

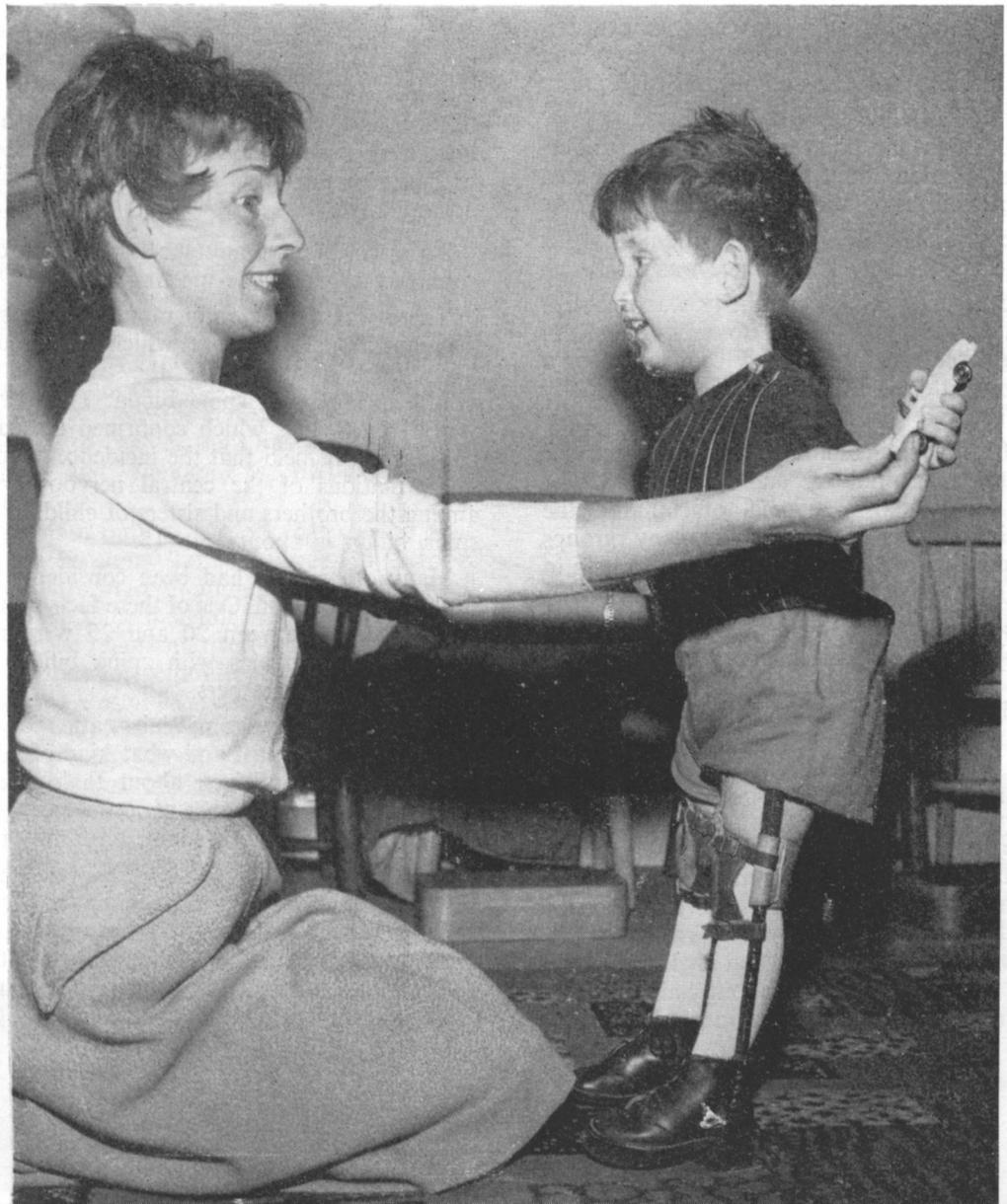
LINK



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

Summer 1966

One Shilling



The conference page

Three important meetings were held recently. An outline of the discussion and decisions taken is given in the following reports.

Representatives from many parts of the country met at Birmingham on May 22nd. The attendance showed the tremendous progress that has been made in so short a time to make this a fully national Association.

The chairman introduced the meeting, then delegates told a little about their own local associations. The variety of activities carried out by the different groups was most impressive, showing that as the Association grows and these ideas spread, the activities of each group can be most comprehensive.

One particular point raised was the difference of opinion about the relationship between the national Association and local associations.

The establishment of sub-committees for education, publicity and finance was discussed.

The urgent need for publicity was debated, and delegates were asked to seek out from amongst their members likely candidates for a sub-committee. A leaflet campaign and a lobby of M.Ps. were also suggested.

A finance sub-committee was proposed for the future, as publicity and funds grew. The need for a full-time paid official for the Association was stressed, and many groups offered direct gifts to the Association to help in these early days.

The meeting closed with tremendous strength of feeling and enthusiasm for the future, with an impatience to set about the many urgent tasks before us.

Congress

The British Association of Paediatric Surgeons held its 13th annual International Congress in London in July. One afternoon of the three-day meeting was devoted to a Symposium on Spina Bifida and Hydrocephalus. More than 100 surgeons, about half of them British, the remainder from many European,

Asian and American countries, were taken by bus to Queen Mary's Hospital, Carshalton, where they heard papers covering a wide range of subjects, including the organisation of services in districts remote from the main centres and the need for more educational facilities.

Overseas members were asked to note the name of Mr. Armour, our Overseas Liaison Officer.

Research

The tenth annual meeting of the Society for Research into Hydrocephalus and Spina Bifida was held in Cardiff in July. The members of this society are those who are particularly interested in these disorders, surgeons, paediatricians, pathologists and other specialist doctors.

As in the past, many specialists from other countries attended the meeting.

There was a very wide range of discussion. The most important aspect which was discussed by several speakers was the causation and family incidence of spina bifida. There was a study from Wales which confirmed the earlier findings in Sheffield that the incidence of major malformations of the central nervous system among the brothers and sisters of children with spina bifida is about 1 in 15.

Many other facts had been considered in a study from Scotland. One of these facts was that mothers aged between 20 and 25 were more likely to have babies with spina bifida than older or younger mothers.

In another study from Wales, attention was directed to how much and what kind of advice should parents be given about their affected child and about the chance of recurrence, which should be coupled with advice on family planning. This study strongly supported the value of a parents' association.

Other papers dealt with the result of treatment by modern methods, and compared these with earlier experience in parts of the country before systematic treatment was available,

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Editorial: How YOU can help

The Association has grown through the first months of its formation, and at last we have been able to see something of the benefits of a nationally organised society.

"Link" is one example of this. The means of contact, supply of information and interesting news from nationwide sources, co-ordinated by members of associations as far apart as Glasgow and London, is already proving valuable.

But this is only a part of what can be done and will be done in the future. On October 15, delegates from all affiliated associations will meet to elect the first full executive committee. This will be representative of more associations than the present committee, which has worked so hard to establish the Association in its present form. This increased representation will provide a more varied opinion, and share out the tremendous amount of work which lies ahead, to the benefit of us all.

Around this new committee, several working sub-committees will start immediately to look into the major problems which concern us.

A sub-committee to organise publicity on a national basis is vitally important.

To be an effective Association, we will need to channel money from charitable sources to

where the need is greatest. The need IS great. More research into more problems; new equipment for more new treatment centres; and a definite encouragement for young and enthusiastic medical staff to stay in this country to seek the answers to our problems, so that we can have the best that is possible for our children.

It boils down to one thing — MONEY.

In all this work, much of the effort to provide the information and the manpower must come from you the members. It was evident at the May meeting in Birmingham that delegates from some areas considered that their children had all the facilities they required both medically and educationally. Yet those from other areas knew that the situation was far from satisfactory.

We cannot ask for the impossible, but it is reasonable to expect that known successful techniques be practised and that the services be organised to make best use of the skills and resources available.

What is the situation in **YOUR** area? Only by knowing of the lowest standards and the highest, can your Association set about the task of bringing the lowest up to the highest.

Our secretary says . . .

Very few honorary secretaries are volunteers. They, like myself, seem to drift into it. Obviously there must be a basic interest.

I have also been a secretary of quite a large cricket club and I took this job on because of a sheer love of the game. I cannot pretend to love the words *spina bifida*, in fact we must all feel exactly the opposite. However, we are faced with them and the reactions of most of the people I have met is to accept the challenge and do one's utmost to tackle the problems involved.

This then is one reason why I undertook this particular job and, in so doing, I feel better equipped to help my daughter and to support the medical experts. You could say, therefore, that one of the motives is partly self-centred. There is also the challenge of a new project and seeing it through.

If I were naturally a philanthropist, I might well have been doing this work in my spare time anyway. I am not. But, being a great believer in fate, I accept the task it has put my way.

But, for how long? The work is growing and one's spare time is limited and this combination

adds up to delays and eventual inefficiency. This is why it is imperative that we get ourselves in a position to pay for an expert. A skilled organiser/secretary will be a first class investment.

He or she, will pay their way in a very short time, for the employment of such a person will mean more active excursions into fund-raising, quicker dissemination of information and getting in touch with the right people at the right time.

When one thinks of the work to be done in building up a flourishing association that can provide so much for our children, one could almost shudder and say "When can it be done?"

We can all do our bit, but we need more than this. Every member must provide the money for paid staff by supporting local branches in every possible way. You can only take out what you put in, especially in a voluntary organisation.

Initially you lived on a wave of emotion. We now need the material effort from everybody.

T. L. Williams

A READER WRITES . . .

One of mother's biggest headaches is finding a good reliable baby-sitter — someone who has experience of children, is young, but sensible enough to deal with their upsets and is available at almost any time.

This is not as difficult as it might seem. It can be done through a baby-sitting group.

Eighteen months ago, I advertised in local shops and the clinic for parents to form such a group. After a slow response, there were more than a dozen very active members after six months. This is how it works :

Of twenty or so mothers in the group, someone is willing to baby-sit for you whenever you want them to. You lose one point for every half-hour they sit for you, with double-time

after 11 p.m. They are credited with these points. You can run up a maximum debt of 36 points, then you must start searching for someone for whom you can sit.

The points are recorded in a book once a week — in our case at a morning coffee session at a friend's house when the children play with each other and get used to potential baby-sisters. — Mrs. G. Raymond, 3, Burton Road, Manchester 20.

Send your ideas and views to "Link". These will be published — space permitting. We regret we cannot use any letter unless full name and address is enclosed — although pen-names may be used for publication.

A CARAVAN FOR HOLIDAY FUN

We had always considered a caravan holiday as out of the question. The lack of mod. cons., and the problem of a small boy requiring a reasonable amount of space to have enough exercise "swimming" around on the floor, was enough to deter us at the first thought.

But seeing the mention of a 6 berth caravan in the Spring "Link" and there being only 3 of us, we decided to try our luck. "It's bound to be a bit crude," we thought, "not like being at home or in a hotel." But we were pleasantly surprised. The Liverpool Association's caravan, situated on the Robin Hood site near Rhyl, had everything needed for the change that's as good as a rest.

For £595, the caravan with modifications, includes a ramp to the double doors, with grab handles, to help overcome difficulties with wheelchairs or calipers; gas stove, with gas heating and lighting, and a permanent kitchen sink. There was no difficulty with the gas, as the cylinders were changed when required (not often) by a man from the local garage who toured the site several times a day.

I had dreaded having to wet shave, but my fears were unfounded, as there was an electric shaving point in the toilet building 40 yds. from the caravan.

With running water only a few yards away, a minimarket just a short walk across the site, a shop which hires out high chairs, push chairs, transistor radios, bicycles, and many other useful things, the site rent of £48 per year seems quite reasonable.



The Liverpool Group's caravan.

There were no space problems with three of us. Andrew slept by himself in the double bed in the separate double bedroom. Our own double bed was the foldaway type. No need, therefore, to use the two single ones which could be made from the seating accommodation in the lounge area of the caravan. This lounge is spacious, enough for Andrew to have plenty of play room during the day, and enough to allow reasonable movement of a wheelchair, as is the kitchen.

The caravan contains all the necessary kitchen equipment, as well as ample bedding. This has been obtained for £25, against an estimate of between £50 and £60, by thrifty shopping and a few gifts.

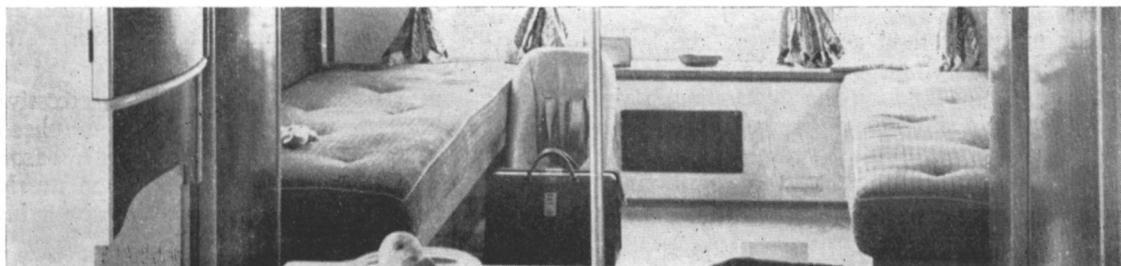
For between 12gns. and 8 gns. a week, depending on the season, I can recommend this as a most enjoyable holiday.

The Liverpool Association has now paid for its caravan, and of this it can be proud. The caravan could be moved to another site, but as it is situated in an area as versatile as North Wales, I doubt whether they will find this necessary.

The profits will be low, but the service to members is great. What more can our associations do?

Stephen Hinchliffe

Below : Part of the caravan's interior.



What is hydrocephalus ?

Hydrocephalus can accompany spina bifida - or it can occur on its own. At one time the pressure on the brain almost inevitably caused damage and mental deficiency. But recently, great strides have been made. Mr. R. B. Zachary, consultant paediatric surgeon at a main treatment centre, talks of the problems of hydrocephalus - and the progress being made in the surgical field.

Hydrocephalus means "water in the head", and, of course, all of us have a certain amount of water in the brain and around it. The fluid is produced in the normal cavities of the brain — the ventricles, which is why we speak of a "ventricular tap" when we wish to take a little of the fluid for examination. This is done by passing a fine hollow needle into the ventricle, either on the left or right side.

The fluid normally passes from one ventricle to another and then on to the outside of the brain, just at the junction of the head and neck. Some fluid passes down the spine around the spinal cord and a sample can often be taken by passing a fine needle into the lower part of the back — a lumbar puncture. The fluid is formed by a sort of filtering process from blood vessels within the ventricles and is finally absorbed back into the blood stream by veins on top of the brain.

Fluid pressure

If there is any obstruction to this flow of fluid (called cerebrospinal fluid, or C.S.F.), there will be an accumulation of fluid within the ventricles and it is this abnormal accumulation of C.S.F. within the ventricles that we call hydrocephalus.

The more the fluid accumulates, the larger the ventricles become and the greater is the pressure of the fluid on the developing brain. Of course, in a small child the skull can expand to take up some of the pressure but, if the hydrocephalus is not treated at all, the brain is likely to suffer from pressure and from expansion of the ventricles within.

Obstruction can occur at one of several narrow places in the normal pathways of fluid and this may account for the method of treatment in one child being different from that in another. Narrowing of normal pathways may cause obstruction but if, in addition, the walls of the pathways are inflamed — as in meningitis — this may cause complete obstruction, so that hydrocephalus may arise from an illness AFTER birth, as well as being associated with spina bifida which is discovered AT birth.

Special chart

If the child's head is very large there is little doubt that the child has hydrocephalus. Yet many parents (and doctors) will agree that when we see a child very frequently (say every day) we may not notice that the head is unusually large. That is why we keep a record of the head circumference on a special chart for each patient.

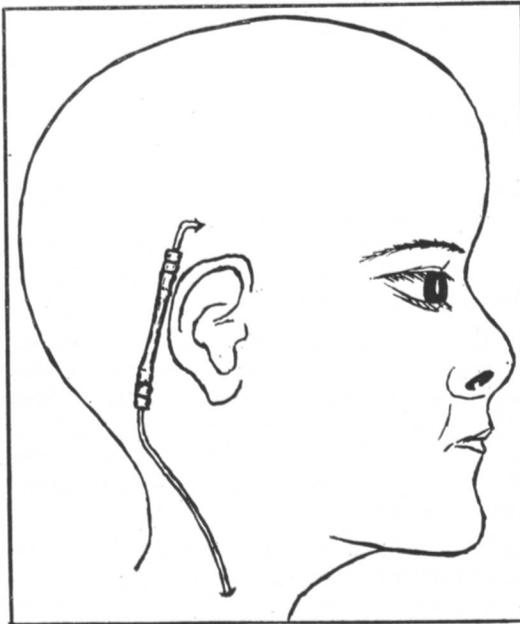
These charts show the usual range of measurements for children at various ages, and we can say whether the child's head measurement is outside the normal range or not. We generally take a few measurements at intervals to find out not only whether it is beyond the normal range but whether it is increasing faster than usual.

It is also true that there may be excessive fluid within the ventricles even if the head measurement is normal, and it is for this reason that special investigations are done on nearly all babies likely to have hydrocephalus associated with spina bifida.

This special test must be carefully done and involves removing a small amount of fluid from the ventricles and replacing it with sterile air. The air will show up on X-Ray and in this way we can demonstrate how severe is the hydrocephalus and often where the obstruction lies. In addition we can estimate how much pressure the fluid is exerting on the brain and whether the fluid itself is abnormal.

We might possibly find that the fluid is obstructed within the brain itself or that it can flow down around the spinal cord but is prevented from flowing back over the surface of the brain to be absorbed.

Since almost all hydrocephalus is due to obstruction of the flow of cerebrospinal fluid, one might think it possible to remove the cause of the obstruction, but this is rarely possible.



The head of hydrocephalus child showing the approximate position of the one-way valve and the incision into the skull. The valve fits under the skin, and is unnoticeable once the hair grows. Drawing by Trevor Nash.

Consequently surgical treatment is almost always directed to by-passing the obstruction. If the level of obstruction is within the brain itself one can construct a sort of short-circuit in some cases, bringing the fluid into the spaces outside the brain where it can be absorbed in the usual way. In almost all children with

hydrocephalus this procedure is not possible and the fluid must be shunted either into the blood stream or into some body cavity where it can be absorbed.

The abdominal cavity is chosen most frequently for the latter type of shunt. It is a cavity which normally contains a little fluid and the C.S.F. appears to be absorbed from it quite well.

If the fluid is to be shunted directly into the blood stream it is essential to use some type of one-way valve, so that blood is prevented from running back up the tube. It probably does not matter very much which sort of valve is used so long as it allows the ventricular fluid to spill over when it reaches a certain pressure and also prevents backflow of blood along the tubing.

The tubing of the valve system starts in the ventricle of the brain (usually on the right side for preference), comes out of a small hole in the bone and lies under the skin behind the ear. From here it runs down into the neck, where it enters a large vein and continues downwards to lie either in the lower part of the large vein or more usually within the heart itself.

Flushed out

In this way the excess fluid is taken from the ventricles directly to the heart, which in normal children it would reach by a more roundabout route.

In most children the valve system works without any attention, but a method of pumping is included so that the system can be flushed out either regularly each day or alternatively only if there is any tendency to obstruction.

We all know how our plumbing system at home can cause trouble and in the same way the valve system may become blocked, but can usually be put right again quite simply. The aim of treatment is to keep the pressure of the fluid low and to stop excessive enlargement of the head in the very important first few years of life when brain growth is most rapid.

NEXT ISSUE : The story of John Holter, the engineer-inventor of the valve that has brought relief to thousands of hydrocephalus patients and hope to parents. Dr. John Lorber, of Sheffield University, will also tell of John Holter's personal tragedy.

Mr. P. P. Rickham, senior consultant paediatric surgeon at Alderhey Children's Hospital, points out the social problems which will arise as the result of early and successful operations for spina bifida.

SURVIVAL ISN'T ENOUGH

For the last seven or eight years a number of centres in Britain have adopted a policy of operating on all babies with spina bifida as soon as possible after birth. The time has come to examine the social implications of this policy.

The incidence of spina bifida varies from place to place. In general, between three and four babies have spina bifida in every thousand births. It must be realised that nearly two-fifths of these children are still-born or have such severe associated malformations that they will not survive more than a few hours. Surgery has nothing to offer in these cases as they never reach a surgical centre alive. This still leaves us with roughly two children in each thousand births who could be subjected to surgery.

Before discussing the results of surgery on these babies we must know what would happen to them if no surgical treatment was available. Dr. Laurence, in South Wales, has made a study in an area where no surgical treatment was available in the past. He found that only 16 per cent of these children survived to school age.

Careful study

In Liverpool, we have operated upon all babies with spina bifida admitted to hospital regardless of the severity of their malformation since the beginning of 1960. With the help of the school authorities we have carried out a careful follow-up study of these children. It was found that practically all the deaths in this group occurred before the age of two years, the vast majority of these dying within the first three months of life.

By the time they were old enough to be considered for schooling, 56 per cent of them were alive and, with more efficient organisation, it is possible that this figure could be slightly improved upon.

Such survival figures are of little importance unless we know about the mental and

physical state of the survivors. Our studies have shown that the mental faculties of these children are very encouraging. Only between 10 per cent and 15 per cent of the survivors who had severe brain damage were so backward that they were considered ineducable.

The distribution of the intelligence of the remaining 85 per cent was the same as in the general population, and there were as many dull, normal and very bright children among this group as we find among children without spina bifida. That means that 85 per cent of these children can, and should, be educated.

Early operation

This is surprising when it is remembered that at least four out of five of children with spina bifida also have hydrocephalus. Early operation on both the spina bifida and hydrocephalus has undoubtedly improved the outlook of these children.

Having found that 85 per cent of the surviving children SHOULD be educated, we must decide whether they are able to attend ordinary schools or whether their physical handicaps, such as paralysis of the legs and incontinence of the urine and stool, may make them unsuitable for education in ordinary schools.

The school authorities found that in just over half of these children the physical handicap was non-existent or so slight that they would benefit from education in ordinary schools.

The other half of the children with normal intelligence had, however, more severe physical handicaps and will have to attend a school for physically handicapped children.

What do these figures mean when applied to the country as a whole? About one million babies are born in Britain every year, three thousand of them with spina bifida.

If the policy of immediate operation on all these children is adopted nationally we can expect that roughly 1,200 of them will be alive

when they reach school age. Five hundred of them will need admission to schools for physically handicapped children. As the education authorities have only recently become aware of this problem there are, by and large, nothing like enough special schools available for these physically handicapped children.

This will be the great bottle-neck of the future and should engage the attention of spina bifida parents' associations all over the country.

Not only must there be schools but they must be the right kind. They must provide good education as well as special medical and nursing supervision, facilities for physiotherapy and vocational training. In some part of the country excellent new schools for these children are now being built but there are still nothing like enough and practically nothing has, as yet, been done to train the intelligent children for suitable jobs.

In fact, unless considerable efforts are made to provide these children with suitable employment once they have reached school-leaving age many of them may find themselves unemployed.

But with help, most of them should be able to play a useful part in the community.

I believe that as parents' associations for spina bifida children become more established all over the country they will have to draw the attention of national and local authorities towards this problem, otherwise no satisfactory solution can be reached.

NEXT ISSUE: An expert deals with the problem facing parents of spina bifida or hydrocephalus children: Can it Happen again?

New committee

To form a democratically elected national committee, a special meeting has been called for October 15th in Birmingham. Delegates from local associations will be able to attend.

It is hoped that the elected committee will be larger than the existing one, and will show a reasonable representation of local associations already formed.

Jane's Fund



Jane — the baby for whom the fund started.

Jane's Fund has a special place in the South Hampshire group's activities. The fund was founded on a great-grandmother's love when Jane was born with spina bifida to teenage parents in 1964.

In Gateshead, Mrs. Ridley received news of her great-grandchild's birth and how doctors had conquered the added complication of meningitis which threatened her first days.

The old lady decided to make her own contribution, and each week she put aside 5s. from her pension, saying "that's Jane's Fund."

When she died a year ago, aged 80, Mrs. Ridley left an envelope containing £25 and the wish that it should be used to help Jane and children like her.

She also left an insurance policy to be divided among her relatives and two of these shares went into the fund.

When Mrs. Humphries, a widow of Bridgemary heard of Mrs. Ridley's sacrifice, she too decided to give 5s. each month from her pension. And Jane's Fund was firmly launched.

Although Jane died earlier this year, her fund is flourishing. Jane was paralysed from the waist down but she was a child who knew, and spread, happiness.

South Hampshire members are determined to continue Mrs. Ridley's work to ensure that Jane was not born in vain. Two of their staunchest helpers are Jane's parents.

Film notes

Ann Pacey, film critic of the "Sun" newspaper, discusses some films which she believes will be of interest to parents or the whole family.

Charlton Heston makes a magnificent job of portraying the British soldier-mystic, General Gordon, in the epic film "Khartoum", now showing in London, in all its Cinerama splendour.

I spent part of the time in Egypt while Heston, the director Basil Dearden, most of the other stars and two complete technical units were shooting the film last year.

Impossible really, while watching Heston's cool and controlled performance now, to forget him in the desert struggling with a grumpy camel who loathed him almost as heartily as he loathed it.

In the film the camel appears to be the most equable animal on earth.

Holiday offering

Back home, Walt Disney has come up with his usual holiday offering "Lt. Robin Crusoe, U.S.N.". Not, I confess, up to his normal imaginative standard. It has Dick Van Dyke trying rather desperately to get some fun out of the old Pacific-island situation, with help from Nancy Kwan as a native chief's daughter, fighting for women's rights.

Parents may be interested to catch up with a controversial and, for me, almost, unbearably moving film about mentally defective children: "A Child is Waiting".

Starring Burt Lancaster and Judy Garland, and covering its ground with a gentle care not to over-sentimentalise or over-sensationalise, the film portrays actual defective children in an American institution. And it does, I believe, a great deal of good in bringing their particular problems into a fiercely uncompromising light.

Judy Garland may appear a somewhat too emotional actress to play the role of an untrained, would-be helper who is really working out some of her own troubles by trying to aid the children concerned.

But Miss Garland, who I'm told got to know the children well before she even started the picture, brings it off superbly. And after all, the role itself — that of the sometimes misguided amateur trying too hard to help — is surely a true representation of many on the fringes of child welfare.

BOOK REVIEWS

A very interesting and often entertaining paperback published last year will provide parents of spina bifida (and other handicapped) children with many useful ideas for their children's play, and guidance in developing their interests by the skilful use of play in their early years.

The book "Play with a Purpose for Under Seven" by E. M. Matterson, Penguin, 4s. 6d., is, of course, intended for all children. Undoubtedly the chapters on creative play, music, books, story telling and pets have the most direct bearing on the child whose movements are very limited, but even in the chapters on adventure play, there are ideas which could be applied to handicapped youngsters.

A delightful feature of the book is the way that the writer foresees the problems of mess in indoor play, and makes really useful suggestions to get round this.

Apart from experiencing a slight sense of guilt, by realizing how far short one has fallen in one's duty as a parent when reading the book, it makes very easy and enjoyable reading. It is packed with useful hints and ideas, and we highly recommend its inclusion in every household's bookcase.

"Equipment for Physical Medicine and Rehabilitation" is a coloured booklet, obtained free from Carters Ltd., 65 Wigmore Street, London, W.1. It is interesting to see the different equipment available for physical handicaps. I sent for it because I wanted to see what they had available under their "children's items."

All one would need for much of the equipment would be a somewhat large bank account! But a handy-man could improvise much of the equipment.

Norman Kjelgaard



Members and children of the Bristol group enjoying themselves on a recent outing.
Picture by North Somerset Mercury.

Swimming helps

Many children find a visit to the swimming baths beneficial. The headmaster of one of Dr. Barnardo's schools for handicapped children has advised us of two methods used in their private pools.

The first is for the child to express his bladder before applying a gamgee pad and "Sandra" incontinence pants underneath his bathing suit.

For children who have had an ileostomy operation, and have received medical permission for this form of therapy, the second method is used. A special rubber cap is fitted over the rubber flange and the child wears "Sandra" incontinence pants under the bathing suit.

It is necessary to discuss the matter with the local Baths Superintendent before using a public pool. We invite readers to pass on details of any baths offering special facilities for physically handicapped children.

But parents should remember that every case should be considered individually for suitability to this type of therapy.

Children's corner

13 Cowlersley Lane,
Cowlersley, Huddersfield.

Dear Boys and Girls,

Thank you all so much for the very good pictures and drawings you sent in for the last competition. It was very hard to decide who should win a prize, but in the end I sent 1st prize to Stephen Kenny, age 7, of Northern Ireland, and 2nd prize to Angela Powell, age 5, of Standon, Stafford. Very good, Stephen and Angela.

I had no entries from the 8 - 15 years group.

This time I should like you all to write a little story about where you went on holiday during the summer, and what interesting things happened to you while you were away.

The competition will be open to all brothers and sisters, too, and will again be in two age groups: 7 years and under and 8 - 15 years. Send your story to me at the above address.

Regards,
UNCLE ED.

ANNE ROSS ANSWERS

In our last issue, we wrote of the courage of Anne Ross, the 21-year-old spina bifida girl from the Scottish highlands.

Here, she answers questions put to her by Mr. Norman Kjølgaard, our Scottish editor. We hope that her answers may help parents of younger children to equip themselves to overcome the problems they will face in the future.

Q: When did you first realise that you had a physical disability? Can you remember any feelings you had about it?

A: When I first went among people and discovered that I could not do everything others could. I became slightly frustrated as I appreciated that I was slightly slower at some things than my contemporaries.

Q: What is your attitude to schooling — did you encounter any difficulties?

A: Schooling is very important and can be a headache. This depends on the degree of co-operation which local education authorities give and varies from area to area.

In some cases it is practically impossible to get any co-operation from education officials. But parents must fight tooth and nail to get the best possible education for their child. The child may not appreciate this at the time but will realise the value of your insistence when he starts job hunting.

More essential

I feel that whenever possible a child should go to school as he misses a lot of companionship from children of his own age if he is taught at home. This is even more essential when he reaches senior school-age and can take part in debating societies and after-school activities.

If a child must be taught at home, his parents should try to get the various subjects taught to him by teachers who are currently teaching those subjects in school. This ensures that the child is being taught by modern methods.

I would also urge parents to keep reminding the education authority that their child exists if he is being taught at home,

Q: Any hints on making life more interesting for a young child who cannot run around at the same speed as others?

A: The two basic essentials are to understand the child's natural interests and cultivate them and to teach him patience. Example is the best teacher. I am lucky because although not very patient by nature I like working with my hands.

My mother encouraged me to knit, sew and do basket work. And I spent hours reading, doing jig-saws, playing patience, sorting my stamp collection, writing and watching television. Don't rule out sports just because a child can't run. Two of my greatest pleasures are swimming and table tennis.

Boys can play billiards and darts and you can compete on level terms with your opponents at these pastimes.

Q: How did your parents tackle the problems of giving you as full a life as possible?

A: By letting me mix as much as possible with people of my own age. I was allowed to try everything that my friends did — except for things which were absolutely out of the question.

If I discovered I couldn't do a thing I gave it up. But often I was able to join in.

Christmas cards

A special Christmas card has been ordered for the Association. The card, a pleasant snow scene, advertises the Association on the inside, and the profits will be shared between the local and national associations. Place your own order with your group secretary.

Richard Fund Christmas cards can be obtained from the secretary, Mrs. D. A. Jewitt, 21, Moor Bank Road, Sheffield 10.

News from the groups

Bristol

On July 9th the Association gave a party for the children at Failand Village Hall. Children and parents from a wide area, including Bristol, Somerset, Gloucester and Wiltshire were there and the Bristol Lions, a charitable association, gave assistance with transport.

Money, gifts and help came from many sources and special thanks were expressed to the crew of the M.V. Halifax City who sent a cheque for £50.

A number of Portishead and Clevedon parents are meeting regularly in Bristol and Mr. and Mrs. Michael Dash of 'Mandips', Valley Rd., Redcliffe Bay, (Tel. Portishead 3569) would be glad to hear from anyone who is interested.

Central and North London

On July 2nd, members went to Coney Hill School, Kent, which is run by the Shaftesbury Society and is at present the only school in the country designed specifically for children with spina bifida (5 years or over).

They were welcomed by Mr. Allen Field the Headmaster and after a short talk on the school from its early beginnings to the nursery school extension for small children now being built, toured the building. They saw bright airy classrooms with specially designed chairs and gay toy-strewn bedrooms with intercom. to the Night Nurse's room. In the bedrooms an important feature was the mattresses which are of Polyether foam for easy sterilisation to prevent the ever-present risk of pressure-sores and to allow the air to circulate. The bathrooms have high baths for convenient manoeuvring in and out of wheelchairs, and another special fitting is a small sloping mirror at floor level and another by the lavatory seats. Each child is taught to examine his feet and buttocks for chafing and sores — a very good preventive measure — and carries everywhere a small square of polyether foam on which to sit down.

The tour ended with an excellent tea which was followed by a talk illustrated with slides, by Mr. D. Ellison-Nash, F.R.C.S., the school Medical Director.

Huddersfield

Recent activities have been a meeting addressed by the Medical Officer of Health, a Coffee Morning and Bazaar, organised by Mrs. Brook, which raised £20, and bus trips to Blackpool. A visit to Wellburn Special School was very interesting; Mr. Williams the Headmaster did a great deal to make this a most successful outing.

A gift of £10 has been received from Huddersfield Lions club.

The committee are endeavouring to arrange a meeting with the Hospital Management Committee regarding the arrangements for early operation for Spina Bifida children and early contact with new parents. Further negotiations are being arranged with the Local Authority to press for schooling for the Spina Bifida children over 5 years old who are not yet being educated.

N. Hants, S. Berks and W. Surrey

This group has a steadily increasing membership and meets bi-monthly.

A very interesting talk was given by a Urinary specialist, from Chailey Heritage, who outlined many of the special problems encountered by Spina Bifida children and gave much heartening advice.

A talk illustrated by slides was also given by an Orthopaedic specialist from Chailey Heritage. The doctor pointed out how the pattern of handicap had changed over the last 20 or 30 years. At one time at Chailey Heritage there was a predominance of tubercular cases, then of Polio and Thalidomide children and now there is a majority of Spina Bifida children in residence.

A further donation of £100 has been received from the Bonhomie Society Southampton, which has been forwarded towards the purchase of video-tape equipment

required at Queen Mary's Hospital for Children, Carshalton, where it will be used to speed up the investigation of bladder functions of Spina Bifida children.

As a result of a raffle in July, the group made over £100.

The Group have been promised the co-operation and help of local M.P.'s., one of whom has asked to become a member of the Association. Future plans include talks by a Child Psychiatrist, Health Visitors, and Mr. A. Field, Headmaster, Coney Hill School Hayes, which caters specifically for Spina Bifida children, also a visit to Lord Mayor Treolar's Home, at Alton.

North Lincolnshire

The Branch have donated £50 to the National Association funds and are planning to have their first Branch meeting in Scunthorpe in September when it is hoped that Dr. Childs the M.O.H. for Scunthorpe will give an address.

Every effort is being made to promote the activities of the Branch and the interests of parents throughout Lincolnshire.

North West

The North West Association continues to increase its membership and regular meetings for parents are being held in all parts of the area: Manchester, Salford, the Wirral, Preston, North Wales, Mid Wales and Shropshire.

The next general meeting will be on Saturday, November 19th at 2.30 p.m when Mr. Strach the Orthopaedic surgeon will give a talk in the Natural History Theatre inside Manchester University.

Scotland

Scotland has been very fortunate in that Professor Norman Dott, the eminent and internationally acclaimed neuro-surgeon, has agreed to become the Honorary President of the Scottish Division. It was he who suggested the setting up of a Spina Bifida Unit in Edinburgh and this Unit now functions there.

A therapy group has been started in Motherwell which allows the Spina Bifida children to have physiotherapy there without travelling a distance to the parent

hospital. An attempt is being made to have physiotherapy given at centres as near to the children's homes as possible to avoid fatigue. The Association received very active help from the parent hospital and also the local authority in setting up the Motherwell group.

Efforts are being made to have as many children as possible absorbed into pre-school play-groups and nursery schools so that they may be part of the "normal child community".

Arrangements have been made for close liaison with the Scottish Paraplegics Association to ensure that Spina Bifida children and adults may enjoy competitive sport and other social activities.

Southampton

About 60 members, and especially the children from our area disappeared on a picnic into the New Forest.

The Group had a stand at the Southampton Show during July.

Our thanks go to Miss Alexander for telling on June 23rd how Southampton Education Department is approaching the problem of Education for Spina Bifida and Hydrocephalic children. Her advice to parents and the Southampton Education Department's aware-

ness of the problem was appreciated by those present. Generally speaking both Portsmouth and Southampton's attitude to education is that attendance at normal schools is to be made available wherever this is possible. Every year in Southampton there will be 9 additional children needing special or normal schooling. Miss Alexander's final advice was "Allow your child to do things for himself".

South Wales

It was earlier reported that an appeal had been launched by Tenovus for £15,000 towards a Spina Bifida Unit for Cardiff Royal Infirmary. The figure attained so far is well above £13,000 and Tenovus have passed on instructions for the work to commence towards the end of August.

A raffle organised by S.W.A.S.B.A.H. in conjunction with the Tenovus appeal realised over £450.

Various local groups of the association have organised successful summer outings for Spina Bifida and Hydrocephalic children.

Surrey

Carol (Cas) Bryant, a member of this group has achieved great heights in sport although confined

to a wheelchair. In 1965 she attended the Paraplegic Olympic Games in Tokyo, Japan, and won two gold medals. This year, after 3 weeks in hospital Cas has attended: The National Games at Stoke Mandeville, Bucks, and gained 8 gold medals and 5 seconds (certificates); been to France and won 4 more gold medals; and in the International Paraplegic Games at Stoke Mandeville she won 5 gold medals, 2 silver medals and 3 certificates. She also took part in the Commonwealth Games.

A Jumble Sale was held in March, a good attendance was obtained and about £35 was raised.

At an April meeting Mr. R. A. Smith, Director of Queen Elizabeth's Training College for the Disabled, Leatherhead, spoke to parents about the work of the College. This was of great interest to all and a lively discussion followed.

A Christmas Bazaar is planned for Saturday, November 26th in Croydon, and anyone who feels they can help in any way is asked to contact the Secretary.

Sussex

Having been launched in February 1965 the Sussex Association (S.A.S.B.A.H.) adopted its Rules elected a full committee on March 12th, 1966. It became an officially Registered Charity on June 6th this year.

The Group were able to hold a Garden Party in July at which all members of the family were made welcome and pony rides were one of the attractions.

One of the newest members has adopted a spina bifida boy who is now nearly five years old and makes good progress in his new surroundings.

As the Association covers one of the largest counties the Committee have offered to visit more distant members who are unable to get to the main meetings, so as to make personal contact with them. It is hoped this idea will become popular.

Wessex

Mr. W. J. White the Group Secretary reports that the Wessex Group of A.S.B.A.H. was formed at a meeting on 26th June in Dorchester.

News from overseas

We have made contact with the very flourishing Spina Bifida Association in Houston, Texas, U.S.A. This Association has been at work for a few years now and has a large and clearly very active Committee. They in their turn are in touch with other groups in many other parts of America, and we hope to contact some of these as soon as we can. They also know of a group in Japan.

In New York our contact is at present with the Association for the Aid of Crippled Children and they have offered help in supplying us with some of the booklets they have published. Great interest is shown in New York in all aspects of international cooperation.

One of the leading centres for advanced work on spina bifida and

hydrocephalus is Melbourne, and the Spina Bifida Clinic there cares for over 200 children at present. Close co-operation is maintained with the Education Department for Victoria, so that the medical and educational sides are developed together. They tell us "the Clinic has become a reference point for doctors, ancillary workers and parents". Similar Clinics are now in being or in formation in the other main centres in Australia and also New Zealand.

We are engaged in making contact with many similar groups in other countries, notably in Europe, and the policy of our national Committee is to encourage the formation of organisations such as our own, so that an international body can eventually be formed,

The gadgets column

Requests for plans for gadgets have been rolling in, and we hope the information being sent out is of use. New ideas and suggestions are being examined by Mr. D. M. Forrest and his colleagues at the Westminster Children's Hospital and we hope to be able to add to the list of plans already available. We again ask for as many new ideas as possible. Very often it is the very simple or seemingly trivial ideas which are the most helpful.

Unfortunately, the cost of this service, the making of duplicated copies is proving to be rather heavy. So we have decided to charge a shilling per plan to cover expenses.

If you would like any of the plans of gadgets listed in our last issue, send your remittance and a stamped, addressed envelope to Alistair Wood, 7, Garthwen, Llanfairfechan, Caerns.

Here are extracts from two members' letters.

The first is from an adult member who has spina bifida.

Little garter

"I first used a rubber urinal when I was eleven, and used the Down Bros. 'Chailey' type, with disposable polythene bags. When these began to fill there was often some 'drag' because of the weight of the fluid. To combat this my mother thought of using a little garter which was worn just below the knee, and had a fabric pocket 1" x 1½" for the tap to go into. Thus the bag was kept up a little, and as well as being less heavy, was also better when walking around.

"Another helpful tip for anyone who uses a rubber urinal and who is active, is to thread the tapes into a piece of rubber tubing of about 6" so that in between the legs there is a larger surface area, and not a knife edge formed by the tapes."

The second letter describes a crawling board on which a child can propel himself about the house.

"All it consists of is a piece of strong ply-board and four Shepards castors, which are attached 3" from the edge of the board. I found

that the most suitable length measured from the child's ankle to the shoulders and about 16" wide."

The Minister of Health is aware of the need to reduce the weight of wheelchairs and to make them more compact. Research is going on at the Loughborough College of Technology and it is hoped that improved wheelchairs both for adults and children will soon be available.

Help for the asking

Mrs. Day of Fulham writes :

Our son, Peter, has had a history of vomiting since he was born, and even now at 2½ is sick two or three times a week for no apparent reason. I wondered if this is just a personal thing, for he is perfectly well in himself and weighs 30lb., or whether this is common in spina bifida babies, especially when they are on their stomachs a great deal.

Our doctors replies :

It is not common for spina bifida children to be sick in this way, but I suggest that Peter may be eating a little too much if he weighs 30lb.

Order 'Link'

Place an order for "Link" regularly — which will be four times a year — by filling in the details on the cut-out below and sending it to your group secretary. Cost : 5s. per year inc. postage.

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