

INK



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

Summer 1967

One Shilling



Kindness can be a handicap

The Scottish Spina Bifida Association has been doing a national survey with a questionnaire going out to all members. This is giving us the opportunity of building up a card index system with information which will greatly help the Association in the future.

We have left a space for views, hints, etc., by parents. This is a little gold-mine for all, as parents have been asked to pass on information no matter how unimportant it may seem to them, as we can all learn from each other's experience.

It is under this heading that several parents have written "Treat the child as a normal member of the family". This made us stop and re-think on this aspect of our children's development.

Let us suppose that we have all managed to reach the stage of treating our children as ordinary persons within the family group; let us suppose we never discuss his condition in front of him except to pass on necessary information; let us suppose that we subject him to the same discipline as others in the family, have we then solved the problem of ensuring that our children are treated in a normal way?

Normal lives

It could seem, however, that unless we can tactfully change the outlook of some members of the general public then much of our determination to help our children lead normal lives is being undermined.

Speaking personally, we have found that could adults react to our handicapped child in the same way as children then there would be no problem. But what does one say to the adult who strongly chastises his child because he approaches our handicapped child and asks why he uses this or that walking aid. Also, people are genuinely keen to help but the kind of help they would offer is liable to destroy the child's confidence in himself. Only recently our child was equipped with elbow crutches and this meant he had to devise a method of getting in and out of the door of the car. We remove the front passenger seat during week-days and he can put his crutches in ahead of him, wriggle his knees on to the floor of the car, push himself up on his crutches, then get himself round ready to sit down. Now this is obviously a slow, laborious process at present and as often as not I am sitting in the driver's seat letting him

get on with it. I am losing count of the times people have come up and made to lift him in and I have had to thank them but say "No. He is learning to do for himself".

It must be difficult for those not dealing with handicapped children to realise that not having known full power in their limbs the children are adaptable to a degree that would possibly elude us adults! And again, it is undoubtedly true that such ignorance must make our children's condition seem very pathetic at times. The other day, our child was making his way round our local self-service store, and lagging well behind me, when a woman came alongside me and said, "Would you look at that poor, wee soul back there. We aren't half grateful enough that we don't have children like that". How to explain to her that the "poor, wee soul" was absolutely jubilant at his further foray into the field of independence, and that our happiness was tremendous as we saw him demonstrating yet another example of adaptability.

Is it possible that in the final analysis it will be our attitude as parents which is likely to have the greatest influence of all on public opinion? It is quite likely that our friends and relations will take their cue from us—and as a pebble dropped into a pool gives out an ever-widening circle so a healthy attitude by us will reach out to a far wider group of people than we can imagine.

A big thank-you to those parents who have written in our Scottish survey—"Treat the child as a normal member of the family".

Elsie Wilson.

Our cover

Yet another enterprise of the South Hants group provides our latest cover picture. Jane Baker, aged nearly six, is one of the children who take a regular Sunday morning dip in the therapeutic pool of a Portsmouth swimming bath. Branch officials gained permission for the weekly use of the pool from the bath's superintendent, Mr. Bland.

Jane's leg control is affected by hydrocephalus. Since starting the hobby her leg muscles have strengthened.

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Editorial: These aims cost money

Our Association is now entering the third stage, and perhaps the most vital part in its short life.

A few years ago, due to the ever increasing number of surviving spina bifida patients, various groups of parents and doctors were simultaneously thinking about some form of Association to promote the wellbeing of those suffering from spina bifida and hydrocephalus.

First of all one group started, and then another, and yet another. This then was the first stage, the conception of some form of association for those concerned with spina bifida.

And secondly, the important realisation by the organisers of these early associations, that strength would eventually lie in numbers and in unity.

Now to the third stage. From the unity has come the strength, the pooling of resources, the spreading of ideas and the arrival at the position where we can embark upon an ambitious publicity and fund raising campaign.

But who is behind all of this?

There are the doctors. A few devoted men who have given freely large parts of already busy lives to guide us through these early stages.

And many "interested persons", a large number of people who have many and diverse reasons for

being concerned, but the concern is basically the same and we are thankful for it.

But mainly they are parents. It is quite obvious that the power of parental love is always going to make itself felt when the lives and happiness of children are at stake.

Following the publicity and fund raising resources should be available to allow us to embark on the most important work of A.S.B.A.H., the ambitious aim, with which the "pioneers" set out a few years ago. Vast amounts of research still need to be done. More hospital beds still need to be provided, more surgeons still need to be trained to undertake operations for which there are long waiting lists such that some children will "never have" important operations at the present rate of progress. Sound education for all, to suit individual requirements and training for jobs.

All these, and many more benefits, were the aim of the "pioneers" and are still the aims of those in the forefront of the A.S.B.A.H. organisation.

Achieving these aims will cost much, in money and in voluntary effort and at this stage every member, every interested person, must stand by and be willing to help wherever possible in the months which lie ahead.

Now — will he walk?

Many parents of spina bifida children must ponder this question when first faced with the enormity of the youngster's handicap. In the latest of our series of medical articles, an orthopaedic surgeon gives an encouraging answer.

The most common region of the spine to be affected by spina bifida is the lower part of the spine or lumbar spine. It is in this region that the nerve centres for the supply of the bladder and lower limbs is situated and it is not surprising, therefore, to find that the feeling and movement in the lower limbs is often defective.

In some babies, it seems that all the elements of the spinal cord and its nerves are reasonably well formed and the defect is largely one of lack of covering of these delicate tissues by bones and skin. In this situation, while the baby is in the womb, the delicate tissues have been protected and the legs have been able to work and kick normally. During the course of delivery, there may have been some temporary upset to the function of the spinal cord and its nerves but, if successful surgery is carried out sufficiently early, movement in the legs, which may be temporarily halted, can recover and may do so fairly completely.

A return to complete and normal activity in the lower limbs is probably only possible in one in ten babies with open spina bifida. In the remainder, there is a greater or lesser degree of abnormal formation of the nerves and of the spinal cord so that, even if early surgery is performed to cover over the exposed nerve tissues, complete recovery is not possible. Even so, any muscle action that can be retained and any skin feeling that remains may be useful to the child or may be made use of by the Orthopaedic Surgeon in restoring ability to walk. If early surgery to the spine is not done, the exposed neural tissues may become destroyed by infection and even if there was activity in these nerves, it is lost and there is a great likelihood that the legs may remain completely paralysed permanently.

Many children are born with obvious deformities at the joints of their lower limbs. The obvious deformities that can often be seen are in the feet which may appear to be twisted in various

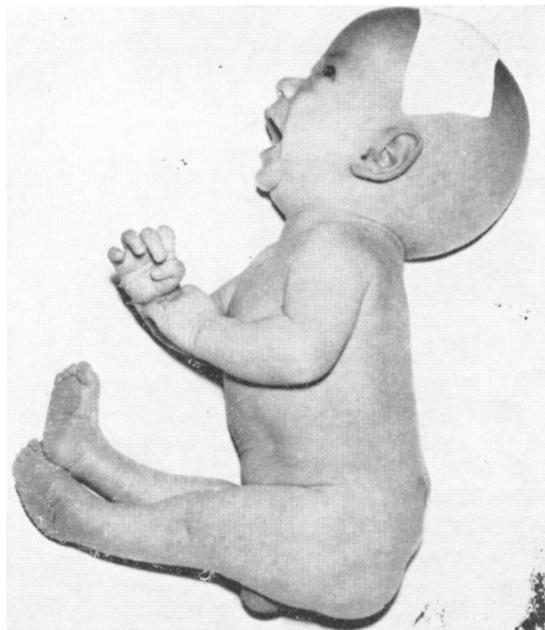
directions of deformity. Although it is not so easily visible, the same kind of deformity can be present at the hips and sometimes they have been dislocated out of joint while the child was still in the womb. These deformities have almost certainly arisen because some of the muscles in the lower limbs were working while the child was being developed in the womb while others were paralysed and the strong muscles have pulled the developing parts of the limb out of shape.

The Place of Orthopaedic Surgery

It is the job of the Orthopaedic Surgeon to make the best of any muscle function that there is in the lower limbs and to straighten, as far as possible, any deformity at the hip, knee or foot. It is not, generally speaking, advisable to try to correct the deformities by splints or plasters in children with spina bifida because of the liability of the insensitive skin to break down and ulcerate if continuous pressure is applied to it. The only safe way to correct deformity and to improve function in the lower limbs is by operation.

When the baby is very small and is still struggling to thrive after operations on its back and possibly on the head for hydrocephalus, orthopaedic operations must wait. Apart from this, the baby's tissues are so small during the first six months of life that complicated operations would be made even more difficult if they were attempted during this time. The best time for operations to be done to put the deformities right and to do something about the muscles is between the sixth month and the second year of life.

What is required is that the tight tissues, often in the groins holding the thighs together, or in the feet and ankles holding the foot into a deformed position should be lengthened. Where some muscles are acting strongly it is often possible to transplant one or more muscles to take the place of those that are paralysed. For



These two pictures are of the same boy—Gordon Carter, of Caister, Lincolnshire. He is seen above—as a baby—with deformed hips and feet. Left, he is seen walking after his operations.

instance, one of the muscles that bends the hip up can be moved through to the back into the region of the buttock so as to become capable of straightening the hip down and, at the same time, if there is any dislocation of the hip, it can be put back into joint and held there by the transplanted muscle. This operation is a very major operation but its value in allowing the child to walk in due course of time is very great. Where there are several deformities several operations may need to be done during the course of the first two or three years of life, the number varying between two and sixteen operations, depending on the circumstances. The aim is to try to get all the deformities straightened out and the muscles put into their best position by the time the child is ready to start to walk.

When will Walking be Possible?

Almost all children who have suffered spina bifida walk later than a normal child would. There are a number of reasons for this. Even when a child has good muscle activity in his legs, he may have trouble with balancing because the centres in the brain may have been disturbed by hydrocephalus. If he has diminished ability to feel in the feet, it is not easy for him to learn

where his feet are or where he is putting them and he has to develop other ways of getting balance. When there has been a lot of deformity and a lot of paralysis, he may have to learn how to use the muscles that the orthopaedic surgeon has transposed to other places, and if his legs are completely paralysed so that there are no muscles that the orthopaedic surgeon can move about, he has to learn to rely almost entirely on his arms and trunk to get him along, with the help of splints to support his lower limbs. It is seldom that a child below the age of three and a half can learn the complicated manoeuvres needed to walk with supports in this way.

The Ultimate Result

This may vary from a child whose legs are so nearly normal that he is able to run about like any other normal child down to a child who will only be able to walk at the most a matter of one hundred yards and then only provided there are no difficult steps to negotiate. Now that children with spina bifida are receiving better treatment in the earliest days of life the ultimate results are becoming much better in terms of ability and activity in the lower limbs and, in general terms,

Continued on page 15

AND THEN WE WERE FIVE

In our last issue, an expert discussed the chances of parents having a second spina bifida child. Here, Mrs. T. Sutton, of Rugby, tells how she and her husband found a solution—by adoption.

Well, nearly! Legally we are still four, but in a few months, if all goes well, we shall have our third child.

My husband and I always wanted three children. Our first child, a son, was born two days after Christmas 1962. I had had an operation to make it possible for us to have our own family so we decided that, as we had had a rather late start (I was nearly 27 when Adrian was born and we had been married seven years), not to wait too long for our second and on 15th October 1964 Jackie was born.

I did not realise that anything was wrong although the birth seemed to take ages, but on recollection the midwife was listening for a heartbeat every minute or two. Then, as our daughter was born, the midwife said "Oh, my God! No!" I shall always be most grateful that her emotions got the better of her, because I knew from the very beginning that something was wrong. When I asked her what it was she explained and said that I could hold Jackie for a minute then she would have to go to hospital. The doctor was summoned and he explained more fully what 'spina bifida' meant and within an hour of her birth our daughter had gone. Adrian had slept through the lot and knew nothing. My husband and I, in our rational moments, prayed that our baby would die. We saw her once a week on Sunday mornings and it was an ordeal. She looked so beautiful, but we thought she would die at any time. When she was six weeks old we plucked up courage to ask the doctor what was to be done and he said we should take her home.

For the first few weeks she was home the district nurse came every day to dress the lump on Jackie's back, then gradually we got used to handling this awkward little baby. The difficulties many of you already know, the most obvious one of not being able to lay her on her back which has to be experienced to be appreciated. When she was three months old the orthopaedic surgeon put irons on her feet and barred them together and at that moment I thought I could never again feel

such pain and despair. I started smoking again that day after 15 months without. The sight of that small baby in those thumping great irons was unbearable.

However, there was much more pain to come. At six months we went to Birmingham to see about the operation to remove the lump and the surgeon advised waiting another six months. Without any warning he said we 'should not be too worried about her head'. No one had ever mentioned her head before and here we heard of hydrocephalus and again that blow hit me. During the next six months Jackie began to become a real baby, then back to Birmingham. The lump had grown quite a lot and was weeping by this time. The surgeon said now that the operation must be done as she would most certainly get meningitis if left any longer. He also admitted after a great deal of pushing from me that the operation could be less than successful and there might even be brain damage again from meningitis.

The first time

We spent hours talking and worrying about the operation and the prospects for this child of ours but realised an important fact, that now we loved our daughter and could not, as we had done one year earlier, pray for her to die. So in October 1965 Jackie was operated on for a valve to be put in her head and then for the lump to be removed. The first time we saw her in hospital lying on her back was something I shall never forget. She came home after six weeks in hospital having had her first birthday there, and what joy in our hearts. Adrian was as thrilled as we were to have his sister back and we thought that at last everything in the garden was lovely.

Jackie made up for lost time and really asserted her personality and we were happy. We should have known it would not last for as soon as we made the regular visit to our local hospital doctor he hastened to point out that she was not as good as new and we still had to watch her head and kidneys. However, we gradually seemed

to settle to a steady normal life and then came the day I cried in hospital from sheer joy instead of despair. We were sent to Sheffield to see a surgeon for his opinion on what should be done in the orthopaedic line. He said that although her hips were dislocated there was no point in re-setting them and then "when she's about four and a half we'll get her walking". We were stunned; no one had ever mentioned walking and we just could not believe our ears.

I have told you of these things, and there is much left untold, because our experiences in that first year had a great deal to bear on our later decision and I know that lots of babies have the operation at birth and so their parents are spared some of the difficulties and heartaches that we had to live through.

Anyway, we were chugging along with a son of 3½ and a daughter of 20 months—so what now? We read articles on the chance of having another affected baby. We asked if the fact that our first child was normal shortened the odds and no one knew. We decided that for ourselves we would settle for two, but what about Adrian? Jackie's life was still not certain; how would he cope if she died? Can a child share his grief with his parents? Would he ever get over the gap that would be left in his life? The answers we thought were "No". So for his sake something must be done. We were still not prepared to take the chance. A friend suggested we tried to adopt a baby. We did not think we stood much chance but went to see the local Children's Officer. She did not think we would be penalised because of our handicapped daughter but could not be sure. Anyway, we applied to the County Council while

she wrote to them explaining our position. We saw the Adoption Department representative and talked for 1½ hours. She said that if we thought we could cope it was all right by her but it would be up to the County Children's Officer to decide. We went ahead with the usual interviews then we suffered a hold-up as Jackie, by some mysterious quirk, broke her leg and spent another three weeks in hospital. On my birthday we had the letter to say that we had been accepted as prospective adoptive parents. What a birthday present! We got everything ready then waited what seemed ages but was in fact just under two months. When the 'phone call came and the lady said she had a baby boy for us I was hysterical with joy. Adrian could not make out why I was crying and laughing at the same time until I managed to tell him that "next week we are going to get our new baby".

More confident

The Sutton family of four set out the day before Good Friday to collect our new son. As we got near our destination I started thinking of the young girl who was giving up her child and I wept for her misery. When David was handed to me my feelings were indefinite. Perhaps even an anti-climax. I had felt this way when Adrian was born; no rush of maternal love that I had read about, only terror and bewilderment that I had to look after this mite. I had looked forward to my second child; being more confident I thought I would enjoy this child. Now I was looking forward to our third child, confident that I would enjoy him.

Now, as I write this, we have had David two months. Adrian and Jackie adored him from the first moment. My husband and I are growing to love him as we did the other two. Do I feel any differently? Only once, when he was suffering from very bad colic and seemed to be very miserable with pain the thought flashed through my mind that we were doubly responsible for this child: to him as to any child, but to his mother especially who had made such a sacrifice to give her baby the best kind of life. Apart from this thought, he is no different from our own. After all, Jackie was six weeks old when she came home and David was five weeks when we had him.

In our next issue, Mrs. Sutton will tell of the reasons why she and her husband decided on adopting their third child.



Jackie (left) and Adrian Sutton.



Above: The happy couple—Rose and Lawrence—after their wedding at Farnham, Surrey. Below: The bride surrounded by admiring fellow-patients from Woodlarks home for the disabled.



THE WHEELCHAIR WEDDING

On Saturday, 24th June, attractive 37-year-old Miss Rose Hibberd was the only June bride in Britain who did not walk down the aisle. She was wearing the traditional white . . . but she was pushed down the aisle in a wheelchair.

For Rose, a sufferer since birth from spina bifida, is crippled from the waist downwards. But her bridegroom, 37-year-old Mr. Lawrence Chapman understands . . . because he, too, has spina bifida.

Rose, originally a Derbyshire girl, was abandoned by her parents at the age of three, and has always lived in hospitals or nursing homes.

This wedding, which took place at St. Thomas' Church, Farnham, Surrey, at 1.30 p.m., should never have been possible at all. It is the first time two people suffering from spina bifida have ever married. We know the odds against children living more than a few years before the valve came into use.

Somehow Rose and Lawrence lived beyond childhood and then came together by a string of amazing coincidences. Rose answered an advert in a magazine from somebody seeking a pen-friend.

The advertiser was Lawrence Chapman of York Crescent, Claydon, near Ipswich. They wrote a number of letters to each other, then Rose plucked up enough courage to tell Lawrence that she was a spina bifida. Two days later a letter arrived from Lawrence. He also had spina bifida.

Rose and Lawrence met each other for the first time last year when they went on holiday together to a disabled people's holiday centre in Norfolk. Love went with them.

During the holiday Lawrence proposed. Lawrence has obtained a ground floor flat in Ipswich. They are both very independent, but Lawrence's mother will be there to do the things that are really impossible for them.

After a honeymoon at the same disabled people's holiday centre, Rose returned to the first home of her own she has ever known.

The reception took place at Woodlarks, a home for the disabled near Farnham, where Rose has



Rose inspects her wedding dress.

been living for the past nine years. The wedding has been the topic of conversation among the other disabled girls, most of them also in wheelchairs, for many months.

When she left, Rose took her one homely possession with her . . . a budgie named Nicky. Rose has taught him to say "Hello, Lawrence. Pleased to meet you".

Rose is not minimising the difficulties involved in setting up a home:

"I'm quite adaptable", she said, "but it will be very different. Having lived in institutions all my life, and having had everything done for me, it will be difficult, but I know we will be happy".

Lawrence passes the time at home by making jewellery and repairing clocks and cameras. Lawrence's best man was Ivor Davies, a member of the committee of ASBAH.

"This is the biggest challenge of Rose's life", said Mr. Davies. "All her life she has never had to make decisions. Now she has to make them all herself".

His wife provided the material for the wedding dress, and this was actually made by people living at Woodlarks.

Rose was given away by Mr. George Towndrow, of Ashover, near Chesterfield, Derbys. He and his family befriended Rose when she was in hospital for ten years near their home.

A reader writes . . .

Our magazine, *Link*, was one year old last issue and at that time I was moved to write some criticisms to our editor. The two main points were that we need *Link* more often and that we need more personal articles. I did not realise at the time that this magazine, which is a help to us all, has no paid staff but is the work of Mr. Hinchliffe and others who devote much work and time to make it possible and that while it is a "spare time job" we will not get more issues. My first point then is answered that these people are giving their all to produce our magazine four times a year and unless the Association is willing to make it a full-time paid job we shall have to be extremely grateful for what we are getting.

However, we can all do something about my other point. Personal experiences—yours and mine. Yes, yours is important. The way you have coped; the problems you have solved and the lessons you have learned. You have taken the blow and have found a way to stand up again.

There are many people who could benefit from your experience. Could you not find a moment to write to your fellow readers and tell them how you have managed? Any gadgets you have devised to help your children to lead a fuller and easier life. What seems simple to you might be just what another mother is searching for. Our editor is working for love, not money, to make this magazine for us. Let him not think we are apathetic and unwilling to help.

I am writing to tell you that this magazine needs your contributions to keep it alive. I will start the ball rolling by telling you why we decided to adopt a baby rather than take the risk of it happening again. Will you not make a snowball of opinions and advice? Perhaps someone who has had a second handicapped child could tell us how they felt.

I would like to hear from mothers whose children have had to go to a residential school. This is something we have to face in a few years and are very worried about it.



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View of life

I'm sure we should all like to hear from those who are themselves handicapped. My daughter is 2½ and is paralysed from the waist down. How will she feel when she's 16 years or more? Is there someone in the position, who can tell us how they view life?

Doctors are making a real effort on our behalf with their articles. Now is the time for us to pull our weight. I am an ordinary woman now, with three children and I help my husband in his business, so if I can find time to write a few words I'm sure you can.

If you are facing what seems an insurmountable problem why not ask *Link* to help you through its readers? Others may have an answer for you.

If you find *Link* a help in your life then you must do your utmost to make it the best magazine ever published.

Mrs. T. Sutton.

Mrs. Sutton's article appears on page 6.

Thanks for stamps

The Secretary acknowledges with thanks receipt of an anonymous gift of just over 1,000 Green Shield Stamps posted in Loughborough.

ARE YOU TOO SHY?

Since the article in *Link*, eight people have written to me although I have written to many more who have not replied. Of these eight, four are ladies, four gentlemen. Their ages vary from 22 to nearly 60. Their disabilities vary almost as much.

Although without exception they all have difficulties because of their disabilities not one of them will admit that there are difficulties for the simple reason that they have overcome them to such an extent that they have ceased to bother them. For example one person told me that his problem was that he was shy, he didn't seem to worry about the fact that he couldn't walk.

The feeling of this older group seems to be that we want to help the younger ones as much as we can. We would also like to say something most sincerely to the parents. Your child will never feel as sorry for himself as you will.

Many of the group have spoken to parents to encourage them including myself. I would certainly do my best to travel to see any group who wanted me and I know the lassies in Scotland do.

I am still anxious to contact more people of the older group, and hope to submit a regular article in *Link* for us.

Can anyone suggest a name for us.

Faith M. Seward.

Research meeting

The meeting of the Society for Research into Hydrocephalus and Spina Bifida was held in London and Carshalton between 29th and 30th June and the 1st July. Members attended not only from Great Britain but also from Sweden, Holland, Germany and other countries and among those was Mr. John Holter who later in the afternoon of the 1st July also attended an A.S.B.A.H. meeting of parents at Carshalton together with Mr. Zachary, Mr. Forrest and myself.

The scientific meeting was well attended and all aspects of the problem of spina bifida and hydrocephalus were discussed in considerable detail. These included a special day devoted to problems of the bladder and kidneys. A good deal of discussion and information came to light about the incidence of these disorders and the possible reasons for their variation in different parts of the world. A new type of catheter was described used in the shunt operation which is now easily visible on X-ray. The treatment of meningitis which often occurs in the early days of spina bifida was discussed and the long term results of treatment of hydrocephalus were presented. A group of patients was shown to have recovered their vision after they became blind as a result of hydrocephalus and meningitis and there were many other subjects as well as a practical demonstration of orthopaedic appliances for the treatment of spina bifida children.

the need be better met by another existing body? What would be of the greatest benefit to the greatest number? In short, we have to be able to answer the kind of questions which a discriminating donor would be entitled to ask.

In some fields, experts are divided in their opinions as to what is the best thing for *spina bifida* victims (this is especially so in the field of education) and this fact adds to the difficulties involved in preparing our "case" for the appeal.

A new brochure about A.S.B.A.H. is being prepared by P.B.A. for temporary use pending the completion of basic research.

All new stationery will incorporate the re-styled A.S.B.A.H. symbol. We intend in due course to drive home the letters "S.B." as the first step to making people conscious of spina bifida. Local associations wishing to incorporate the new symbol in their stationery can obtain a block of it, free, from the Association's office at Benjamin Franklin House, 36 Craven Street, London WC2. (930-6856.)

Members who may have occasion to write to Philip Barron Associates should note their new address: Royal London House, 21A Brighton Road, South Croyned CR2 6EA.



IT'S THE SYMBOL OF HOPE

Although the launching of a national campaign is still a long way off, good progress is reported by the committee liaising with A.S.B.A.H.'s consultants on public relations and fund-raising, Philip Barron Associates.

A London office has been found and a full-time secretary has been recruited. P.B.A. have covered a lot of ground—literally as well as metaphorically—carrying out the research which is essential if A.S.B.A.H. is to appeal for the right things and support its case with indisputable facts.

We cannot simply shout "Help!" Many questions have to be answered before an appeal can be launched with full force. Not only *what* is needed, but also *where*, *when* and *how much* will the items cost. Could

WHERE CHILDREN ARE HELPING THEIR FRIENDS

Children need other children. For handicapped children this need is even greater. But every mother of a pre-school age child knows how difficult it can be to find a place in a nursery or play group.

When the child is handicapped the problem is magnified. Impossibility often replaces difficulty.

That is why the handicapped under-fives of Kent are lucky to have Dr. Alfred Elliott as their Medical Officer of Health. Eight clinics for handicapped youngsters are flourishing in his county.

They provide facilities for the children to compete and associate with their peers. A physiotherapist gives the treatment which is so vital to physically disabled infants. And the service does not stop short there. The mother's welfare is considered, too.

She can mix with other mothers and compare problems and solutions. And she can attend sessions where experts give encouragement and help over a friendly cup of coffee.

The first clinic opened experimentally in 1963 at Aylesham, Kent. It dealt so successfully with its severely physically handicapped patients that the facilities were extended to other parts of East Kent.



Play-time at the Gillingham clinic.

Seven of these special care clinics are now in operation, all run by the M.O.H.

In October, 1965, Dr. Helen E. Mair, Medical Officer of Health for Gillingham, opened another clinic in her borough. It works under the immediate direction of Dr. Mair. More than 148 children, aged between two and five, attend these eight clinics.

And the question of opening more in other parts of the county is under consideration. The main obstacles are finance and staffing problems.

The Gillingham clinic opens three mornings a week and caters for 18 children. Until February, they were mentally and physically handicapped, but a clinic for the mentally retarded has just been opened at Wigmore and is run on a voluntary basis by the mothers.

A mother who visits the Gillingham clinic regularly reports on its excellence.

"The clinic provides group therapy, physiotherapy and play with a large selection of toys", she writes.

Very understanding

"One child would only sit and do nothing else when she arrived 14 months ago. Now she walks when held upright, moves around the floor in a sitting position, plays with toys and even helps with the tidying up.

"Another girl would not talk or mix. But she improved tremendously, has now gone to primary school and her teachers are pleased with her progress.

"The physiotherapist attends twice a week and a great deal of the improvement shown is due to the affection and treatment she gives. I have found all the staff very understanding and kind to children and mothers.

"We mothers can talk over any problems during any clinic morning. In addition to this facility there is a regular coffee morning each term when mothers, staff and doctors can get together to discuss all the aspects of caring for the children."

The children of Kent are very lucky indeed. *Link* will be proud of the day when clinics like these are accepted as national rights, and are so commonplace that they will not rate a mention in this magazine.

News from the Groups

DEVON AND CORNWALL

A jumble sale organised by our Plymouth members on 15th April realised over £40.

We regretfully announce the death of our old-age pensioner friend and helper, Mrs. Conning, who was in the midst of running a raffle on our behalf when taken ill.

At a meeting in Plymouth on 4th March, Mr. J. H. de Pijke, Superintendent Physiotherapist at the Plymouth School and Centre for Spastics gave us an interesting and helpful talk on the care and management of the hydrocephalic and spina bifida child. On this occasion we discussed at length the National Association's Appeal for financial support, and all our members were asked for donations on a no-interest loan basis. So far £110 has been forwarded to National headquarters.

Our most recent meeting on 29th April was the first to be held in Exeter, and proved most successful, resulting in several more families joining us—our membership now totalling some 36 families.

Our speaker, Miss G. M. Bastow, a health visitor for Exeter City, with special responsibility for the welfare of the handicapped child throughout school life, gave us an account of her own work in providing a "link" between the parents and child and the various facilities available in Exeter.

Of special interest was news of a venture, commencing shortly, whereby provision was being made for some dozen pre-school age physically handicapped children (of normal intelligence), including several spina bifida and hydrocephalics, to be received into a Nursery School group on three afternoons a week.

Miss Bastow answered our many questions and all two dozen members present enjoyed the following lively discussion.

LINCOLNSHIRE

Our stand at the Welfare Exhibition at Grimsby on the 3rd and 4th May was a resounding success and we achieved much publicity from it. We would like to tender our sincere appreciation for the valuable assistance we received

from Mr. Zachary who loaned us a model and Dr. Janet Hunter (Grimsby) who loaned us X-ray viewers and photographs.

A jumble sale organised in March by Mr. and Mrs. Keeble and Mrs. Dunster raised £23.

Mrs. A. I. Bristow (Horbling) raised £34 in a fine individual effort. Our efforts to increase membership is now being rewarded and to date we have 43 members.

NORTH EAST

Our group is coming along fine now, there are 26 families meeting in the North East. We hope to increase our membership during the next month or two. When our meetings first began we didn't have a permanent meeting place. We have managed to arrange to use the Neurological out-patient waiting room of Newcastle General Hospital for our monthly meetings. Many of our children attend this department.

We are all greatly indebted to Mr. Douglas Lee, headmaster of the Sanderson Orthopaedic School, Gosforth, Newcastle-upon-Tyne. Mr. Lee arranged our inaugural meeting at the end of January. He is very interested in our children and our problems. His contact with us began in the orthopaedic school where he regularly comes across spina bifida children.

NORTHERN IRELAND

Since being formed in November 1966 the Belfast Branch, with a membership of 45 families, has collected £85 at local football matches. At two jumble sales £50 was raised. A Dramatic Society put on a play in Newtownards and the proceeds also went to our worthy cause.

The Northern Ireland Council for Orthopaedic Development have been in close contact with the Branch and are giving us every assistance.

At a meeting in March Dr. Ian Forsythe, Paediatrician and Mr. J. Piggot, F.R.C.S., were guest speakers and gave interesting talks on Spina Bifida and its problems. Mr. Piggot also consented to being Vice-Chairman of the Belfast Branch. A keen interest in our work

is being given by the medical profession.

SOUTH BERKS., NORTH HANTS. AND WEST SURREY

At our meeting in March, parents were very interested and heartened to see and hear by way of film, of the wonderful work being done in the education of physically handicapped children at the Lord Mayor Treloar School, Alton, Hants. The film is available to other Groups from Major Lloyd, Lord Mayor Treloar School, Upper Froyle, Alton, Hants.

A small group of our members visited the Lord Mayor and Florence Treloar Schools on 25th May, and were most impressed with the high educational achievements of the pupils, and the excellent facilities available.

In April, a talk on spina bifida was given by our Secretary, together with a talk about the North West Frontier, India; this was organised by one of our members as a result of which we raised £30.

A number of our Committee members have been invited to speak at local Rotary and other charitable organisations' meetings, and are raising money in this way.

During the past year, our membership has grown from approximately 70 to 105.

SOUTH MERCIAN ASSOCIATION

On 1st April, Mr. Bullock, the Secretary of Chailey Heritage, came to Stevenage to give a talk about the Hospital/School and to show his slides of Chailey.

The second Annual General Meeting of the South Merician Association was held on 6th May. With the exception of the Hon. Treasurer, all existing officers were re-elected. Mr. E. Kinsella anticipates leaving the area within a few months and Mr. C. Greenfield has been appointed Hon. Treasurer. Three new members have been appointed to the Committee to bring it up to full strength.

Fund raising for our caravan continues and our target is so near

that the Committee are inspecting sites and we hope to have the caravan on a suitable one in time for the main holiday period this year.

SUSSEX

S.A.S.B.A.H. now has nearly 90 members.

A meeting was held in Brighton in May, when the Superintendent Physiotherapist at Chailey Heritage spoke about walking problems. She was most informative, and interesting to those present as most of them had young children who had not yet mastered the skill, either with or without aids.

A coach was hired from Brighton on the 1st July to take members and their families to a Rally at Queen Mary's, Carshalton. Picking up points in the country were Burgess Hill, Haywards Heath and Crawley. This constituted the group's meeting for July.

Write ups of general meetings have regularly been sent to a dozen or so local papers throughout the

country and most of the Editors have been good enough to publish them. Individual members have also sent reports of their coffee mornings, etc., and a little publicity has been gained in this way.

The Group took advantage of South Hant's offer in the last *Link*, and now have their own information substituted in the leaflet "What is Spina Bifida and Hydrocephalus?"

S.A.S.B.A.H. has the offer of first refusal to purchase an excellent caravan which is suitable for handicapped persons. There was an overwhelming response from members to the note sent out by the Secretary and money is being raised in various ways by individual members. As a small incentive, a week's rent-free holiday is being offered for every £50 donation, per family.

Plans are being finalised for the selling of Christmas cards again.

YORK AND DISTRICT

Due to a combination of a short article in the local paper and a lot of visiting by members of the com-

READY FOR ACTION

Mrs. Carol Whalley has been appointed to take charge of our office. She will help with preparations for the proposed national campaign.

Mrs. Whalley, aged 25, was born in Manchester, educated in Wales, and graduated in History at London University.

An experienced secretary, she lives at East Molesey with her sales - manager husband.

mittee, the attendance at our general meeting was much greater than at previous meetings and several new members were added to our lists.

After the meeting, at which it was decided to have a day trip to Welburn Hall Special School summer fete for members and friends on 1st July, a film was shown. This was "There's no discouragement" about the education of handicapped boys at the Lord Mayor Treloar School.



Children of the Sussex Association at play at the Crawley Training Centre for Mentally Handicapped Children.

Will he walk?

Continued from page 5

children with spina bifida are better off than many spastic children and less affected than some children were in the days of the epidemics of poliomyelitis. Even so, more than half of them will probably have to go to schools with provision for the physically handicapped—that is to say with the minimum number of stairs and with facilities for exercise, physiotherapy and special swimming pools. Children with spina bifida have one advantage above all else compared with children affected by other forms of paralysis and that is that their upper limbs are almost always completely normal.

Only a very few children will be unable to walk and these are children whose intellect has been damaged by severe meningitis or untreated hydrocephalus in infancy together with a few children who develop severe spinal deformities—and even these can be tackled by orthopaedic surgery to a certain extent. All the rest will walk eventually to an amount that will make them useful citizens in later life.

Words of Warning

The parents of a spina bifida child should never forget that parts of the lower limbs, particularly the legs and feet, may be insensitive to feeling. They can be liable to be burned by hot water bottles, radiators and fires and the skin is also likely to become ulcerated by any sustained pressure upon the insensitive region. For this reason, the use of any kind of splints to try to correct deformity must be exercised with great care. This applies particularly to splints worn at night which should be avoided wherever possible.

Great care must be exercised in the provision and fitting of shoes, especially with regard to possible pressure on the toes. Any area of the skin that appears suspiciously red has probably been subjected to pressure and the only treatment for it is to relieve that part from pressure permanently.

The bones of the lower limbs of children with spina bifida are likely to be fragile and they may even break by themselves—for instance, when the child is in bed at night and turns over. The child feels no pain but the fractured bone is revealed by the development of sudden swelling in some part of the limb. Fractured bones in children with spina bifida join up very rapidly and all that is

needed is to avoid the part of the limb becoming deformed or bent out of position.

As the child grows, it is important that careful watch be made to ensure that all the muscles that have been working in earlier life continue to work and that no new deformities are developing. If there is a deterioration in the activity in the legs this may perhaps mean that there is some new complication arising in the spine for which further operation could be necessary. The development of new deformities as the child grows may also demand yet more orthopaedic operations to put things right.

To all but a very few, the answer to the question "Will he walk?" is "Yes, he will".

CHILDREN'S CORNER

Dear Children,

It seems a short time since I wrote to you and yet quite a bit of the year has passed. Many of you will have had a birthday and be a year older and perhaps you will have been on holiday somewhere.

The competition this time is all to do with holidays. Don't worry if you haven't been away anywhere, you will all have had a holiday from your school lessons and had time to do different things so you will be able to enter just the same.

I have made up a code, you will find the instructions for the competition in code so you will have to work it out first. If you can't manage on your own ask an adult to help you.

4 18 1 23 1 16 9 3 20 21 18 5 15 18
23 18 9 20 5 1 19 20 15 18 25 1 2 15 21 20
25 15 21 18 8 15 12 9 4 1 25.

Find the missing trees (answers at the bottom of the page).

Can you peel me an orange?
A bee chanced to sting Robin.
At the zoo a kangaroo can be seen.
There's not a drop in either tin.
I can get it if I reach.
My soup is not as hot as yours.

Congratulations to competition winners Shirley Cook and Ian Anderson, I hope they liked their prizes and will enter many more competitions.

Write and tell me if there is anything special any of you would like in Children's Corner and I'll do my best to include it. Next time I hope to tell you how to make one or two things.

Cheerio for now,

Faith.

Answers: elm; beech; oak; pine; fir; ash.

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