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Link

Sept/Oct 1974 5p

Association for Spina Bifida and Hydrocephalus (ASBAH)

A happy event

Cover Story
see p. 13

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

All enquiries to: Mrs. K. Charrett,
46 Tillbrook Road, Regents Park, Southampton.
Telephone enquiries: Totton 3365
(Mr. Mortimer)

THE SHASBAH TROLLEY FOR HANDICAPPED CHILDREN

Patent applied for in
UK, Commonwealth Countries, USA, Canada

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

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

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

Standard model for children one to five years old costs £8.25 plus carriage.

Large model for children five to ten years old costs £11.50 plus carriage.

These prices include VAT which has now to be paid on these aids in the UK. Overseas prices on application.

Produced by **Southampton and District Spina Bifida and Hydrocephalus Association**

Link No. 34

Association for Spina Bifida & Hydrocephalus (ASBAH)

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Editorial

It is good to note that despite the financial pressures of last year Local Associations were able to expand their service to their members. In fact, when one considers that they rely almost entirely on voluntary effort Local Associations have an amazing knack for getting things done.

Most of them provide toys and equipment, they publish newsletters and offer help with hospital travelling expenses and other financial problems. There are nine playgroups, providing play experience for the youngsters and a breather for the mums. Eight Local Associations offer a baby-sitting service. On the leisure front there are now 30 groups offering holiday accommodation—caravans, chalets, beach huts, run by the local groups.

Amazingly all these activities and many others are organised almost entirely by voluntary effort. The paid staff of all the local groups numbers only about a dozen.

Magnificent though it is one cannot help but think there must be a limit to what can be achieved by this voluntary effort. In the social worker field we already draw on professional expertise and it may be that in other areas too, with volunteers fully stretched, the only way forward will be to seek the help of staff.

There is always a nagging feeling that the public may consider that money spent on salaries would be better spent elsewhere. But there is evidence that the efforts of volunteers would go even further with some professional support.

This question was discussed at a recent Association Council meeting after reports were heard from two representatives. We carry the reports on page 5 (*Growing Up*).

A good publicity and information service within ASBAH and the Local Assocations is of great importance. News about the assistance that could be offered by the Family Fund certainly seems to have got around, and a great many spina bifida families have applied for some kind of help to this Fund, administered by the Joseph Rowntree Memorial Trust.

In fact more help has actually been given so far by the Fund to families with spina bifida and hydrocephalic members than to any other single disability. Nearly one-third of the money spent so far has gone to 'our' families.

Although financial aid cannot ease all the strains, it can do much to make life easier for those who live with a handicap.

The 1974 NAIDEX Exhibition will be open from October 16 to 19 at Harrogate, 10 a.m.–6 p.m., closing at 5 p.m. on the 19th. (NAIDEX stands for National Aids for the Disabled Exhibition, in case you didn't know!). Two large exhibition halls will be full of the latest aids and appliances for disabled people, and of special interest this year will be a section on vehicles. Once again ASBAH will be having a stand.

News from the groups

Sewing machine is tailor made

Severely handicapped children at Mossbrook School, Sheffield, are being taught dress-making thanks to a new invention by a local dad, Mr. Len Wiles.

Mr. Wiles, who has a handicapped son, spends his spare hours making and dreaming up inventions for the disabled.

This latest is a device that helps children with little use of arms and legs to use electric sewing machines.

Len has designed a bar that enables them to operate the machine with their stomachs, instead of their feet.

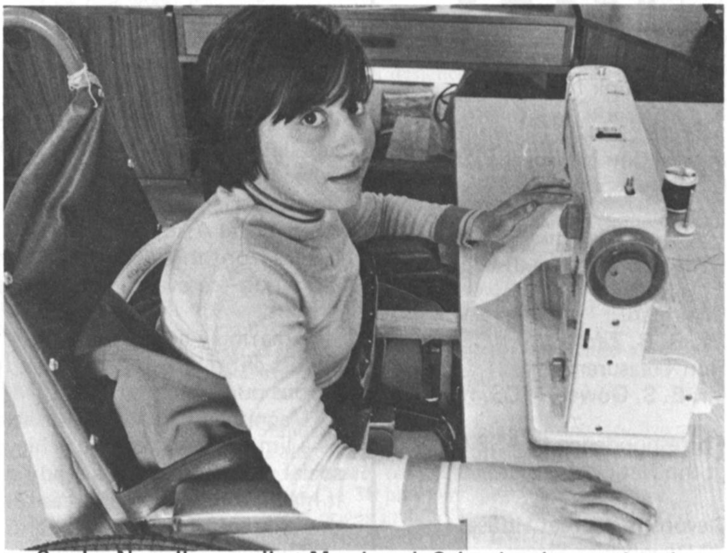
Mr. Wiles came up with the bar idea after hearing from the school Principal, Mr. E. Mullen, that some of the children were having great problems in using the sewing machines.

His invention is now in use at the school.

£300 'walk-or-wheel'

North Hants, W. Surrey and S. Berks. Fifteen spina bifida children took part in the Sponsored Walk or Wheel. They were sponsored per foot travelled over a maximum distance of 100 feet. Some children walked in calipers, others wheeled in trolleys, and one boy walked a mile because 100 feet wasn't challenging enough for him! Contestants enjoyed a picnic afterwards. The event raised about £300 for the Association's work which includes two playgroups.

Don't forget to write to the Editor with news of your group.



Sandra Newall, a pupil at Mossbrook School, using an electric sewing machine, fitted out with a special bar instead of with conventional foot pedals. It enables children who have little power in their arms and legs to use the machine. Photo: Peterborough Evening Telegraph.

Well done cooks!

Bucks. Members will long remember the long hot weekend in June when they 'slaved over a hot barbeque' and roasted 12 pigs for visitors to the 17th-Century Fayre at Lord Hambleden's Estate. There were 5,000 visitors the first day, and 15,000 on the second, and the cooks felt quite roasted themselves by the time it was over. Still they raised the magnificent sum of £230.

John is Chairman

South Hants. John Rae who has been the hard-working Secretary since 1964 when he started this local Association has now become Chairman. He remembers the start of the group when it covered a vast area including Bournemouth and surrounding districts, Wessex up to Dorchester, the Isle of Wight and Channel Islands, and there were about 60-70 members. Now the Association numbers 80 members living in a much more compact area in Portsmouth, Gosport and Fareham.

A grand sports day

Staffordshire. This year the Association was again fortunate in being able to use Keele University's fine sports centre for a Sports Day. About 200 children and adults attended from several Local Associations in the Midlands and Wales. There were events for every age group, even for parents. The Mayor and Mayoress of Newcastle-under-Lyme presented prizes at the end of what proved to be a grand day.

News from the groups

Growing up

How two Local Associations have grown over the years, starting as small groups of parents and now established as larger, developing organisations with part-time secretarial help.

These reports were given recently to ASBAH Council members, who asked that they be reproduced in 'Link'.

Trafford Association (formerly Flixton and Urmston) was started to offer service to members, to raise funds and to publicise their activities and needs. Parents began it and other were 'roped in'. The first Secretary was a parent, but subsequently one with no family ties was found.

The members wanted the Association to grow in stature to meet the growing demands upon it, so after much deliberation a part-time Secretary was appointed, and the work has gone ahead by leaps and bounds. Donations have trebled. There is now a Welfare Committee made up of people professionally concerned, and a Social Worker will soon be starting work seconded by the National Association to the Trafford and Salford area.

* * * * *

The North Hants, West Surrey and South Berks Association was formed in 1964 and there are now 100 families with a spina bifida member and over 100 Associates or Friends.

The Association runs an equipment pool, publishes 'Inter-Link' and holds meetings, and in 1968 a playgroup which had been run by another voluntary body was taken over for two afternoons a week. About a year later a second was started in another area. A Social Worker was responsible for these and they also had their own leader. There was significant financial support from the National Association for two years.

A small office in Guildford with a part-time Secretary has enabled the work to be co-ordinated.

When the first Social Worker finished her term of service, it was decided to extend the social work to reach families in any part of the Association's area and a part-time worker was appointed, and she has just been joined by a second. These Social Workers are appointed by the National Association in co-operation with the Local Association and their work brings real support and help to families in their homes, according to their needs.

Maisie, 72, in the swim

Worcestershire. More than 200 youngsters took the plunge at Worcester Swimming Baths, and made £1,000 for their local Association. The oldest 'youngster' taking part in the sponsored swim was 72-year-old Maisie Howell. Although she only has one leg she managed seven lengths of the pool in 15 minutes!

This painting 'Children at Play' by Brughl has been presented to the Marjorie McClure School for physically handicapped children at Chislehurst, Kent, in memory of the late Mr. Ted Whitehead, former Chairman of Bromley Association. A similar picture was also given in his memory to Cheyne Hospital, West Wickham, Kent, and presented by radio and TV personality Leslie Crowther. The Memorial Fund also bought a garden seat and two tubs for the play area of the Marjorie McClure school.

In the picture (left to right): Mr. C. Wright and Mrs. M. Nation, Committee members; Mrs. Hadfield, Headmistress; Mrs. Locke, Committee member, and Mrs. Whitehead, widow of Mr. Ted Whitehead.

The Stoke Mandeville Games

The sporting competitions for the disabled at Stoke Mandeville are renowned, but rarely do we hear about them from the participants' point-of-view. Two young people, who both have spina bifida, took the trouble to write something about them for 'Link':

By
MAURICE HAMMERTON, a student at Thieves Wood residential school, Mansfield, Notts.

In 1973 at the Stoke Mandeville British Sports Association for the Disabled Junior Games our school team had the most successful meeting the school has ever had. We got 22 medals, 12 of them were Golds and 10 were Silver. We also won a Silver cup for relay.

We started loading up at 1.30 and left school at 2 p.m. We got there at about 5 p.m., tired but excited.

After we had been to our huts to get settled in, we went to the dining hall where we had a meal, and after that we went down to the stadium.

We spent the evening talking, practising and looking around.

On Saturday we got up at 6.30 a.m., and after breakfast the Games began for us. In the morning we did the field events and the slalom, and after dinner we did the track events and volley ball. When we had finished we had tea, and afterwards there was a disco. We went to bed at about midnight.

After breakfast on Sunday we did the swimming and the finals of snooker and table tennis. We had dinner and then loaded up to come back.

On the way home we stopped at a service area for a drink. Then on to Thieves Wood for a happy reunion with the ones who stayed behind.

By STEPHEN BLAZYNSKI, a student at Mossbrook School.

The Stoke Mandeville Games were the 'brainchild' of Sir Ludwig Guttmann, C.B.E., a German professor. The Junior Games were started about eight or nine years ago, but the Senior Games began 26 years ago in 1948. The number of participants has grown each year from 90 to this year's figure of 353.

The atmosphere can be quite tense during the field events with competitors doing their best to try and win a gold medal for discus, javelin, medicine ball and shot, to name but a few events, and by the end of the afternoon the atmosphere is even tenser when they reach the climax of the wheelchair races. In some ways one could call it "The Aylesbury Gold Rush" because this is the time when the medals pour in.

In the evening entertainment is provided by a group of musicians. Sunday is also very hectic with the swimming events taking place. The same sort of tenseness is encountered towards the end of the swimming events, when the relays start and more medals are won.

Winning a medal is in itself a great achievement but winning a Gold is a magnificent experience as many children who have been to Stoke Mandeville will know.

Teenagers welcome

GWEN MEERS, Sister at the Leon Gillis Unit, writes:

Many of you are already familiar with the Leon Gillis Unit at Queen Mary's Hospital, Roehampton, but if not, may I mention that we have been offering an assessment, treatment, and advice service for the young hydrocephalic and spina bifida patients, as well as the limb deficient child.

Last year a long overdue extension was built comprising six study bedrooms, an activity room, physiotherapy room, assessment bathroom, and shower toilet on the ground floor. On the first floor we have a bed-sitting room situation, including a kitchen, bathroom and conference/sitting room, approached by lift or stairs.

We felt there was a need for teenagers to come and try out the facilities, to see if they could cope with daily living with minimal help, in an assessment situation.

We are very willing to help with any practical problems, and would like to hear from you how these needs could best be met.

Naturally your family doctor would refer you if it was felt we might be able to help.

We would be interested to hear from you and we could arrange a visit for you.

The full address is: Leon Gillis Unit, Queen Mary's Hospital, Roehampton, London SW15 5PN. Tel.: 01-789 6611.

Aids and equipment

A new lace-to-toe bootee called the Piedro is now available through the National Health Service. These bootees may be provided for children "suffering from spina bifida or other diseases or disorders causing gross sensory disturbance of the feet", says a circular sent to all hospitals by the Department of Health and Social Security.

As the photograph shows the Piedro is a very stylish boot. It is available in red and brown, and it is hoped to introduce blue in the near future.

The bootees are made of leather, fully lined, with non-slip rubber soles; caliper sockets are easily fitted and the soles can be built up if necessary. Odd sizes can also be supplied.

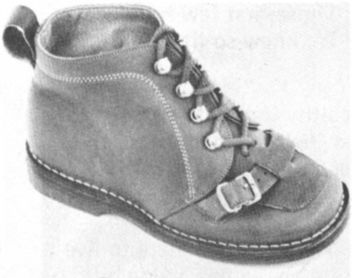
They are kept in stock sizes:

Metric	English (approx.)
23-26	6-8½
27-28	9-10
29-31	11-12½
32-36	13-3½
37-42	4-8½

There are three different widths – narrow (D), Normal (E), and wide (F).

They are available for immediate fitting and it is hoped the delay, which most of you experience when waiting for new surgical boots, can be drastically reduced.

If your child is going to require new footwear when you have your next doctor's appointment, and you like the look of the Piedro Bootee, please take this page of 'Link' along with you and show it to your Consultant so that he may see it and order for you if he thinks they are suitable.



Piedro bootee

For younger children there are lace-to-toe bootees, called 'Shoo Shoos', which can be bought from F. E. Abbott & Co. Ltd., 104 Homerton High Street, London E9 6JG, at a cost of £2.90 per pair which includes postage and packing.

These bootees are made in leather in infants' sizes 2-7, including half sizes. Caliper sockets, shoe raises and any other adaptations required can be carried out by the hospital or firms under contract to the Department of Health and Social Security. Shoo Shoos are only available in white but can be dyed.

The best way to make sure that you obtain the correct size when ordering these bootees is to place your child's foot flat in a standing position on a piece of paper and then draw a line at the back of the heel and also the tip of the big toe, keeping the pencil upright. Take the measurement – in inches – between these two lines and send it with your order.

Value Added Tax

You will be pleased to hear that as from June this year certain essential aids for the disabled have been zero rated for the purpose of VAT. These include appliances which were exempt from the old purchase tax, such as powered wheelchairs and hoists, and equipment which has been specially designed to relieve a severe abnormality and is the subject of a doctor's certificate.

A slippery problem?

One of the problems of sitting down in calipers, especially if your knees are locked straight, is slipping. Children slip and slide off car seats, chairs and in prams. A non-slip plastic is manufactured by Dycem Plastics Ltd. and has been found to be most useful. It is available in bright, attractive colours, blue, red, yellow and green, in 8½ in and 10 in circular pads, in 14 in x 10 in rectangular pads, and in reel form in 8 in and 16 in widths.

Their latest product is a non-slip netting which is particularly useful on chairs and has been used on pony saddles. It can also be placed under cushions to prevent them sliding, and of course under rugs and mats which are on slippery floors. The netting is available by the yard in reels. It can be cleaned by wiping over with a damp cloth, but remember Dycem loses its non-slip property when wet, therefore it is no use in the bathroom.

For further details and orders contact: Mr. C. J. Stone, AIDME Developments, 70 Leigh Road, Wimborne, Dorset.

Please mention 'Link'.

Felicity Birkett

Let me tell you about my precious first born, Sarah, the child whom I worshipped and who I hoped would fulfil all my dreams. My baby was the first grandchild in both families, so it was a great shock to all when Sarah was born in March 1967, on our fourth wedding anniversary, and Michael — my husband — and I were told that she had spina bifida. Those first few hours after Sarah's birth were like a nightmare. We knew so little about her condition.

Parts of this personal story may seem frightening and depressing, but 'Link' considers it well worth publishing because through it all there shine rays of optimism, happiness and hope. Sarah's life was brief, but happy. She brought happiness to her family and friends, and although she died Sarah lives on in the hearts and minds of those who loved her. What's more, her life has led her mother to look for ways of helping other children with spina bifida.

Sarah was in an incubator on her tummy, the aperture on her back had been closed. I so desperately wanted my daughter to live, and I visited the hospital daily. On the fifth day Sarah's head was noticeably swollen and the Sister told me this was hydrocephalus and it had to be drained. Sarah was duly taken for another operation. The following day I returned to be greeted by even more scars and stitches. I was numb with shock.

Sarah made a speedy recovery and just 15 days after her birth I was allowed to take my precious bundle home.

The reactions from people were very different, ranging from pity by people who could not, and never will understand how necessary and important Sarah was to me, to the love and devotion so readily given by all who were privileged to know her.

Except for a valve revision when Sarah was 11 months, our first years passed uneventfully, but happily. Sarah grew into a contented, healthy little girl.

Michael and I eventually decided to increase our family, and were overjoyed when in December 1969 I gave birth to a healthy baby girl, Clare. Sarah became quite "the little mother", shuffling around on her bottom, dragging those healthy-looking legs behind her, helping in any way that her disability would allow. I was, and still am, very proud of her.

We were fortunate to live quite near a new spina bifida school, "Mossbrook", and in September 1970 Sarah spent her first full day away from home there. I was rather apprehensive, but Sarah adored her school, her friends and the staff.

It was about this time that we moved to a bungalow to make life easier for Sarah, and shortly afterwards she had to have a second operation on her dislocated hip and spent 15 weeks on her back encased in plaster.

In the Winter of 1972 a forewarning of the disaster to come occurred. Sarah had been taken ill at school and rushed to hospital. She had all the symptoms of a blocked valve, except that for a few seconds she appeared to stop breathing, and her pulse was very faint. By morning she was well enough to leave. I was so grateful that she was well that I never pursued the reason for this attack, something I have since regretted. Apart from another slight repeat of this problem just before Christmas we entered 1973 without further upsets.

Sarah's learning capabilities didn't seem to be making much headway, despite my constant encouragement. I was extremely upset by this but decided it was something I had to accept.

Looking back over 1973 this was the best year we spent together as a family. Sarah was so well. The summer was ideal. Her friends called and played with her constantly. Our holiday — our first since Clare's birth — was spent in a hotel at Tenby, Wales. My girls had a marvellous time and we were still talking about it when Sarah returned to Mossbrook in September.

On returning from school on Monday, September 17 Sarah complained of stomach pains and was quite sick. As several local children had the same complaint I assumed that Sarah had a "tummy bug", and sent for the doctor. By the following day she was much better but the doctor advised me to keep her away

SARAH

by

Mrs. Susan M. Hammond

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So I come to Thursday night. Michael and I were awakened by Sarah's screams. She had a pain over her eyes and forehead. We immediately sent for our understanding GP who advised us to take her to hospital. Michael returned at 4.30 a.m. with the news that she had settled down in hospital, and that it seemed like a blocked valve and the operation would be performed later that morning.

I reached the hospital early and as I put the theatre gown and socks on my precious child I felt an inward fear. I sensed things were not at all well. Sarah had been sedated and was sleepy, but Michael and I sat holding her hands. When Sarah returned from the theatre I began to panic inside. She only had a "burr hole" investigation performed as her valve was apparently working perfectly. I arranged to stay all night, and Michael left at 7.30 p.m. to collect Clare from my parents and take her home.

I sat holding Sarah feeling this was the only comforting thing to do as she was still drowsy.

Sarah's breathing suddenly became laboured and I shouted for a nurse. I was told the anaesthetic had settled on her chest and a respirator was needed. I sent for Michael. Two specialists had been summoned and after a special exploratory x-ray to prove that the valve was still functioning they came to speak to Michael and me. Their words were useless. I already knew my precious daughter was going to die.

Sarah was transferred to the Intensive Care Unit. I cannot remember with clarity just what happened next. I do recall going to tell my parents. I remember taking sleeping tablets the doctors had given me, and the tears and prayers.

The next day we sent straight to the Intensive Care Unit. Sarah was white, extremely cold and the noise from that respiratory will haunt me for ever . . . there was no sign of recognition from her. I felt so inadequate, and know the surgeon did, too, when later he came to tell us our precious child was dead.

What did I do? I asked "Will Sarah wear calipers in Heaven?" I wanted to feel that at last she would run, jump, splash in puddles; the heartbreak was to know I could not see these important acts.

We agreed to a post-mortem and it was found that Sarah had a brain malformation, which although associated with spina bifida, was uncommon. This condition is not compatible with long life.

Seeing Sarah for the last time was a great help to Michael and me. She was an attractive child, but in death she was just like a huge wax doll, so perfect, so statuesque, so peaceful.

Clare was a tremendous help. She brought everything into perspective. Life had to go on. Her needs were always present and I had to get on with the job of being a mother and wife.

Immediately after Sarah's death I tried to fill every moment of the day by working in the home and making impromptu visits to friends and relations. I thought by doing this I would be able to erase all the hurtful things connected with that unhappy ending. It took almost six months before I realised that I was making a mistake and that I had to slow down. This led to severe

Turn to page 11

ASBAH AT WORK

ASBAH's Annual Report, out this month (September) reports on the main features of the National Association's work, but also reflects the achievements of the 70 Local Associations.

ASBAH is concerned with encouraging new research schemes, and there was progress in this field during the year, although the vital clues to the causes of spina bifida are still to be found. The development of ante-natal diagnosis by amniocentesis has brought comfort to many parents of spina bifida children expecting another child. For every positive result there are about 20 in which no abnormality in the foetus is found. The Research Fellowship into any aspect of work into hydrocephalus and spina bifida has been advertised.

ASBAH is concerned, too, with promoting new and improved schemes to give support to families. Together with other organisations it has been pressing for government assistance towards the cost of hospital visiting, and has been urging a better and more speedy service in the supply of calipers and footwear.

ASBAH backs up the work of the local groups in many ways. It gives financial assistance in cases of hardship, offers general advice and provides an equipment and appliance advisory service. The report says that several projects are now being developed in the design of mobility equipment suitable for hand propulsion.

Good schooling, training and employment opportunities are of paramount importance, and recognising this ASBAH is recruiting a full-time officer to give specialised help with training and employment. The film 'Growing Together' launched during the year is concerned with schooling.

One of ASBAH's publications during the year was 'The Nursery Years' concerned with the importance of stimulating young children during the vital early years.

The appointment of a Senior Social Worker was a feature of the year's work. He is co-ordinating and developing ►

Club for campers

A National Camping Club for disabled campers has been formed, for anyone over 18 who is able to look after himself or can provide his own helper. Able-bodied members are also welcome, which means that a family with a spina bifida son or daughter could join. The Club started in May and two camps are organised for this year. In 1975 there are plans for four camp meetings in different parts of the country. For the £1 a year subscription members get a quarterly newsletter with news of different sites and equipment, and a discount scheme has started for camping equipment. Details from *The Secretary, Mr. F. J. Strong, 28 Coote Road, Bexleyheath, Kent. Tel.: 01 303-0753.*

Despite Disability

"Despite Disability", with its sub-heading of "Career Achievement", and a Foreword by Member of Parliament Jack Ashley, tells eleven stories of triumph over adversity.

The eleven contributors are all severely physically handicapped, including one with spina bifida, but all have worthwhile jobs and a sense of purpose. The book in the "My Life and My Work" series is published by Educational Explorers Ltd., 1974, price £1.85.

ASBAH's social work practice.

Social work can do much to relieve the strain on families. So, too, can the provision of good short-term care where children can spend short periods during crises or when parents need a rest. ASBAH has given grants to two such projects already under way, and also plans to open its own home providing short-term care facilities.

The Annual Report comments that the courage and determination shown by those who have spina bifida, and by their parents, arouses much of the local effort and enthusiasm, and must surely be a spur to us all in the future, so that they may have all the resources and support which we can possibly

SARAH

Continued from page 9

depressions. I became obsessive with Clare, fickle in my moods, and reluctant to go out. I was finally persuaded, by Michael, to visit our doctor. I needed to reveal my emotions to an independent person.

It is almost four months since I broke down and needed the assistance of anti-depressant drugs, and I am now much better.

I found the most difficult thing to accept was that we all had to alter our way of life. For so long everything we all did revolved around Sarah's timetable, and now we were able to do so many things that before we did not consider. This made me feel very guilty.

We are now making plans for the future, a holiday in the summer, and when Clare starts school I hope to find a part-time job, ideally somewhere that the knowledge and experience I acquired whilst caring for Sarah could be put into practice.

The actual hurt I felt when Sarah died has become easier. I can now remember the happy times more easily than the sad ending, and when I think of my darling daughter I am filled with an indescribable inner warmth.

Holiday at Holmbury

Mr. R. W. Lazell, Chairman, ASBAH Greater London Liaison Committee.

Chalets and bungalows equipped for the handicapped now provide for more and more family holidays. The Greater London Liaison Committee felt that in addition to this many handicapped children would benefit from a holiday spent with children of their own age group, independent of their parents. We thought that if such a holiday could be arranged it would also be a break-through for parents who would be able to relax for one week in the year knowing that their handicapped child was enjoying a holiday in much the same way as any other youngster but with special needs provided for.

We arranged for twenty 8-13-year-olds to spend a week at Holmbury St. Mary, Surrey—a very beautiful country area. We used the Felbury House Training Centre which had been the base earlier in the year for our school-leavers' week-end. The Warden and members of his Youth Club could not have been more helpful, nor could people in the neighbourhood.

The programme included two afternoons for swimming, horse riding, a visit to the local town to buy presents to take home, trips to Brighton and the zoo; art, crafts and pottery, folk music etc. During the last two or three days the children were recorded on film so that at a later stage parents will have the opportunity of seeing what a wonderful holiday it was.

All of us who were privileged to enjoy the company of these delightful children have happy memories not only of the activities but also the quieter moments spent just talking together. We learnt to appreciate even more how much love and care is given by parents in bringing up a handicapped child.

We were fortunate in having on our staff for the week two devoted nurses from Down Bros., Hilary Gatfield and Yvonne Quinsey.

Both staff and children were very sorry when the week was over. We certainly hope to have a similar holiday next year. Should other areas consider the idea we would try to send them a more detailed report.

Health matters

Taking some of the fear and upset out of a stay in hospital

A very important part of helping our children to face hospital is being frank with them. The hospitalisation will be frightening and upsetting. But if they know what is going to happen and that it will not be pleasant, but that we will be with them, it will be easier for them.

We cannot really make the experience a pleasant one and I don't feel that we should pretend. Our role is a supportive one, to try to minimise his upset.

I don't really feel there is any best age for surgery, although the first year is probably the best time because the child's knowledge is so limited his fears are also limited. As the child enters his second year, the separation from the parents and family is very hard on him, and he is still not able to understand fully what is to be accomplished by the surgery but, again, with less understanding there is less real anxiety. As the child increases in understanding his fear of death or abandonment become real possibilities to him and this is very upsetting.

I remember, during one of our hospital experiences, hearing a very frightened youngster of about six cry out as the parents were leaving, "Please don't leave me. I will be good. I will love you."

We must try and minimise severe reactions like this by preparation for the hospitalisation and reassurance to the child that we love him and are very sorry that he must leave us for a while and by telling him how happy we will be when he returns home. We must let him know that we know he doesn't want to go and that we will visit him while he is there.

In the case of spina bifida, especially with the shunt revisions, we are not always able to prepare the child very much in advance. But a child's sense of time is not very great and just five or ten minutes of talking to the child in a calm and reassuring way is very important.

I think the most important thing is to be very honest with the child so that he feels that he can place his trust in us. Tell him when something will hurt and when something won't and gradually the child will realise you are right and will be less anxious. With the IVP kidney study, muscle exams, casting, eye tests and X-rays, most of the upset comes from fear and not actual pain.

While the child is in hospital the parents should try to be with him as much as possible. For the most part it is good for the child to meet other children, and see them in a similar situation, and it is also good for the mother's tensions and feelings to get out of the hospital and have a little time to herself.

A hospitalised child will be very demanding and because we want him to recover as soon as possible afterwards and return to the normal family routine, it is sometimes best not to overdo the attention in hospital.

When the child leaves the hospital we will be nursing not only the physical wounds of the surgery but also the emotional wounds to his personality that are a result of the separation and fear and these emotional wounds will heal much more slowly. Some children will regress in their behaviour for a while and the parents must be patient in allowing the child to readjust to the home routine.

An edited version of an article by Jeanne Hanson which appeared in the Newsletter of the Wisconsin Spina Bifida Association.

ASBAH's short-term care appeal is urgently in need of support. Please make it known to all your friends. See next page.

►

Cover story

A happy event

A baby, Iain, first child of Alan and Jackie Moran of . . .

It's the sort of announcement you can find in the births column of any newspaper, but there is something rather special about Mrs. Moran and her family.

Jackie Moran was born with spina bifida and a dislocated hip. Despite gloomy forecasts she battled on. After four years in hospital, two of which were spent encased in plaster, Jackie was sent home.

Further operations edged Jackie closer to a normal life and when she left school she had gained three first-class passes in CSE examinations.

In April, 1972 she went back to Oswestry Orthopaedic Hospital to have her toes straightened. Seven weeks later she married Alan.

Now she writes: "My husband and I were overjoyed when my pregnancy was confirmed.

"On my first visit to the ante-natal clinic the doctor decided that the baby would have to be delivered by caesarian section for I have spina bifida and am only 4ft 3¼in tall and weighed 4st 9lb at the time. April 5 was the expected date of the baby's arrival.

"I felt unbelievably well throughout the whole of my pregnancy, but as time went on I began to get very nervous.

"On the morning of February 15 I awoke in agony, so I made an appointment to see the doctor. My husband took me to the surgery and by this time I realised I was in slow labour.

"I was only kept in hospital overnight, and allowed home the following morning, but labour didn't cease and I was prepared for the theatre about 3 p.m. the following afternoon.

"In the theatre, the doctor told me I wasn't having a caesarian section. I was terrified because I hadn't prepared myself for the alternative—a normal delivery. I was in such a panic that I had to be given a general anaesthetic.

"My husband was at my bedside when I awoke. Our darling baby was born at 4.25 p.m. on February 16, weighing 3lb 15oz. He was in the incubator in the premature baby unit for the first four days of his life and then transferred to a cot in the special care unit until he weighed 5lb 6oz. I was allowed home five days after the birth and Iain was home four weeks later."

Iain is now 17 months and mother, baby and father are all doing well.

ASBAH's short-term care project

A 'holiday home' in sight

Throughout the year, but especially during school holidays, there are constant requests, both locally and nationally, for help in finding suitable homes where a spina bifida or hydrocephalic child may be cared for—to help the family, to give the child a holiday with others of the same age, or because the child has no family to go to.

Provision is very limited, and though through ingenuity and persuasion we hope no one has been left in the lurch, there are many families who need the help but who do not seek a place.

It has now been decided, on the recommendation of the Welfare Committee, that the Association should open a Home to meet these needs.

It has been decided that the location should be in a holiday district and central, but northerly, where there is less provision. Accessibility to suitable treatment centres has also been considered. A possible house has been found in Ilkley, and subject to planning permission and other essential reports, the Association hope it may be possible to buy this house for this purpose.

A full description and photographs must of course wait till plans are further advanced, but as always, the National Association wants to keep members fully in the picture. Also the Finance Committee are anxious for the purchase price to be in hand before a full commitment is made, in view of the difficult economic climate at present prevailing.

Our Appeals Department are therefore looking for support (see page 14) to all our friends including Local Associations, and to new ones, so that this project, which we believe will be widely welcomed, may go forward.

Appeals and publicity

Last year the staff of the GPO E. Central and Foreign Sections organised a sponsored football match on our behalf and here is the "team" lined up with Mr. Windsor Davies ready for this year's match. Last year they raised £100, this year £150 and are already planning next year's match. This continuing support is very encouraging.

I am most grateful to the parents who responded to my requests for photographs in the May/June issue of LINK and the Publicity Sub-Committee is now working on detailed plans.

The proposed publicity campaign will not, however, be staged this autumn—in view of the political and economic uncertainties of the times we have been advised to wait a bit, to make sure of a better response.

This gives us more time to perfect our plans and to produce some really telling literature. So, if there are any more photographs about do please let me have a look at them—I can't have too many. I promise to take great care of them.

The Dorchester Ball has also been postponed, because of the financial climate. It was to have been held on October 31—Hallowe'en Night—with turnip lanterns and witches on broomsticks. Now it will be Wednesday January 22, and will be called something like The Mid-Winter Ball, with snow-maidens instead of witches.

A generous donor has already promised to provide the beef for the dinner and our friends in Showbiz have promised to come if they can—to any LINK readers who feel like a night out in London we can promise a warm welcome. More detail later.

Our good friends in the Independent Order of Foresters are really digging on our behalf and I am very much enjoying the dances and socials to which I am invited. A big "do" in Sheffield is the concert at the City Hall on Saturday, November 30, with the Brighouse and Rastrick Brass Band and the Treorchy Male Voice Choir. Again, if any LINK readers can come to the concert we shall be delighted to see them or at a classical concert at the King's Hall, Bellevue, Manchester, on Friday, November, 29, when the Bayer Company's Orchestra will play music of Brahms, Chopin and Vaughan Williams. ASBAH has been allotted 1,000 seats at 75p each with no deductions for expenses.

We need help, please, from all our good old friends and as many new ones as we can find for this year's special project—the Short Term Care Appeal (see page 13).

ASBAH feels particular concern for these children with no loving family to support them. Will you try to interest your friends?

A university first

Kulukundis House, the first unit to be built for severely disabled students at a British University, was opened at the end of June by Mr. Jack Ashley, MP, at the University of Sussex.

'Open' course

Applications are due for an Open University course on The Handicapped Person in the Community. The course runs from February to November 1975 and is for people of all kinds including parents and professional workers who have some knowledge of the problems of a handicap. It is hoped that at the end of the course students will have a clearer understanding of what it means to be handicapped, and a greater knowledge of the scope and limitations of the relevant services in the country. They should also be able to take a lead in involving their local community in positive action for improved services. The cost is £55 and applications close on 25th October. Details from: The Open University, Walton Hall, Milton Keynes, MK7 6AA.

ASBAH publications and publicity

Your Child with Spina Bifida, 3rd Ed., by Dr. J. Lorber, MD, FRCP	20p*
Your Child with Hydrocephalus by Dr. J. Lorber, MD, FRCP	15p*
Equipment & Aids to Mobility by O. R. Nettles, MCSP, ONC. A folder of four booklets . . . complete set	25p*
Clothing for the Spina Bifida Child by Barbara Webster, SRN, RSCN	15p*
The Nursery Years, by Simon Haskell, M.A., Ph.D., and Margaret Paull, Dip. Ph.H.	
General information leaflets	100 for £1
Leaflet for young people	100 for £1
Scottish Spina Bifida Association booklets	
The Spina Bifida Baby by O. R. Nettles, MCSP, ONC	10p
Growing Up with Spina Bifida by O. R. Nettles, MCSP, ONC	20p

All available from: ASBAH, Devonshire Street House, 30 Devonshire Street, London W1N 2EB. (*Special rates available to Local Associations.) Bulk orders of Scottish Association booklets to: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh, EH4 2BW (at special rates).

Posters. Double Crown, 5p each, "Future Bright", 10 for 20p.
Flag Day emblems. 1,000 for 50p.
Cards for notice boards. 10 for 10p.
Car stickers. 5p each. Postage extra.
Fund-raising items. Price list/details on request.

Films

The first four films may be hired from Concord Films Council, Nacton, Ipswich, Suffolk. Enquiries about purchasing these four to ASBAH.

What is Spina Bifida? Black/white, 16 mm, 25 minutes. Shows the early treatment of a baby born with spina bifida and hydrocephalus, and the involvement of parents. **Hire: £2.**

A New Lease of Life. Colour, 8 mm, 25 minutes. This film, made by a parent, shows by a series of animated drawings the nature of the spinal lesions and refers to treatment. **Hire: £2.**

Like Ordinary Children. Colour, 16 mm, 30 minutes. Two teenage girls describe their disability and their feelings about integration into society. The attitude of girls from a local school to those with handicaps is also shown. **Hire: £4.**

Growing Together. Colour, 16 mm, sound, 40 minutes. This film is about education and the choices of day school available to spina bifida children. Discussion topics to accompany this film are being prepared. **Hire: £4.**

What Shall We Do Tomorrow? Colour, 16 mm, 22 minutes. It deals with the problems and achievements of spina bifida youngsters, with comments from parents and teachers. It shows, too, some local money-raising events. The film was made for Mansfield & Worksop Local Association. Enquiries to: The Secretary, Mrs. E. Freeman, 23 Melbourne Street, Mansfield Woodhouse, Notts. Tel.: Mansfield 26860. **Hire: £3 plus carriage and compensation.**

Local Association offers

Badges. Silver and green enamel with pin fastening. Replica of the Spina Bifida emblem. Bulk orders are welcomed particularly. Price: 22p per badge. Postage extra. (For a single badge please enclose s.a.e.) Apply to: Mr. K. McKenzie, Badges Secretary, Salisbury & District ASBAH, 111 East Gomeldon Road, Gomeldon, Salisbury SB4 6LZ.

Badges for children. Good quality 1¼in diam. SB symbol and the words, "Spina Bifida Children" in black on green background. Price: 25 badges for 75p; 50 for £1.40; 100 for £2.65, including postage. Cheques and postal orders crossed and payable to "SASBAH". Send with order to: Mrs. I. Olditch, High Lea, Turners Green Lane, Wadhurst, Sx.

Ties. Heavy weave washable terylene with SB symbol on dark blue *or* dark green. Sold by N. Hants, S. Berks and W. Surrey ASBAH. Price £1.10p plus postage, while stocks last. Reductions for bulk orders. Cash with order to Mr. B. High, 10 Woodruff Ave., Burpham, Guildford, Surrey. Please state colour.

Inter-association holiday opportunities

Camber Sands, nr. Rye, Sussex. New, well-equipped chalet, in pleasant situation near the sea available for families with spina bifida members. Sleeps six. Please apply to Mr. S. Evans, 1 Coniston Gardens, Wembley, Middx. 01-904 7840.

Cleethorpes. Three-bedroom bungalow to accommodate 6-8 persons at Humberston Fitties, nr. Cleethorpes, Lincs. Further information from Mrs. W. Steele, 59 Louth Road, Holton-le-Clay, Grimsby.

Great Yarmouth. Self-contained 6-berth caravan at Caister Beach Caravan Camp, nr. Gt. Yarmouth. Details from Mrs. E. N. Barefoot, 23 Marlborough Road, Southall, Middx. Tel. 01-574 5067.

Looe. Bungalow, two bedrooms, spacious accommodation at Millendreath Holiday Village, nr. Looe, Cornwall. Mr. Keith Jackson, 202 Exeter Street, Plymouth.

Looe. Holiday bungalow at Millendreath Holiday Village. Sleeps six. Fully furnished. Further details Mrs. Cook, 19 Winslade Road, Harestock, Winchester. Dates still available April, May, Sept., Oct.

Mablethorpe. Self-contained 6-berth chalet situated at Golden Sands Estates, Mablethorpe, Lincs. Apply to Mr. Ken Hall, 17 Walhouse Street, Cannock, Staffs.

Mablethorpe. 25ft. self-contained 6-berth caravan. Situated at Golden Sands Holiday Estates, Mablethorpe, Lincs. Details from Mr. J. Cannon, 28 Deerpark Crescent, Wingworth, Chesterfield, Derbys. Tel. Chesterfield 78952.

New Forest. Well-equipped chalet, sleeping six people. Within easy reach of Bournemouth, Beaulieu, etc. Swimming pool, paddling pool, restaurant and playground on site. Details from Mrs. A. Rae, 16 Clifton Road, Lee-on-Solent, Hants. Tel. Lee-on-Solent 550242.

Rhyl. Open plan 6-berth caravan, partitionable into three, situated at the Robin Hood Holiday Camp, Coast Road, Rhyl, N. Wales. Bookings available 1st-May-30th September to Liverpool Association, 46 Manchester Street, Liverpool 1.

Selsey. New well-appointed, self-contained 16ft. x 30ft. 6-berth mobile home for families with spina bifida members. Sited at Selsey, Sussex. For full details please send s.a.e. to Miss G. M. Clarke, Badgers Copse, Rudgwick, Horsham, Sx.

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