

LINK



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

Spring 1970

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Our Cover

Jeannette Prentice aged five — a Spina Bifida child — shows how to use the trampoline in her school playground in London.

EDITORIAL

I usually sleep like a log but on rare occasions, perhaps I am over-tired or not tired enough, I don't drop off at once.

I have a formula for insomnia—no drugs, no hop pillows. I just lie there and think of all the really bad things that have happened to me in the past.

The day the sash-cord broke on a frame window and came down bang, trapping the fingers of both hands. Eventually a man came with a crow-bar and got me out—he made a mess of my windows in the process.

The day I heard that I had failed an examination which was important to me. The day I got caught whilst swimming in the currents off the North Devon coast and thought I would lose my life in a very stupid way. The day I had to have a much loved dog put down.

Then I switch over to Channel 2 and think of the good things that I have known. The day my School Master (we called them that in my day) said to me "Parsons you seem at last to show the glimmerings of intelligence".

The day I went fishing, very early in the morning and watched the sun come up and draw the mist from the lake with all the beauty that only Turner could have put on canvas. This was the day I caught my first roach which weighed over the pound.

The day I took eight wickets for thirteen runs (Chipping Barnet C.C. v London Colney C.C.) village cricket; boots and braces stuff but real cricket.

The day I . . . and then suddenly it's morning.

An old recipe based on an old theme, with one exception; count your blessings last.

PRE-SCHOOL-AGE CENTRES

By MRS. E. WILSON

Lanarkshire Branch Scottish Spina-Bifida Association



Children from Lanarkshire Sports Club

GAINING CO-OPERATION

Undoubtedly, concentration on the pre-school age Spina Bifida child is of absolutely vital importance. It is impossible to stress this too strongly. Between the ages of 2½ and five years we can gain the child's co-operation and thereby increase the potential mobility and independence for the years to come.

The County of Lanarkshire in Scotland is a large one, parts of it densely populated and parts of it rural. Most parents of Spina Bifida children live approximately 20/25 miles from their child's hospital and therefore the same distance from therapy. It was therefore decided, with the approval of the hospitals concerned, to set up centres for physiotherapy and play therapy within the County.

These were set up, one by one, in local authority premises, and thus our Branch avoided the running costs of such establishments.

PHYSIOTHERAPISTS AND SUPERVISORS

The Branch paid for a physiotherapist and a supervisor at each Centre initially, but having proved the need for the Centres over a period of time we then approached the authorities to take over financial responsibility for the physio-

therapists and supervisors. We now have four Centres in our Shire and have so far catered for some 40 pre-school-age children.

FUN IN THE BATH

Hydrotherapy is available for the tiny tots as access is granted weekly to a nearby College of Education which has a lovely, warm pool. The benefits which accrue from exercise in the water are almost secondary to the children's pleasure in moving around and having fun. No serious attempt is made at this stage to teach them to swim, but rather the emphasis is on them becoming confident in water and learning to move independently.

PARENTS HELD

Parents play a very active role in our pre-school centres. They are instructed by their physiotherapist in moving the young baby through the movement patterns, and can therefore feel involved in their child's progress right from the very start. When the child is old enough to join the play therapy the mothers withdraw to another room where they help with much of the clerical work of the Branch.

THE CONSTANT CHALLENGE

By MRS. JOYCE M. DAVIES

● Having gained a place in a primary school for your handicapped child a new set of problems often confront both the mother and the pupil, and many new anxieties emerge. In the beginning one was confronted with the anxieties of survival, degree of handicap, surgery and the integration of the new handicapped baby with the family.

INTEGRATION

Having coped with all these and having managed to survive the heartache and misery involved, now one has to meet the new and more responsible challenge for the integration of the child into a more competitive and challenging field—the world.

The child itself has to take on a new role, knowing that he is a “little different” from his colleagues, he no longer has the protection of the parents and the hospital staff, and has to learn to fight for himself. Often this process of integration can be more painful for both mother and child, but it can also prove to be the most rewarding challenge of all.

To a mother faced with this new integration of her child, I would say—if you have not done so before, treat your child first and foremost as a child, and secondly as a handicapped one. Do allow him to suffer the frustrations of any other child and subject him to the same rules as the other children in your family. When the settling-in period is over, don't expect too much in a short space of time—remember that he is a child and has to find his own level with his contemporaries and accustom himself with a new daily routine. Education isn't purely something one acquires from school or books, but is to a large extent learning to live with each other and being compatible and happy.

NORMALITY

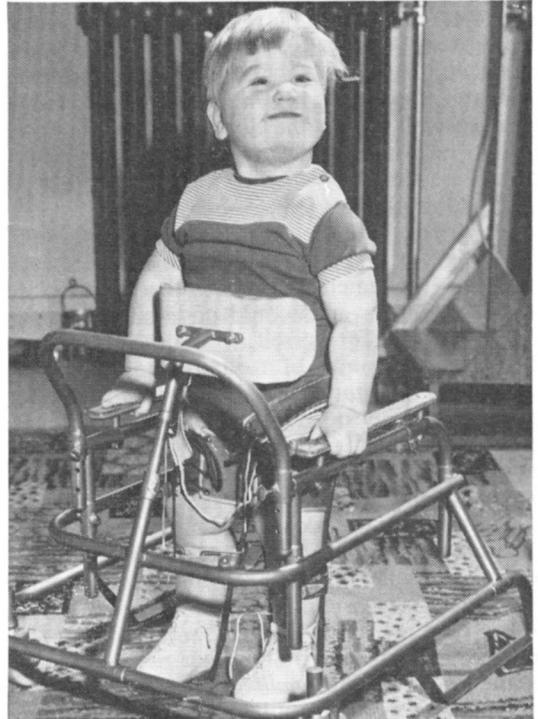
Before becoming the mother of a Spina Bifida child, to me the word “normal”—with regard to people—meant someone who was free of either physical or mental handicap, but I was soon to realise that there is no such state as “normal”, and although handicapped children are classed as, under average, average or over average in ability, this is also true of the remainder of people. Handicaps are not always visible—everyone has a handicap, whether it be in character, personality, ability, status or opportunity. I feel too that when a tragedy such as Spina Bifida hits you, it hits you from the out-

side and if the family all stand together and fight back, it can't get in. It's when the trouble comes from inside yourself that it really matters! We are told that if we eat the right food that it promotes growth and builds a defence against future attack—accepted with humour and humility I feel that sad experiences can do the same.

BROADER HORIZONS

Mothers have many phobias, and these can so easily be passed on to the child. Local branch meetings of ASBAH are excellent for an interchange of ideas, but don't let them be the limitations of your horizons. Your child will ultimately have to live with the world, so get out into it yourself, so that you too will know the extent of the challenge that lies ahead. Life is full of challenges and opportunity not wholly dependent on physical faculties.

None of us would want either ourselves or our handicapped child to be smothered with kindness and sympathy or indeed be singled out for special treatment.



“Look, mummy, I can walk” says Mark Roberts, Hamilton, Scotland.

THE SHREWSBURY SPLINT

The following is reproduced from a letter sent to Dr. C. M. Bannister, Senior Registrar in Neurosurgery at the General Infirmary at Leeds by Mrs. Yvonne Menary Smith of 18 Myrtle Avenue, Bishopthorpe, York. It is published in the hope that any parent who has had the Shrewsbury Splint prescribed may find the information useful.

Our visit to Clinic this afternoon set me wondering on the way home, why the Shrewsbury splints were such a disappointment to many of the other parents. Is it really that the splints are unsuitable for the children or is it the way by which the children are taught to use them?

I found it awkward at first to know how to begin to teach my daughter Louisa, as the only instructions we were given were "stay in front of her and don't leave her alone too soon".

We knew that the splint worked by the child pushing on the breastplate and that the splint moves from side to side. Consequently I took her hands and pulled. By this method she was frightened and was jarred each time the splint jerked forward, so I had to find another way, which I did. We thought that if "our method" was easier and "unknown", then perhaps other parents might benefit from it.

OUR METHOD

1. I fastened Louisa into the splint and FROM BEHIND placed my forearms underneath her armpits with my wrists against her chest. Then, by pushing her gently but firmly from side to side and forward with my arms we played a game of walking up and down the room, to and from toys, sweets, etc. Great fun!! By this movement I was able to:—

- (a) make her feel secure;
- (b) operate the splint;
- (c) force her body to make the necessary movements against the breastplate so that she would understand how to walk for herself.

2. After a couple of hours she understood sufficiently to stand by herself and wave her trunk from side to side, thus imitating the basic movement. Now that she felt secure and was enjoying herself I moved in front of her. I took her hands and gently pulled first right and then left repeating the command "Side, side" or "One, two, One two," as evenly and rhythmically as possible. The splint moved and Louisa was guided across the room.

3. After a few days the child reversed the action and instead of me pulling her, she used my fingers as an aid to pulling herself along. The change can be felt quite clearly. Finally my hands were used simply through habit to be touched as she walked.

The teaching must have sunk home because one day she grew tired of being parked on her own in the middle of the room and decided to walk towards a chair by herself. Look Mum, no hands!

Our final observations were that we found it better to leave *all* the teaching to one person, as there was a tendency for my husband to differ slightly—obviously no two people do this in exactly the same way, and this confused Louisa. Also another person in the room at the time upset her concentration.

This is how Louisa learnt to walk in the splint and it took her about five days. It is a wonderful aid and we are delighted to have it, especially as she is only 15 months old. I am not in any way trying to generalise and say that all the children should be able to handle the splint, but I hope this information will be of use to yourself and perhaps the parents of other proud "toddlers".



Sian Morgan aged 2½ years. Mrs. P. J. Morgan's letter on page 9 refers.

GENERAL MEETING REPORT

Mr. R. B. Zachary presided and welcomed the 100 members, representing 40 local Associations and also members of the Executive Committee and representatives of the Trustees. He outlined the proposals for 1970 agreed by the Executive, which were to be pursued with energy. The Association intends

(1) to ensure that all midwives and district nurses are fully informed about spina bifida and hydrocephalus

(2) to appoint an equipment officer to test appliances and equipment and collate information on them, which will be readily available

(3) to obtain information on the need for residential provision for children who lack parental homes and act on this information as appropriate

(4) to offer welfare services area by area as invited

(5) to publish a booklet on the urinary tract and develop "Link" as the main vehicle of communication for members

(6) to survey educational needs and plan accordingly and take steps in preparation for a new film to be produced in 1971

(7) to discover the probable demands for vocational training in age groups and seek to ensure that the facilities will be available

(8) to support local Associations in every way possible and continue and maintain contact with groups overseas.

In the general discussion which followed, points raised included experience and suggestions on urinary problems, an outline of the recent

OUR NEW GENERAL SECRETARY

Mary E. Oughtred was born in Liverpool and has lived in Leicester, London and the East Riding of Yorkshire. She was educated in Kent and the University of Hull. After a scientific education she moved into Social Work as a voluntary worker, transferring on to the staff in the war.

She served all three branches of the Forces through the YWCA in isolated units and hospitals, later in the West Midlands supervising centres first for the Forces then clubs and hostels including their purchase and adaptation.

She then spent four years in the Training and Personnel field in London followed by 16 years youth service in Sheffield, where some of the pioneer work for physically handicapped young people was developed including those with spina bifida.

Miss Oughtred now finds herself involved in her third national voluntary association—she writes, "I care about people and to serve them, I also care about good administration, but there is a chain reaction here and we all depend on each other in this business of efficiency.

"I believe in a partnership between statutory and voluntary work and am sure that both are needed in work for our members. Although local ASBAH's are autonomous, I hope to see a family feeling develop right through the Association. We are all part of one Association and need each other for ideas and for the strength we can be if united in our common purpose: to give those with spina bifida and hydrocephalus the fullest opportunities and to present a common front to those willing to share in this endeavour."

work, sponsored by A.S.B.A.H. Ltd., in the Staines, Hounslow & Districts Association, by Miss Freda Townsend; ideas for encouraging parents to join their local Association, including the value of visits sometimes taking one's own child. The meeting heard of the new Centre to be opened in Liverpool and congratulated the Association there on its enterprise.

The development of regions within the Association was debated and on a vote, it was agreed by a large majority that the best plan for the present would be to have Regional Liaison Committees to undertake joint activities and co-ordinate, with the Local Associations continuing to be the affiliated units of work.

Mr. Zachary outlined the grants made by the Spina Bifida Trust which was open to receive other applications. Local Associations were invited to send donations to A.S.B.A.H. Ltd. to further the proposals outlined at the opening of the meeting.

Other points covered in the final discussion session included details of the North East & East Midlands Conference in May at Skegness, ideas for encouraging referrals from hospitals, the development of pre-school play groups and co-operations with Brownie packs later; the need for the development of competitive sport; an Association Insurance scheme; and a section of "Link" to make known facilities in one local Association open to others.

Mr. Gaman, the Honorary Treasurer of the Spina Bifida Trust voiced the thanks of all to Mr. Zachary for his masterly chairmanship.

SOLVING A BATHING PROBLEM

By Mrs. Fiona McNeill, Ballymena, Co. Antrim

My six-year-old daughter Christine suffers from hydrocephalus and is unable to support her very large head, she is also mentally retarded. Being very heavy I had great problems in getting her washed

She was too big to sit in the baby bath and could not sit in the family bath. I am very slightly built and I found it impossible to support her in the bath without someone else to help me as it meant I had to hold her head above the water, while her daddy washed her.

A New Idea

One day I was at the hospital physiotherapy department and I saw some surgical collars made from polystyrene, it is also used as casts for broken limbs. The flat sheet of polystyrene is put in an oven to warm and then removed and wrapped round the broken limb.

As the polystyrene cools, it hardens and forms a strong but light limb. I spoke to the physiotherapist working with this polystyrene and she told me it was a new idea in the medical world.

I told her my problem and asked her if she could make a complete mould of my daughter, she was rather surprised but didn't see why it could not be done.

I brought Christine along, the polystyrene was heated and I laid her down on top of it and moulded it round her body including her head.

No Bullrushes Required

When I lifted her out, there was the shell exactly the same shape as Christine's head, back and legs, I placed this shell in the family bath, my husband made a support to clip on to each side of the bath and below the head-piece of the shell, filled the bath up and laid my little girl in the shell (rather like Moses in the basket) and the polystyrene floated on the water, yet allowed the water to come through.

Christine was delighted and so was I as I can now bath her myself without help and I find it much easier to give her passive physiotherapy in the bath as the warm water helps her to relax. I hope my success will be a help to other mothers. I know their children will benefit.



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

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

THE SHASBAH TROLLEY FOR HANDICAPPED CHILDREN

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

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

The Trolley weighing only 14lb. is strongly constructed completely 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, and adds much happiness to the child's life.

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

Produced by the

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

OUR READERS WRITE

The Editor is not responsible
for opinions expressed.

SIX FINE SONS

● Having heard so much about Spina Bifida recently—it was almost unknown in my generation—I thought it might give hope to other mothers of these children if I told you of my daughter who was a Spina Bifida baby.

I have been told that hers is a most unusual case. Now, a married women with six sons, she can walk normally though one leg is a little weaker than the other.

Unfortunately she is totally deaf but is able to talk perfectly and lip read.

All her sons were born without undue trouble and they can all hear and are doing well at school. My daughter is a wonderful wife and mother and around her a very happy family has been created.

I was heartbroken when she was born with such a disability—I did not wish her to live. How wrong I was!

This letter may bring comfort to others; mothers and even grandmothers like myself.

Mrs. I. M. BROWNE
63 Abbey Rd., S. Croydon.

PART-TIME S.R.N.

● I have a 3½-year-old daughter with Spina Bifida and Hydrocephalus, and I would never change her for the world. She is a pleasure to look at and listen to. All her friends are normal children and play with her as if she were normal herself. They are all interested in her condition (being that much older than she is) which I have explained to them and they know how to handle her. She is completely paralysed from the waist down, but it doesn't stop her getting about. She crawls everywhere, and also has her trolley.

We are now waiting for her "clickety-clacker" callipers to be completed. She has had ordinary callipers and found her confidence in them, so I hope she will continue to progress in the new ones.

I am working part-time on night duty in a hospital in Merthyr, have done so since Siân was three months old, so you see we live quite normally. Although we have a handicapped child, we treat her as normally as possible, as do all our family and friends.

I really enjoy reading *Link* and always pass it on to the family and friends. Carry on with the good work!

P. J. MORGAN, S.R.N., O.N.C.
Merthyr Tydfil.

FACING THE FUTURE

● I am writing this letter in reply to Mrs. B. Godfrey's letter in your December issue. We also have a Spina Bifida baby just one year old. We have to visit the children's hospital at Carshalton every two weeks to get Michael's feet strapped to help bring them round so that he will be able to walk.

Regarding Mrs. Godfrey's letter, I feel very sorry for her and her son; for her, because she must be under great strain and for her son, because his mother is trying to get him put into a home. By writing this letter she is not helping other parents who have Spina Bifida babies, because she is saying that when our babies get older we *must* face the horrible prospect of getting our young children into some form of residential school, and then when they leave school to find somewhere else for them to live out their adult lives.

If we all thought the same way we would be shirking our responsibilities.

I am well aware that in some cases it may be the only way the child will get the attention it needs, but surely not in every case.

Mrs. Godfrey says that her son was no longer the "odd one out". It is up to us as parents to see that none of our children normal or otherwise, are the "odd one out".

I think that there are already too many children and young people in homes because their parents just cannot be bothered to look after them. These children are adding to those in the homes who have no one to care for them or because their parents are sick or for other reasons. Surely it would be criminal to add to these when we don't have to?

I am myself a polio victim since the age of 4 years old, so I know something of what my son is to go through. I spent almost all of my childhood in and out of hospital.

So if anyone should say that because of my disability I am not able to look after my son I will say "I will not give my son up for anyone".

MRS. J. CRABB,
2 Cobham House,
Arthur Street, Erith.

I have received other letters on this subject in very similar terms. Pressure of space makes it necessary to publish only the above.—Editor.

NEWS FROM THE GROUPS



Angela Page aged 13 of Rotherham, Yorks, receiving the Guides V.C. from the Guides' Commissioner for Rotherham. Angela is an active member of her group—despite her handicap. Immediately behind Angela's wheelchair is her sister Denise, an athlete of considerable promise. The girls' parents, active Committee Members of Don and Dearne Branch would like to hear of other Spina Bifida Guides in the Association.

North East Association

The North East Association for Spina Bifida and Hydrocephalus is now almost exactly three years old. The first meetings were held in the crypt of a church in Newcastle, but now the Association meets in the General Hospital. There are at present nearly a hundred members.

The Association enjoys good relations with local hospitals and education authorities. During the past two years talks have been given by an orthopaedic surgeon, a neurologist and a paediatrician; and by local Directors of Education, Medical Officers of Health, physiotherapists, nurses, welfare workers, and so on.

A number of films have also been shown, and meetings are usually well attended. The Association has also been instrumental in helping some members to obtain for their children an education of the kind that they, the parents, thought desirable.

Some handicapped children attend local primary schools, or day schools for the delicate and physically handicapped. The services of home

teachers have been supplied for some children, and the local authority has reviewed the case of at least one child to the parents' satisfaction.

The severely handicapped daughter of one member attends a local grammar school and is doing very well. One of the nearby urban district councils has made available its new swimming bath and learners' pool for an hour each Sunday.

A local branch of the Round Table recently presented the association with a magnificent caravan, which is now semi-permanently sited on the coast near Holy Island. Many individuals and groups of people in the district have given donations or practical gifts.

On October 11th an Autumn Fayre was held at Stanhope, Co. Durham. All the arrangements were made by Mrs. Margaret Burdis with other members helping out.

As well as the Fayre Mrs. Burdis, who has a Spina Bifida child, took all the orders for members' Christmas cards. Orders poured in to the great sum of just over £1,600.

Mrs. Burdis has worked extremely

hard for the Association all of which is fully appreciated by members.

Don & Dearne

The Branch suffered a severe loss in October when a storeroom at an old school which they used to store Garden Fete, Xmas Fayre and other equipment, including 100 collecting tins and a lot of new and nearly new goods were broken into by vandals and what was not stolen was completely destroyed.

A recent Xmas Fayre raised £365. Charity shop at Thurnscoe £150 and still doing business and a Charity Shop at Wath raised £550.

The childrens Xmas Party was a howling success. While the children were being entertained, the A.G.M. was held and 90% of the members were present. This idea may prove useful to other groups. The following were re-elected: Chairman: Mr. W. Rudman of Rotherham; Secretary: Mr. Tim Murphy of Wath on Dearne; Elected Treasurer Mr. Sam Edge of Skellow Doncaster.

The previous committee were re-elected with the addition of Mr. P. Levitt of Barnsley and Mr. F. Finlay of Wombwell.



Above picture of the Greenhouse presented to Oakes Park Special School, Sheffield (where most of the local Spina Bifida children attend together with a few other handicapped children). The cash for this was donated from the proceeds of the "Great Walk" and the children have been able to take a part in building this greenhouse themselves as shown. The local Education Committee will now take over the upkeep of the Greenhouse.

Warwickshire Association

As the Association is planning to acquire its own premises, Mr. Howe from the Liverpool Association came to talk to us in November. He gave us details as to what is involved in this sort of project.

Donations are still steadily coming in from well-wishers and members organising varying functions. One of particular note was of £255 from the Birmingham Round Table as a result of a "Disco Barn" which they organised in the autumn.

A start has been made with collecting tins and these appear to be a useful source of income when used at the right time and place.

The sale of Christmas Cards has again brought in a more than useful profit. This year it is estimated at £450-£500 when all the money has been received.

A wine and cheese evening is being planned in March for all members at

our usual venue, Brays Road School for Physically Handicapped, to be followed on Sunday, 22nd March, by the Annual General Meeting at the same place.

Miss Townsend, having finished her survey in the Hounslow area, is starting one in this area early in February and after our first preliminary meeting with this lady we feel sure that this will have much value.

Essex Branch

The New Year was welcomed by the Branch with a Christmas Party for children, on January 3rd, at the Baptist Church, Hornchurch. Father Christmas visited after a grand tea and distributed gifts to the 50 children present. Punch and Judy and a conjuring display was also given.

On January 10th an outing to the Pantomime "Snow White and the Seven Dwarfs" was made at the Civic Theatre, Chelmsford.

The January meeting was addressed by the Secretary of the Essex Branch of the I.C.A.A., who gave a colourful talk on the work her Association is doing.

Essex Branch meetings are held on the last Sunday in the month and all parents and visitors are welcome.

Lincolnshire Association

1969 proved to be an eventful year for us as we did begin to see some reward for the untiring efforts of our committee.

At the start of the financial year we decided to accept Associate Members (no subscription). Through this we have been fortunate in enrolling some really active members who are keenly interested in our cause.

Film shows have made a contribution towards the all-round improvement. In fact, one held in Lincoln played a big part in the formation of a new Branch there

later in the year. They are however staying as part of our Association until the end of March 1970. The Lincoln and District Branch will then register and affiliate in their own right.

In June we donated £500 to our own Holiday Bungalow Fund. Later in the year we received the offer of a substantial donation towards this from the Yarboro Round Table.

We have during the last few days acquired a suitable bungalow which will be adapted and modified to suit our requirements. As the bungalow will be on a non-profit making basis only a nominal rent will be charged. It will have mains water, toilet and bathroom, living room, kitchen, sun lounge and 3 bedrooms to accommodate 7 or 8 persons.

Whilst we are giving priority to our local members it will be made available to any member. If anyone should be interested I would be only too pleased to forward particulars of vacant dates, etc.

Another one of our ideas came into being in October and that was the formation of a Social Section Group for organising fund-raising and social functions.

Through attending efforts organised by members in the south-east of the county and giving short addresses was instrumental in fostering interests in that area. Our appreciations go to Mrs. Parker Addelethorpe who raised £130, Mrs. Everton Willoughby £30 and Mrs. Adair Burgh who raised £14. Which proves that individual members with the help of friends can make a most valuable contribution.

For 1970 we intend to organise film shows and to do surveys of Grimsby and Scunthorpe. We shall give these shows the fullest possible publicity and we shall require the assistance of all our members in the Scunthorpe area because we also intend to see the formation of a Social Section Group in that area during this year.

Our own Social Group organised our first ever Children's Xmas Party held in January. This was a great success as everyone had a really enjoyable time. This party was only possible because of the kind co-operation of the Round Table who gave such admirable assistance with regard to the transport. Our Committee wish to express their appreciation to this group for the work and effort they made in organising this party at such short notice. Another idea which we propose to try after the A.G.M. in May is to give each committee member a specific duty.

In other words, to somewhat sectionalise the committee so that we have one person dealing with matters relating to Medical, Educational, Welfare, Vocational Training, Holidays, etc. In adopting this measure we feel that they will become somewhat expert in some of the many and varied problems with which we are from time to time confronted.

I would also like to thank all our members for their most valued co-operation regarding the 1969 Xmas card effort. This was again most successful as we sold approximately £3,500 worth.

Sheffield Association

On the 13th December our Annual Toy Fayre was held. A record profit of £140 was made in two hours. Many of the local schools in the area helped by donating good class second-hand toys.

Stall in Wombwell Market 15th November and 6th December selling Christmas Cards, Paper, Pet Books, etc.

Saturday, 10th January, Annual Christmas Party. Entertainment by Mr. Les. Atkin (the Balloon Man), Tom and Jerry (Films), a Magician, and Punch and Judy!

On 17th January—together with the newly-formed Mansfield and Worksop Association, 80 members and friends enjoyed a 5-course Dinner at the "Shoulder of Mutton" at Hardstoft (Nr. Chesterfield) followed by a Dance. The following day (Sunday) approximately 100 children and parents were entertained at the Pantomime "Mother Goose", by an amateur pantomime society. This was their Dress Rehearsal but said to be the best show of the week because of some of the hilarious mistakes they made! These people invite our children every year, free of charge, and can accommodate wheelchairs, etc. quite easily as the hall is not full. This is an idea other Associations may like to take up.

Frank and Colin's Road Show continues to raise money at various clubs in the district.

Members' children will shortly be able to use a Hydrotherapy Pool at weekends with the kind permission of Sheffield Children's Hospital.

South Wales Association.

Preparation is now being made to launch the first edition of SWASBAH News. This will be in the form of a news sheet, and will be published quarterly so that it can be posted to each member with their copy of *Link* magazine.



TINA BILLETT of Millbrook, Southampton, uses her crutches for the first time.

It is hoped that non-members as well as members will contribute news items. Anyone interested in this project is asked to contact Mrs. Jean Jerwood, 20, Dythel Park, Trim-saran Road, Llanelli, Carmarthen-shire, who has agreed to compile SWASBAH News.

It is now over a year since a stamp appeal was launched by the Newport Branch to enable funds to be raised for the building of a swimming pool for all handicapped children in the Newport & South Monmouthshire Area.

To achieve the target of at least £17,500, very many more thousands of stamps than those already received are needed. The stamps must be in good condition with the surrounding edge of envelope left intact to avoid damage.

Please send all donations to, T. Blight, Esq., 11 The Villas, Sudbrook, Nr. Newport, Mon.

The South Wales Association for Spina Bifida held their Christmas Party this year on January 10th, 1970, at the Cardiff Royal Infirmary, by kind permission of the hospital.

There were approximately 500 guests, 350 of these being children, who were all given a present by Father Christmas, alias Professor Watkins, who played his part well.

CASE HISTORY – PHILLIP BROWN

By HIS MOTHER, MRS. G. D. BROWN

Philip the youngest of our four children was born on the 28th December, 1962 in a maternity hospital; the day after the birth the doctor said, "Your baby has a sizeable lump and a specialist has been in to see him and he will have to be moved to another hospital immediately for treatment." No explanation or any details of what was wrong were given at this stage.

My husband saw the paediatrician five days later who told him that Philip was a Spina Bifida child and was to undergo surgery the following day. He explained that Philip would be incontinent, have a paralysed bowel and have a weakness in both legs, but he would probably be able to walk. The operation was performed the following day and Philip came home six weeks later.

We had regular appointments with the paediatrician at the outpatients clinic and for the first twelve months Philip was like any other normal baby. We knew there would be many problems to be faced as he grew older. At eighteen months Philip took his first steps and just before two years of age was walking; he was a happy and intelligent child.

It is at this stage that one becomes more aware of the daily problems that have to be faced, the difficulty of obtaining plastic pants for use with disposable nappies for a growing child, the difficulty arising from a paralysed bowel when it is not possible for the child to use the toilet because the bowel is prolapsed; these one has to solve on one's own.

We had been advised that further surgery would be necessary when Philip reached seven years of age. When three years and ten months old the paediatrician recommended that Philip should go to a school for physically handicapped children. He was allocated a place at the school three months later; this was a day school, hours of attendance 10 a.m. to 4 p.m. Philip was taken to and from school by one of the buses provided by the Education Authority. We were anxious at first but were delighted that he settled into the routine remarkably well after a very short time. The school was new and very modern with all necessary aids available, the staff kind and understanding.

After eight months at the school we had one of our usual appointments at the hospital and on this visit the doctor said Philip was the right

type of child to have the artificial bladder operation, this was a good deal earlier than he had originally said. We were to see a consultant urologist and at the same time an orthopaedic surgeon for an operation for tendon transplants on both feet.

We saw the consultant urologist and were given a very detailed explanation of the operation that was to be done; this had also been given to us by the paediatrician. A week later we saw the orthopaedic surgeon and again received a very detailed explanation of the operation he was to perform.

Four weeks later Philip entered hospital for the bladder operation, the surgeon at my request arranged with the Matron for me to accompany Philip in the hospital.

The operation was completed and Philip made a rapid recovery. The three weeks we were in the hospital I can only describe as a wonderful experience. We were made to feel at home. Philip had all his toys with him, the doctors and all the nursing staff were kind and considerate at all times, we made many friends and they made a time that would have been a most anxious period a great deal easier for us. Philip was fitted with his appliance and we returned home.

Five weeks later Philip was admitted to hospital for the operation on his feet. I again was allowed to accompany him, we returned home after a week, both Philip's legs were in plaster up to his knees, eight weeks later the plasters were removed and the operation was successful. And so after four months Philip returned to the school for handicapped children.

He was now just turned five years of age and it was suggested by the surgeon and paediatrician that Philip should be recommended for a normal school.

We made our own approach to the Headmistress of a Primary school near to our home. We took two copies of "LINK" Magazine and also discussed Philip's history in detail, and she agreed to accept him. He has settled in very well.

In the summer all the family including Philip went to Holland on holiday. During this period we travelled several hundred miles by boat, coach and train without any ill effect.

JUST A MUM

By MRS. PAMELA SLAUGHTER

I am just a Mum. I've never written an article in my life, but I feel that I would like to give a little encouragement to all new mothers of Spina Bifida babies.

I can remember so well, that morning $7\frac{1}{4}$ years ago, when my son, Robert, was born. The Doctor told me that he had a lump on his back, and that he would have to go to hospital straight away. I had never even heard the words "Spina Bifida" before, and certainly had no idea of all that lay ahead.

My husband, who is a trained nurse, knew only too well, and at this time held very little hope for Robert at all. For the first six weeks of his life he barely held his own. His back was open and leaking, and he was very weak.

Gradually, as the weeks went by, he became stronger, until at last the doctors decided that he should see a Specialist. The great day came. I was to call at the hospital for Robert and take him up to the Westminster Children's Hospital to see Mr. Forrest. I shall never forget this day as long as I live. This was the first time I'd held my son since he was a few hours old. During the three months of his life I had only been able to look at him through a window.

A DAY OF SHOCKS

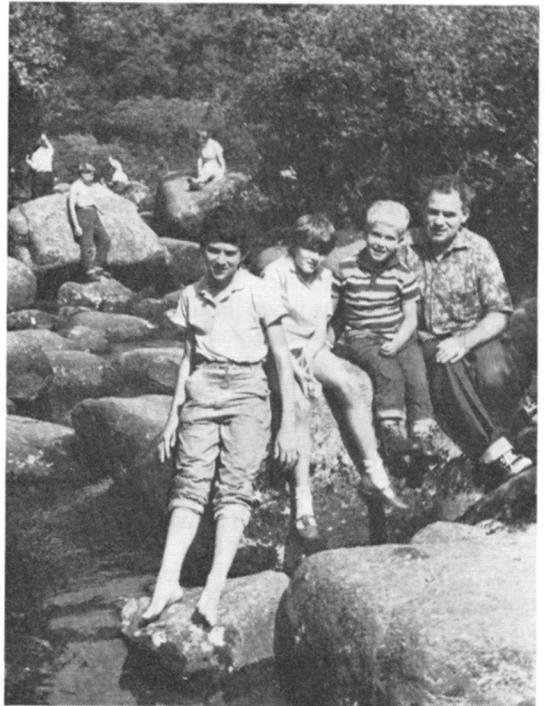
I realised fully, for the first time, all that Spina Bifida and Hydrocephalus could mean. The Surgeon told me in the kind but honest, down to earth way that I've always appreciated, that the road for Robert and for us was a long and hard one. I am ashamed to admit that I felt in my heart that I would rather he should die. What could life offer this poor deformed child? What happiness could he ever find? Now I know, life has everything to offer Robert, and all the others like him. The happiness and joy he finds in life are boundless.

The Surgeon was so right when he said that the road would be a hard one. Robert has had nine operations, some for only minor things, but others involving periods of up to nine months at a time in hospital. There were times of mixed heart aches and joy, but when I look back I only remember the good things, like the time I went to visit him and found him standing up in his cot, the first few steps I saw him take on his own,

and the pride and joy in his little face because he had done it. I remember the time I went to carry him upstairs for his bath, only to find him up there already. "I was alright, Mummy. I knew I wouldn't fall" he said.

Now Robert is a bright, normal seven year old. He goes to the local school with the other children. He walks with the help of below-the-knee calipers and sticks. He has just lately mastered the art of emptying his own urinal bag, so he stays at school all day. We go camping for our holidays, and he joins in everything, even helping with the dishes, and so on.

We never treat him any differently from his elder brother and sister, and if he needs a spank, he gets one. We strongly discourage anyone who wants to spoil him or make him feel special, and we encourage him to do everything he possibly can for himself.



Robert Slaughter and family on the Rocks!

I read with interest Mrs. Price's letter in the Autumn *Link* and feel that her problem is one that a lot of our parents will have to face. We have a daughter Jane, now aged eight, and are finding it harder and harder to keep her amused and happy. Whereas at one time she played for hours with her toys she now wants to be taken out, play with the other children, tires of one toy quickly and wants another. All of which takes up more and more of mum's or dad's time and tends to exhaust one's patience, added to this she is getting quite heavy to lift and realises that she is not like other children, hence frustration for both child and parents.

This is the time when I feel that the parents have to call on all their resources and make that extra effort, for to give in will mean failure, and failure, disaster. I hope Mr. and Mrs. Price will find a way over the present difficulties, perhaps encouraging Yvonne to help mum in the house, drying the spoons and forks, sweeping the mats or washing her own doll's clothes might help. I have had Jane helping me in the garden, trying to push the lawn mower, this also is one way of helping her get her balance as the handle swings up and down.

Patience is a virtue and encouragement a necessity in these times. Recently Jane wanted to come down to the local shop to get a loaf of bread, nothing in that except that she wanted to walk and not ride in her wheelchair. So off we went, dad pushing the chair expecting Jane to be tired after about 200 yards, the most she has ever walked, and Jane on her sticks. Two hours later we arrived back home—Jane still walking having covered about 1,000 yards and the only time she used the chair was to cross one road twice.

Lastly I hope Mrs. Price will find time to attend the ASBAH meetings to pass on her experiences to the parents with younger children.

SID BAKER,
65, Velder Avenue,
Southsea.

TO ALL ASSOCIATION SECRETARIES

Will you please let me know of any services available from one Association to another, e.g., Caravans to let, Bungalows, etc. with costs and dates available.

H. L. PARSONS, Editor.

Extremely well-appointed, self-contained 16' × 22' 6-berth caravan for families with Spina Bifida members to rent. Sited at Selsey, Sussex. For full details PLEASE SEND S.A.E. to Miss G. M. Clarke, Badgers Copse, Rudgwick, Near Horsham, Sussex.

Badges for Children. Good quality, 1¼" diameter, incorporating the S.B. symbol and the words Spina Bifida Children in black on a green background. Available as under in the following quantities only: 25 badges—13s. 0d.; 50 badges—£1 5s. 6d.; 100 badges—£2 5s. 0d. Prices include p. and p. Cheques or Postal Orders should be crossed and made payable to "SASBAH", and sent with the order to Mrs. I. Olditch, 3, Stone Cross Road, Wadhurst, Sussex.

SB Badges—silver and green enamel with pin fastening. Replica of the Spina Bifida emblem. 3/6d. each plus postage. (Single badges, please enclose s.a.e.)

Bulk enquiries from groups welcomed.

Apply: Mr. K. McKenzie, Badge Secretary, Salisbury & District ASBAH, Ballard Down, Gomeldon Road, East Gomeldon, Nr. Salisbury, Wilts.

The Editor would like to express his personal thanks to all Group and Association Secretaries for their response to his appeal for news from their districts. This has enabled him to include more details of the excellent work that has been done and most important of all, new ideas which may be followed by others.

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