleaning preparations be used as these eat into the plastic material of the bags and make them more smelly rather than less, and even tiny traces can make the spout become very sore.

The bags and spouts of the penile collecting apparatus for boys can be cleaned similarly after each use.

So our forecast needs correction. A prolonged dry period should set in and stay fair. Your child should be confident that he can be dry. He will need a certain amount of time (and space in the bathroom) to look after his equipment. He may well need to continue for long periods on some medicine for his urine. He should be encouraged to drink plenty to keep his spout "washed through".

To have to wear an appliance to collect the urine is not to be condemned to a life of limitations but to be introduced to a lot of new possibilities in his school and general social activities.

# Film notes

Walt Disney is alas dead, but his studio will continue to function. And, one hopes, continue to produce the all-cartoon films that delight all children.

Mickey Mouse and his descendants belong to the kids and, like favourite toys, they will not be discarded easily.

Meanwhile, the Disney studios have been helping out in a time when films suitable for children have been very thin on the ground.

For example, take the recently released "Follow Me Boys". Adults may find it embarrassingly sentimental, but this account of the founding of a Boy Scout troop in a small American town before the last war, and the careful—if emotional—tracing of the growing lives of some of its members, has undoubted child appeal.

This is partly because of Fred MacMurray's spirited and sympathetic performance.

It is also partly because children, and especially little boys, can happily identify with the little horrors who make up Fred's troop and get into all sorts of un-Scout like scrapes.

## Long-stayers

Disney's cartoon version of every child's bedside reading, "The Wind in the Willows", shares the same programme

Some of the stalwarts remain in the West End: "The Sound of Music", a ripe example of what the industry calls a "family film", stays solidly at the Dominion in Tottenham Court Road.

"Dr. Zhivago" continues in practice at the Empire.

Another likely long-stayer is "Grand Prix" at the Casino, which gives a Cinerama-camera's in-the-driving-seat view of motor racing.

And, of course, there is the Burton-Taylor rendering of "The Taming of the Shrew" which looks well set for a long run.

Miss Taylor's command of Shakespeare's English leaves something to be desired. The 'O'-level and 'A'-level members of your family may find it all a bit irreverent. But it is visually beautiful, rumbitious, infectious, often delightfully funny.

Beg, borrow or steal a baby-sitter and try, whatever you do, to catch up with "Accident", which I know will remain one of the best and most important films of this year.

Dirk Bogarde and Stanley Baker give faultless performances as two dons caught up in the tangle, and eventual tragedy, of an undergraduate relationship between an aristocratic Englishman and a beautiful Austrian girl who manages to drag everyone into her net.

Ann Pacey.

## Readers' views

Our 3½-year-old daughter, who suffers from hydrocephalus, was unable to support her head with its 26½ in. circumference. She spent most of her life propped up by cushions.

Then we bought a Baby Relax chair which can be used as a high chair and a low chair and has nine different positions from reclining to straight-backed. My husband got some foam tubing, normally used for pipe-lagging, split it up one side and turned it inside out. It was then arch-shaped and fitted neatly round Christine's back from her hips to the back of her neck.

She now sits in a reclining position with this tube supporting her head and she can sit in the garden or the car and see what is happening around her instead of staring at the ceiling all day.

Although Christine suffered brain damage and cannot talk, she has expressed her pleasure with her chair in her eyes. The tubing can be obtained in different widths and thicknesses from a plumber.—Mrs. Fiona McNeill, Co. Antrim, N. Ireland.

\* \* \* \*

My daughter's first attempts to push her baby-walker were frustrated because it was too light and tipped easily. My husband bought 7 lb. bags of cement at 2s. each and cast it in the bottom of the walker, increasing its stability.

This was so successful that he cast more cement in her doll's pram. Both these toys unobtrusively supported our little girl in her walking. She is now able to push lighter toys with confidence and we avoid frustration when she first wanted to push things. A piece of floor-covering makes an acceptable covering for the cement.—Mrs. K. G. Rodaway, Burgers Hill, Sussex.

\* \* \* \*

Junior wheel-chairs tip forward easily on uneven ground. This can be remedied by lengthening the wheel base of the chair, which can be done with the aid of a welder.—Mrs. Stickings, Maidstone.

# News from the Groups

## CARSHALTON

There is to be a Rally and Fete at Queen Mary's Hospital for Children, Carshalton, on the 1st July. Before this, on 27th May, "Friends" of the Hospital are holding a Fete at which the Surrey Association will provide a stall.

## CENTRAL AND NORTH LONDON

Money is coming in slowly but surely as a result of the group's recent appeal. Among recent fund-raisers are Mrs. Dean Bassett (£14 4s. from a cheese and wine party and a bring-and-buy sale), Mrs. Partridge (£4 from a raffle), and Mr. and Mrs. Erik West (£8 from a bring-and-buy sale). A collection by Miss M. Silver among the crew of the *Edinburgh Castle* and a raffle at H.P. Information Ltd. added to the total which now stands at £54.

Mrs. Holly, of 32 Gilbert House, Churchill Gardens, London S.W.1, is appealing for Green Shield and Pink trading stamps to be used to obtain raffle prizes.

After the loss of the chairman to Scotland, the group has another problem on its hands. Mr. Don Maloney, who has given several valuable years as secretary, is moving from the area, and consequently the extremely difficult task of replacing him now has to be done.

## KENT

A showing of films made by the children of Coney Hill School was the highlight of a recent meeting of this branch. The films showed life in the school, where the emphasis is placed on teaching the pupils independence.

Dr. J. R. Ludlow, Deputy M.O.H. for Kent, told about the special clinics for pre-school age children. And specimen valves from the American Holter Company were on show.

The branch has now been registered as a charity with a membership of 50.

## DEVON & CORNWALL

This branch now has a membership of 30 families. Unfortunately, distance creates a problem in this

area and some members find it difficult to attend meetings.

So far, fund-raising activities have taken second place to recruitment. However, the Plymouth members raised £36 with a jumble sale and were grateful for the effort of Mrs. C. Conning, an old-age pensioner who raised £5 single-handed.

A big loss has been that of our chairman, Mr. Stubbs, who has left the district after establishing the local association on such a sound basis.

A Christmas party was held in January, at Plymouth, when a conjurer entertained and our children enjoyed games, and gifts from Santa Claus.

## HUDDERSFIELD

The Christmas Party was most successful. Father Christmas and a magician delighted over 30 children. A similar number were entertained at a pantomime in Leeds in February. Again, a good time was had by all.

Representatives of the Committee were eventually able to meet representatives from the Huddersfield Hospital Management Committee, after having threatened to petition the Prime Minister when he visited the town to open the new hospital in January. The points of dispute were lack of action to ensure that all spina bifida babies had the opportunity of early treatment, and misleading statements made to parents at the time of the child's birth.

## LIVERPOOL

A photographer attended this branch's Christmas party given for 73 spina bifida children and 45 brothers and sisters. Prints were supplied to parents free of charge. Funds were swelled by a draw which raised £400. The 10 prizes offered included a refrigerator.

Other branches might find, as Liverpool did, that a local store will co-operate for special visits to see Santa Claus during the Christmas season. Over 40 children took advantage of special facilities laid on by Lewis'.

A "collection tins" scheme has been operating successfully for a short time. Members have found that local tradesmen and licensees

are willing to have a tin on their counter.

## PRESTON

This group continues to grow, but will remain part of the North-West Association until strong enough to organise its own affairs.

## SCOTLAND

On 19th March, the A.G.M. of the Scottish Spina Bifida Association was held in Glasgow and it might be of interest to know what kind of progress has been made in the preceding year.

There are now 10 groups in Scotland, which means that most of the members have a representative "within hailing distance". A Scottish newsletter is issued twice a year, *Link* is issued four times a year, and a recent innovation is a "chat-sheet" which is issued to members and distributed by the group organisers, and which brings members all sorts of snippets of news and views. There is space left on the "chat-sheets" for the group organisers to add any purely local news of forthcoming events.

The A.G.M. was a great success. A hall to accommodate 200 had been booked, but extra seating had to be brought in. The speaker was Professor Dott, Honorary President of S.S.B.A., and his talk provided many valuable guidelines for the future. Members came to the meeting from as far north as Inverness, from the East and West of Scotland, and came up from the Borders.

Local groups are responsible for financing local projects, but for the work of raising funds for research and administration in Scotland we are using a consultant fund-raiser. He receives a percentage of any money he raises. As we were already committed to this method of fund-raising prior to the fund-raising plans presently under discussion by A.S.B.A.H., we are therefore "going it alone" in this particular direction.

The local play-therapy/physiotherapy groups which have sprung up during the year are proving a great boon to child and mother alike. Where the spina bifida cases are few in an area it is still important to press for therapy. Even if it is only one child it is felt that we must press for therapy services which will lead to encouraging the child's independence.

Much co-operation is possible with local authorities. The facilities available vary from area to area but we are finding that where we show a need the local authorities are more than willing to help us.

The hospitals carry on the gargantuan task of caring for our children. We are finding an increasing willingness to publicise the aims of a parents' association such as ours. Posters are now being prepared for issuing to all the Scottish hospitals dealing with spina bifida cases.

There is so much to be done, but if goodwill counts for anything, then we should be sure of success.

## SHEFFIELD

The Christmas Party was highly successful. The Annual General Meeting, held on 1st April, was well attended. A representative of the BBC was present, talking to parents and obtaining details for a film which the BBC is to make about the work of the Children's Hospital and spina bifida in general.

## SOUTH HANTS

A fancy dress parade was the main attraction at this group's Christmas Party. The winners were Jacqueline Reed as Mary Mary Quite Contrary and Keith Singleby

as Captain Hook. Dr. Horace King, speaker of the House of Commons selected these two spina bifida winners and presented the prizes.

More than 200 children and parents from as far away as Salisbury, Petersfield and Portsmouth attended the party which was organised by the Southampton Committee.

Members now have access to the Victoria Park Swimming Pool, Portsmouth, on Sunday mornings between 9.30 and 12. The branch's mini-bus runs a pick-up service for children and parents who take advantage of this therapy.

## SOUTH WILTSHIRE

Congratulations to members in the Salisbury District on the formation of a new group to cover South Wiltshire. Interested readers please write to Mr. Dennis Callaway of 'Trixadec', 17 Ridgeway Road, Salisbury, Wiltshire.

## SOUTH MERCIAN

In conjunction with the Royal College of Midwives, this group held a meeting at Luton Maternity Hospital. It was the first time the members had met an outside group also interested in the welfare of spina bifida children.

The secretary, Mr. J. J. Meade, outlined the Association's history. The hospital matron was anxious to hear advice from "experienced parents" on how to tell a mother and father that their newly-born child had spina bifida.

Another successful outing was a visit to the Palace School, Ely, a boarding school for physically handicapped girls. A party of 36 parents and children were shown around in groups of six. Each group was conducted around by a senior pupil, which added interest.

More than 30 handicapped children enjoyed a magic and Punch and Judy show at the branch's Christmas party. Each child received toys, balloons and sweets.

Gratitude is expressed to Chells Community Association who held a draw in aid of this party and to the authorities who allowed us to use the day nursery for the treat.

## SURREY

On 14th January the group held a 'gadgets' meeting at Sutton. This was well attended and various aids to mobility were demonstrated, including a baby's wheelchair built by one of the members, and a child's electric car, specially produced for a child with calipers.



Children of the South Hants, Association make a colourful sight in fancy dress at their Christmas Party.

We need a name. A name with a ring to it.

A.S.B.A.H. is difficult to project. It takes too long to explain. Once explained it takes even longer to understand. It is a tongue-twister when spoken in full.

Publicity is easier if the product to be publicised has a name with appeal. Our appeal must be emotional but not sentimental.

## Think of a name!

Norma Jean Baker changed her name to Marilyn Monroe and became internationally famous.

There must be a good name for us somewhere and we appeal to YOU to think of it and suggest it to us. The sooner the better.

## FULL AHEAD FOR PUBLICITY

Headlines here we come! Our national organisation has now hired a firm of public relations consultants to organise a full-scale publicity drive.

The contract for the first six months has been signed at a cost which seems astronomical—£7,000.

But we expect this to pay dividends within a very short time, and Philip Barron Associates, our consultants, are optimistic on this financial score.

Only £5,000 of the promised sum has been raised, but your National Executive feels that a publicity and fund raising drive is essential. The project is not the gamble it seems for Philip Barron already have the successes of the Shelter campaign and the Arthritis and Rheumatism Council, among others, to their credit.

### Monthly bill

They are confident that they can raise A.S.B.A.H. to the top-ten charity chart alongside Spastics and Oxfam.

So we are paying the bill on a monthly basis. We are confident that money will have started to roll in by the time our first £5,000 is spent.

Local groups will be asked to help with research to provide the information which is so vital to the appeal and funds—on loan or by gift—to ensure that we pay our way.

The scheme enables us to employ a full-time officer to establish a small administrative office and to implement the appeals campaign. We are now looking for such a man.

After the initial six months scheme, we should be in a financial position to sign contracts for the following six months.

It is essential that our drive gets under way now. Time lost means money lost.

Success of the national scheme must reflect on local branches. Apart from overcoming the difficulty of having to explain continually of A.S.B.A.H. and its aims, we will find local newspapers will be more co-operative once we are established on a national scale.

Every effort must be made now to give the campaign full support. We need financial and practical help from every member and friend we can muster.

Then the research which is so vital for the future and the practical help which is needed to alleviate suffering now will be a reality instead of pie in the sky.

## Children's corner

Dear Children,

Christmas is far away. We have had winter—a rather mild one this year—and now we are in spring when all the plants grow and baby animals are born. Perhaps you have seen some youngsters by now.

Here is something you might like to experiment with, especially if you are interested in spy stories.

You can make invisible ink by putting some vinegar or lemon juice into an egg cup. Write your message on to paper with a clean pen nib. Let it dry, then you can read what you have written by holding the paper in front of the fire (not too close). The writing will appear brown when the paper gets warm.

Spring is the subject for the competition this time. Send me a poem, story, painting or model about spring. There will be a prize for the best entry in each age group.

Regards,

UNCLE ED.

# ***A S B A H area officials***

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