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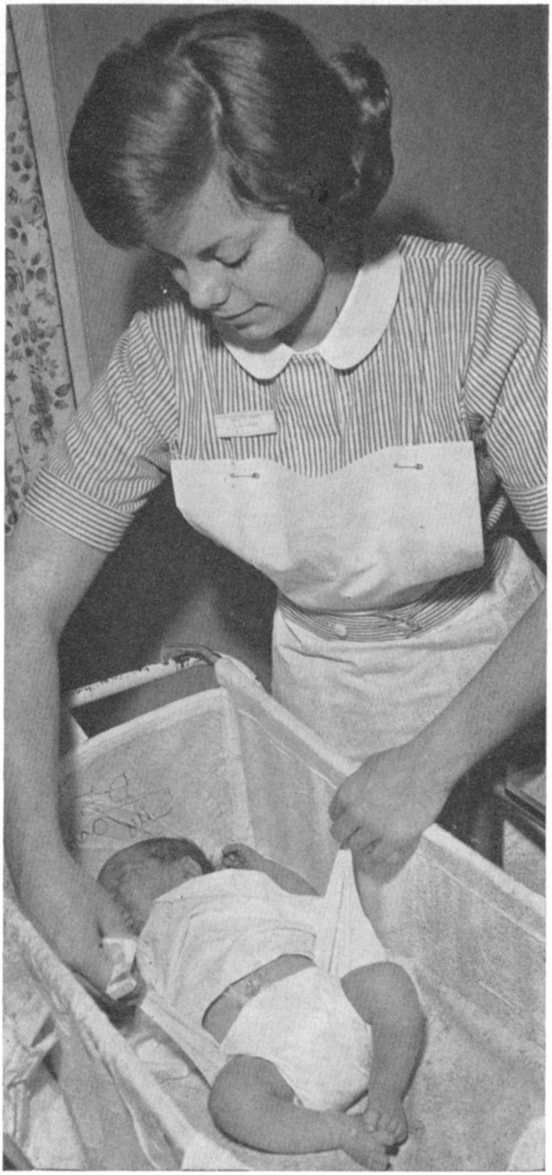
LINK

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

Summer 1970 One Shilling

SOLVING THAT BIG PROBLEM OF THE NAPPY



Lewis Woolf Griptight Limited are pleased to announce that the special reductions to A.S.B.A.H. members of their Sof'down nappies and Tie Pants are to be continued.

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Please send me:— (Fill in and delete as necessary)

Newborn Sof'down Nappies

......Cartons containing 10 packets of 20 nappies (4 weeks' supply approx.) *at 33/4d. per carton* (usual price 41/8d.).

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(Recommended for night-time use)
.....Cartons containing 10 packets of 14 nappies *at 36/1d. per carton* (usual price 45/0d.).

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......Packets each containing 5 pairs of Tie-pants *at 2/- per packet* (usual price 2/10d.).

When nappies and Tie Pants are ordered together there is no charge for postage. If Tie Pants alone are required postage of 6d. for the first packet and 2d. per packet thereafter is required. Nappies alone are postage free.

PLEASE NOTE: We regret orders cannot be accepted *without payment in advance.*

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DIRECT SALES DEPARTMENT (A.S.B.A.H.),

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LINK

SUMMER Vol. 1 No. 15

Chairman: Mr. R. B. ZACHARY, F.R.C.S.,
West Lawn, 54 Clarendon Road, Sheffield, S10.

Honorary Treasurer: Mr. E. S. GOWER.

General Secretary: Miss M. E. OUGHTRED.

Appeal Secretary: Mr. B. W. RELF.

Editor: Mr. H. L. PARSONS.

All correspondence to
ASBAH Ltd.
112 City Road, London E.C.1
Tel. 01-253 2735

Contents

Our Cover

Our cover shows Steven Collett and his mother of Stoke-on-Trent. Both were prize winners in a Mother and Child competition. Stephen, sixteen months old when the photograph was taken is a Spina Bifida child.

EDITORIAL

With this issue I start my second year as Editor of *Link* and during that time I have learnt a great deal. I have learnt tolerance and understanding of people in all walks of life and have made many friends. I was about to include sympathy but sympathy is not enough—it's doing that really matters and I honestly feel that *Link* does something to bring parents together — to share not so much their troubles but their successes.

I am trying to extend this feeling of togetherness and have recently made contact with the Editor of the Australian counterpart to *Link* and also with the Editor of a West German publication. I am also hot on the trail of an American organisation and hope to have news from them shortly. Please read Mrs. Prince's short piece in this issue. She knows what I mean.

THE NUN'S STORY

By SISTER LYNN, CONVENT OF THE SACRED HEART, ROEHAMPTON

I have been told over and over again during the last three years, that as far as can be ascertained, I am the only 100% cured Adult Spina Bifida. It is a thrilling experience for me, but for the sake of my many Spina Bifida friends, I should like to think it is after all not true—that there are others—and so I am setting down my own case, in the hope that readers of *Link* who have also had the same good fortune may let our surgeons know of their existence!

Earliest Days

I was born in April 1914, and as so many mothers have been told since, my mother was told she had a "lovely baby girl but one who would never walk". She was 21 at the time, and I was her first child. As soon as she could get about again, she started on an endless round of hospital attendance with me, but in those days, no one would look at me. One suggested bringing me back in twelve months' time—three kept me for a few days and then sent me home again—all gave the same verdict—nothing can be done. The "lump" on my back was "the size of an ounce ball of wool, looked red and angry and was covered with a fine 'blue' skin".

The First Year

At last, after seven weeks, a young Bart's surgeon, attending Shadwell Hospital for children in East London, said he would like to take a chance. I was 8-9 weeks old when he operated. We have been able to find no records of the operation, Shadwell Hospital having been badly bombed in the Second World War.

I was discharged from hospital when war broke out in August 1914, and the family moved from London to Sidcup where we remained throughout the war. For the first twelve months only my head appeared to be growing, and at 18 months old I weighed 12 lbs. A baby sister (extremely normal!) born then weighed 10½ lbs.! Then 2½ years later, in 1918, twin girls were born.

Learning to Walk

The war over, we returned to London, but my mother felt quite unable to cope with us all, since I was still not walking though the 2½-year-old had been on her feet more than 18 months—and then twin babies. . . . She felt the only alternative was to try to put me into a Home for handicapped children.

It was so long since the operation, and the surgeon was no longer attached to Bart's; having been on active service overseas, and in any case he had given his prognosis at the time of the operation. Fortunately for me, a doctor who was a family friend, began teaching me to walk, using for the purpose, one of these contraptions used for much smaller children, whereby the child is supported by a circle of wood round the waist, which has spokes going down to a larger circle at the base, this being mounted on wheels. Thus the child is kept upright, but moving on the wheels, the legs instinctively "walk". This was when I was 4 years and 2 months.

Normal Life!

By the time I was 5 years old, I was able to go to a normal school, an apparently normal child, and though teachers were warned of my early history and some care taken to keep me safe from rougher children, I never remember being considered in any sense an "invalid" child. I had a large head, but not abnormally large, and my body was developing well by this time. My parents continued to "hold their breath" for a few more years, but gradually it became evident that I was going to live quite a normal life—a totally normal life, not a "near-normal" life! I went on to Grammar school and left at 17½ taking a Civil Service job.

Headaches

I was a strong swimmer, loved hiking and must have walked many miles every summer, also I loved dancing, tennis, and all the activities of a normal girl. If I had any disability at all, it was one I appeared to have inherited from my mother and we never connected it with Spina Bifida, but here we may have been mistaken. I did suffer intense headaches, increasingly over the years, and these have always been with me until four or five years ago—and now I rarely have one. Still, so many other people suffer from headaches and though I generally mentioned Spina Bifida to any medical man, it was never considered to be a consequence of this, and indeed I think, quite frankly, very few, if any believed I could have been a Spina Bifida baby. Of course, when they saw the operation scar over half of my back, they believed it, but still did not connect the two.

Sister Lynn, Registrar of Digby Stuart College, Roehampton, helps at the South London Association Fete.

My Calling

When I began to talk about becoming a nun I met with a good deal of opposition from the family, since I would be giving up a good job and might not succeed in religious life and so on. My father was most upset, and he told the nuns about my early history, saying that anything might happen and that it would be very unwise of the convent to accept me. I was therefore refused by the nuns, but as I felt sure this was my calling in life, I went myself to the surgeon who had operated on me 22 years before, and asked him if he thought I could live the religious life. First he simply could not believe I had ever had Spina Bifida—then he did not believe I could be the baby he had operated on all those years ago. He said he had never done another one, and talking to him then, brought it all back to him and he could remember every detail.

He kept congratulating me (!) and he then assured me that he could give no explanation as to why I should still be living and walking and in every way absolutely normal. His words to me, in answer to my question as to whether I should be able to live the religious life, were: "Don't ask me—I don't know how you have lived so far, but I expect that since you *have* lived so far, there is nothing to stop you going on living".

And so I *have* gone on—I am nearly 56, and have been a nun nearly 34 years. I have had to work extremely hard, especially during the Second World War years when labour was short and life was hard in evacuation. But I have always been one of the fittest—always the one who could be asked to lift and carry—in fact some Sisters have teased me that my second name must have been Samson! None of the other nuns have ever heard about Spina Bifida though I was living in their midst all these years. But this is hardly surprising for I myself have only heard of it once, apart from my own case.

Readers will recall the article in Summer 1969 issue of Link *which featured a lady of 74 born suffering from Spina Bifida celebrating her Golden Wedding.—(Ed.)*

OUR NEW APPEALS SECRETARY

Brian W. Relf comes to us from the National Children's Home, where he has been carrying out similar duties for the past four years.

He was educated in North London at Southgate County School and then spent fifteen years in commerce in the City, with the exception of two years National Service with the Royal Air Force.

Mr. and Mrs. Relf, who live in Barnet with their two children, have been involved in voluntary Youth Work in the district for many years. Mr. Relf is a great believer in team work, and is looking forward to making new friends in the local ASBAHS at the earliest opportunity.

* * *

BOOK REVIEW

INCONTINENCE, some problems, suggestions and conclusions. *Disabled Living Foundation, Vincent House, Vincent Square, LONDON, S.W.1. Price 15s. 6d. (62 pages).*

This booklet about incontinence of Urine and Faeces is essentially for adults and is mainly concerned with incontinence of the elderly. In fact Spina Bifida is dismissed in a single sentence. In spite of these comments however, there is quite a lot of useful information in this little book which is illustrated clearly by some excellent line drawings. There is an extensive section, well illustrated, on clothing the incontinent and while most of the clothing described and illustrated applies to adults, parents of Spina Bifida children should be able to modify and produce their own suitable garments based on the clear sketches which are produced in the book. The use of Velcro fasteners is clearly shown and there is a definite place for this type of fastening for Spina Bifida children with their multiple handicaps.

The booklet contains a useful list of relevant references as well as the addresses of organisations who may be able to help Spina Bifida children and a list of suppliers of various items of useful and relevant equipment. The author is to be complimented on her direct approach and clear English and it is to be hoped that a separate volume on the problem of incontinence in the Spina Bifida child will be forthcoming.

H. ECKSTEIN, F.R.C.S.

SPREADING THE WORD

By MRS. R. PRINCE, Leeds & District Assoc.

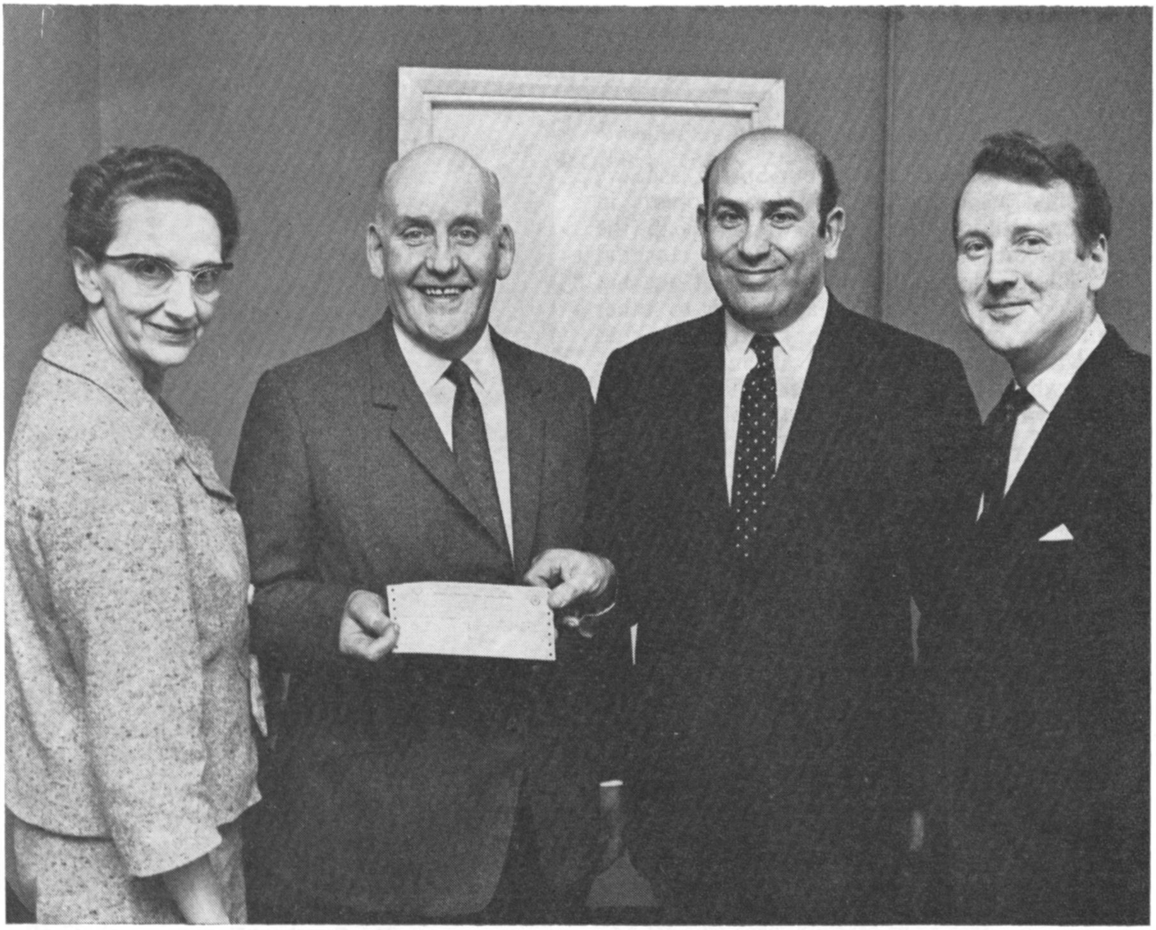
Said to be very important in the relationships between agencies responsible for social services, communication is worshipped in committees, lip service is paid to its importance and everyone complains that it is always breaking down, but how many of those who speak of it in hushed tones would think of asking themselves: "Who would benefit from an extra copy?" when they sit at their typewriter. If you send a "flimsy" to someone often enough they are duty bound to start sending you copies of items of importance or interest to you and their conscience will see that they do.

The necessity to commit to paper is best illustrated by the average committee meeting probably lasting for two hours with very few of those 120 minutes spent in silence; which gives a verbatim shorthand writer a conservative 10,000 words to record. Now—consult the minutes of your last meeting and underline all policy decisions, important and unimportant, taken at that meeting, if you are lucky and have a good committee you will now have no more than 100 words—a bad committee and you won't have been able to underline anything. In those ten lines of type is everything worth communicating.

In this Association *Link* exists to spread the word—but whose word? Each edition carries at least one major article by an expert while the real experts are the parents. A recent edition carried news from four local groups while on the back cover nearly ten times that number are listed. In that same edition were three and a half pages of readers' letters alongside one of Group news There's a moral there somewhere—because it is hard to believe that three months go by in any group without something newsworthy occurring unless that group is ready for the bone-yard.

What we do will be of some importance to those whose interests are similar and you can be sure that most of the readers of *Link* fall into this category.

We "associate" to achieve what we cannot achieve alone. We are alone if we don't know what the other fellow is doing. We cannot know this unless he troubles to tell us, so paraphrase the Post Office slogan and hang it above your typewriter—Someone, somewhere, needs a "flimsy" from you.



Mr. Michael Reynolds, Joint Managing Director of Spar/Vivo presents a cheque for £1,500 to our Appeals Sub-Committee Chairman Mr. W. J. White. Also in the picture are Miss M. E. Oughtred and our new Appeals Secretary Mr. B. W. Relf.

Mr. Reynolds won first prize of £2,000 in the recent Oxo Crazy Chase in which competitors had to navigate vintage cars along a tortuous country route from Croydon to Brighton and the organisers—Brooke Bond Oxo Ltd.—stipulated that all prize money should go to charities chosen by the winners.

We are most grateful to Mr. Reynolds for the major share of his prize and we wish him every success in any future competitions.

Been up in the loft lately?

Provided sufficient support is obtained, the next issue of *Link* will include a section devoted to advertising unwanted or outgrown appliances, special clothing, etc. In addition advertisements of other unwanted articles will be accepted.

Furniture, cameras, books, cars, "white elephants", unwanted presents, toys, etc. may be advertised on a sale or exchange basis.

No charge will be made for the inclusion of any article connected with Spina Bifida but for other items a charge of Two Shillings a line (seven words usually) will be made.

Advertisers should give their names and addresses or where a Box No. is required some indication of the area—the town or county will do—should be given. This will avoid unnecessary travel to view or heavy postage or freight charges. See what you've got and let's have a go.—*Editor*

ANNUAL GENERAL MEETING

The Fourth Annual General Meeting of the Association for Spina Bifida and Hydrocephalus Ltd. was held on June 6th at Granville College of Further Education, Granville Road, Sheffield.

The Annual Report has been sent to all Secretaries of Local Associations. Copies can be sent to members upon request.

NEW TUBULAR WALKING FRAME

Readers will recall that in our Spring issue we published a photograph of Mark Roberts in his new walking frame. This was made by the Orthopaedic Appliance Dept., Royal Hospital for Sick Children, Glasgow, who point out that they are unable to supply appliances to other than their own patients. They have been kind enough however, to supply assembly instructions, which could be followed by a technician or handyman.

Materials required

This Tubular Walking Frame is constructed from 16 gauge seamless steel tubing ¾″ O.D.

The lower half is basically two "U" shaped sections mounted one above the other 6″ apart. The bottom bar is 20″ wide by 28″ overall length, two Flexello O.P.E. 13 castors are fitted with draw bolts on the outer aspect of the supporting legs and can be locked into suitable diameter tubing on the underside of bottom frame. (This allows the wheels to be held in a forward facing position until the child is able to control any side movement.) The castors are mounted in tubes containing S⅝″ tube sockets and positioned approximately 2″ from the front bar.

An adjustable kickplate of 4″ wide by 14 gauge Duraluminium is bolted to a cross bar and slid along the length of the bottom frame on two 1¼″ lengths of ¾″ I.D. tubing, prior to bends being made which join tubing to 1″ × ⅛″ High Carbon steel skids.

The second "U" shaped tube is made with overall sizes of 15″ wide and 17″ long. Four ¾″ I.D. × 1¼″ tubes drilled and tapped are fitted to the inner side of this section at 15″ centres along the frame and 12⅝″ centres across. These tubes carry the adjustable legs of upper framework.

Four collars are welded to the legs at a position which determines minimum hand height, less 1¼″.

The buttock support bar is 11¾″ long and joined to two sliding tubes on the top rail. The buttock support and the chest pad are both made from 14 gauge Duraluminium 4″ wide padded and covered. The chest pad is mounted on ⅝″ O.D. tubing and is adjustable by sliding into the front support of lower framework and is shaped in the same way, giving the whole assembly an "S" shape.

The Completed Frame

The hand rails are ½″ plywood, 1⅛″ wide × 13″ and mounted to top rail on ¾″ spacers. The front hand bar is formed to suit top rail centres and attached to frame with sliding-fit tubes the same as used throughout.

Mr. Forrest writes that this could be a very useful device, but the advice of a consultant or a physiotherapist should be obtained to avoid disappointment or even harm.

TAKE YOUR PICK

Holiday Bungalow

Situated at Humberstone Fitties, Nr. Cleethorpes, Lincs.

Approx. 150 yds. from the shops and 400 yds. from the beach.

The Bungalow has 3 Bedrooms to accommodate 6/8 persons. A Lounge, Sun Lounge, Kitchen and a roomy Bathroom/Toilet fitted with hot and cold mains water facilities.

Weekly rental is £5 per week plus gas by meter.

This Bungalow is being fully adapted to the requirements of a child with walking aids or wheelchair. At the rear is a spacious lawn. Everything is provided except bed linen, table cloths and towels' etc.

We are giving priority to our own Members but are prepared to accept bookings from any member of other Associations.

Vacant dates are as follows:

September 5th, 12th, 19th, 26th.
October 3rd.

A week's tenancy is Saturday 2 p.m. to Saturday 12 noon.

All bookings to J. Wright, 17 Pilgrim Ave., Immingham, Nr. Grimsby, Lincs.

Pen Pals

Stephen Unitt of 15 Castle St., Darlaston, S. Staffs, is anxious to get in touch with a Spina Bifida child at home or overseas. Stephen is eleven years of age.

Mrs. Paul Rauch of 929 Southcourtland Park Ridge, Illinios 60068, is in touch with children of 10 upwards who would like pen pals.

Michael Jones

Michael Jones aged 18½, spina bifida sufferer, joined the Remploy factory at Kidbrooke in March of this year.

He is an excellent worker and, although confined to a wheelchair is both willing and competent to take on any job possible from a chair. He is in the section of the factory engaged in the manufacture of combs, has carried out a number of jobs and is at present on inspection of the finished products.

A mother read this poem and found it helpful, and asks us to publish it.

VERY SPECIAL CHILD

A talk was held quite far from earth
"It's time again for another birth".
Said the angels to the Lord above,
"This special child will need much love

"Her progress may seem very slow,
Accomplishments she may not show.
And she will need much extra care,
From all the folks she meets down there.

"She may not run or laugh or play.
Her thoughts may seem quite far away.
In many ways she won't adapt
And she will be known as 'handicapped'.

"So let's be careful where she's sent,
We want her life to be content.
Please, Lord, find parents who,
Will do this special job for you.

"They will not gather right away,
The leading role they're asked to play,
But with this child sent from above,
Comes stronger faith and richer love.

"And soon they'll know the privilege given,
In caring for this gift from Heaven.
Their special child so meek and mild,
Is HEAVEN'S VERY SPECIAL CHILD."

SKEGNESS—1970

FIRST IMPRESSIONS from MISS M. E. OUGHTRED

Educational opportunity is one of the major concerns of the parents of children with either Spina Bifida or with hydrocephalus (or both) and it was therefore a most appropriate subject for a first major residential Association Conference. That a Region of ASBAH had the courage and foresight to plan this venture and to carry it through with such success is worthy of the very highest commendation.

A full Conference report is to be issued and will be available to anyone who cares to order but, as a little time must elapse before this report can be ready, some impressions from a "conferee" in this issue of '*Link*', while it is fresh in memory, seem appropriate.

One of the problems of parents of small children is to be able to do things together and it was therefore a stroke of genius to arrange for this Conference to be held over the Bank Holiday weekend, at a Holiday Camp so designed that physically handicapped people can integrate fully.

The Derbyshire Miners' Holiday Camp at Skegness was an admirable venue and the 300 Conference delegates and their families present were rewarded, for the effort involved in getting parties organised to come, by fine warm weather.

There were nurses and organisers for the children and plans made for them throughout and in addition a heated swimming pool and attractive playground. Meals were taken all together and the food was ample and efficiently served. There were other groups in the Camp at the same time but this proved no detriment to an excellent feeling of "belonging".

The Conference itself was opened, in the presence of the Chairman of the Skegness Council, by Mr. Alex Lyon, M.P. for York, whose presence underlines the support which both Houses of Parliament are giving at the present time to improving the charter for the disabled. Everyone was struck by Mr. Lyon's sincerity and appreciated his honouring his promise to attend, in spite of the forthcoming General Election.

It is not the intention to attempt a summary of the Conference in this article—speakers from schools, including Special Schools, both day and boarding, educationalists from local Education Authorities and Universities dealt in detail with assessment, placement and aptitude studies.

They helped us all to see how much care and thought is given to trying to find the best possible for each child, at each stage of his or her development and for the Spina Bifida child this means constant review, so that all concerned, including parents, need to be prepared for new plans and adjustments to meet changing circumstances.

Factors to be considered include not only intellectual capacity but health and treatment needs, special training in managing physical handicap and the climate to encourage that essential determination to triumph over difficulties, which leads to maximum independence in adult life.

Miss McBride, an H.M.I. who is particularly concerned with special education, both by her talk and her presence, demonstrated the concern of the Department of Education and Science to plan for the growing number of those with Spina Bifida who will need appropriate educational provision.

Among those who took the Chair at sessions were consultants and educationalists who involved themselves fully in the Conference and whose personal interest and caring was deeply appreciated by both members of the Association and their children.

As General Secretary of ASBAH, I was delighted to have the chance to meet so many members and their families, to increase my knowledge and understanding through the lectures and to join in the discussion groups. I am sure all who were present will be glad to associate themselves with this opportunity to pay tribute, through the pages of '*Link*', to the Officers and members of the North East and East Midland Regional Liaison Committee for such a useful and successful Conference.

NEWS FROM THE GROUPS

Readers will recall the Case History of Phillip Brown in our Spring issue. The happy wedding picture above shows Phillip (far left) in his role as page at his sister's wedding recently.

Don and Dearne

A pigeon show at Wombwell recently raised £40. A great deal of interest was aroused among local tradespeople who donated the prizes for this event.

After a talk about the association's work by the secretary the Perriwinkle Hotel, Wombwell, held a Ladies v Gents football match on Easter Monday and raised £50. They promised that this would be an annual event.

A Charity Concert at Mexborough raised £40 and proved to be an enjoyable evening.

The group is working very hard to provide money for research at Sheffield University into kidney and bladder disorders in Spina Bifida children. Several members have had coffee evenings, bring and buy, etc., for this.

Darlington and District

The above association have donated to Research £25, and £25 towards the purchase of a motor coach for The Sallis Lane School, Globe Road, Darlington.

This is the School the Spina Bifida children attend.

Bromley and District

In January we had our Annual children's party and again the children at Cheyne Hospital and the nursery unit at Coney Hill School were invited and attended. Everyone thoroughly enjoyed themselves, the entertainment was great and "Uncle Don" presided over the whole affair once again. We again owe a great debt of gratitude to the staff of Muirheads, Elmers End, who not only generously donated towards the cost of the party but also arranged it for us. Mr. Gough, a director of Muirheads, attended and "rolled his sleeves up" and also gave great assistance.

At our A.G.M., Mr. Powell our Chairman was voted in and again agreed to stay as Chairman for a further year. Mr. A. Thomas agreed to continue as our very able Treasurer but Mrs. Grayson had to resign after two years as Secretary.

We were, however, very fortunate to obtain the services of Miss A. M. Burgess to act as our Secretary, for which she is well qualified not only due to her office experience but because she is herself an adult Spina Bifida sufferer.

We were very fortunate in that Miss Oughtred, our General Secretary attended the A.G.M. and gave a very interesting talk, which we all enjoyed and for which we are most grateful.

All the Members present felt that we are doing a very useful job and have come a long way since Mr. Whitehead formed our branch two years ago. He is a very active member of the Committee, showing films and visiting our Members as well as arranging meetings, etc.

Liverpool and South West Lancashire

The Liverpool and S.W. Lancs. Association is approaching an exciting time for its members; for Tudor House, purchased last year, is to open its doors to the first children within the next few weeks. It is probable that by the time this copy goes to press the first of its services, namely Day Care, will be functioning.

It is hoped that with everyone's eventual co-operation the Centre will provide Day Care, Nursery Education, Physiotherapy, Hydrotherapy, Short Term Care and ultimately Work Centre facilities with room left over for solving any other problems that the future might produce.

As this is the first such effort by a Local Association we realise that many groups will be watching our progress and we are conscious of our responsibility.

Our sincere thanks go to the Spina Bifida Trust for a grant of £3,000 and an interest-free loan of £2,000 towards Tudor House.

With all this activity you will realise that more and still more money must be raised in and around

(*Continued on next page*)

NEWS FROM THE GROUPS - Continued

our city and we will welcome news of successful fund-raising gimmicks from other Associations.

Our Caravan at Prestatyn is available for some weeks during this summer. If anyone wishes to make bookings please write:— The Hon. Secretary, Association for Spina Bifida, 46 Manchester Street, Liverpool 1.

The weeks available at present are:—

Week comm. Saturday 4th July
Week comm. Saturday 11th July
Week comm. Saturday 8th Aug.
Week comm. Satruday 15th Aug.
Week comm. Satruday 22nd Aug.
Week comm. Saturday 29th Aug.

Bristol

Agreement has been reached with the Hospital Management for our Spina Bifida Unit to be built at Frenchay Hospital Bristol, and it is anticipated that work will start very shortly.

The Annual General Meeting was held on 5th April, 1970 and was well attended. It included the showing of the Spina Bifida film, a copy of which our group has purchased from the National Association. It is intended to use this film whenever possible to educate the general public on the problems that our children have to cope with.

Major money-raising project in the next few months will be a large raffle.

South London Association

This group is progressing well, but like all groups finds that it is the few that are active all the time.

We have been running a Bingo night for some months now in aid of the group and we enjoy doing it ourselves very much, but at times feel we could do with a break, but unfortunately have not the help to do it, there are plenty of ways of raising money, but unfortunately getting help to do it is harder, plenty of people want to join ASBAH but not many to join in the activities, if we are to make a success of ASBAH we have all got to put our best into it.

We feel that we should encourage our children to join in as many outside activities as possible, to join Youth Clubs, the Red Cross and St. John Cadets, Guides, Brownies, Scouts, Cubs, Boys Brigade, all these give added interest to the children, and also give them an interest in us, all of them are willing to help.

Leeds and District

At the Annual General Meeting in March Mr. Arthur Mitchell was again re-elected Secretary of the Group and his report was heartening. It showed that fund raising had been better than in the previous year and the increase in the number of donations from friends of the Association indicated that public relations were improving.

Financial assistance for hospital visiting had been introduced and also the provision of S.H.A.S.H.B.A.H. Trolleys. Membership was increasing largely due to co-operation between hospital staff and our recruiting officers so that parents were being informed of the Group's existence soon after the baby's birth. All were sorry to hear that Mr. and Mrs. Bob Tomlins were leaving the district. They have worked so very hard for the Group.

One of our members, five-year-old Mark Prince appeared with his Mother in a film about Spina Bifida made by the Calendar team of Yorkshire Television. The film featured Mossbrook School at Sheffield which Mark attends as a weekly boarder. Our last meeting took the form of a visit to the John Jamieson School for physically handicapped children in Leeds. Members were given a very warm welcome by members of the staff and were shown round the school.

Lincolnshire Association

The Spring Draw raised the sum of approximately £180.

A film show at Willoughby was attended by approximately 80 people. Apart from the films shown those who attended also heard a most interesting talk given by Sister Kennedy from Scartho Road Hospital, Grimsby. All of which culminated in a most interesting evening.

Our thanks go to Mr. and Mrs. Houlden and Mr. and Mrs. Everton for their kind assistance in making this show possible, which again proves that the kind co-operation of just a few members can make a most valid contribution to our cause.

On April 26th the Social section once again organised a most successful effort. This was a Charity Football match between the Honest Lawyers' Ladies and Ex-Grimsby Town players. Over 1,000 supporters attended, all of whom enjoyed the entertainment which at times was hilarious.

Over the past few months both Sister Kennedy and Mrs. B. Dunster (Committee member) have addressed many meetings of local organisations, and usually these talks are accompanied by the film "What is Spina Bifida"? Their efforts are proving most valuable in creating the required impact in this area. In addition, they have also taken on the task of visiting all known new cases.

Kent Association

The A.G.M. was held on 22nd April at Danecourt School, Gillingham. There are now 130 members, and the majority of the children are under 10—only 15 being over that age. A successful year regarding fund raising and local publicity was reported.

It was noted that the main income to the funds during the past year came from two big Charity Walks, organised in Kent. The annual Grand Dances do not seem to produce the expected profits, although everyone has a wonderful evening—as they did at the Grand Easter Dance held at the Royal Star Hotel in Maidstone on 28th March. About 400 people attended.

Some of the main attractions were a Tombola stall (yielding £45 profit) and a mock auction held by Simon Oates of B.B.C. 1's "Doomwatch" series, in which a donated Goblin Teasmade was auctioned for £35. As a final attraction the Lions Club of Maidstone held their Carnival Beauty Queen finals at the dance.

A monthly Newsletter has proved popular, and serves to help the members to feel a common bond, and keeps them up-to-date with the association's activities. Hints and problems can also be shared and circulated in this way. New members are listed, so that others who live in the same area can visit them and welcome them.

May we also take this opportunity of thanking you for the "Link" magazine, which provides us all with such useful and helpful information—and gives us this essential feeling that we are "not alone".

Hull and District

Flamborough Young Wives' Fayre raised £100, Elloughton and Brough young wives and Trinity young wives raised between them more than £20. A new clothes shop was opened during the Easter holidays and £330 was raised. From this money £150 will be given to provide books on Spina Bifida and Hydrocephalus for the new medical library at Hull Royal Infirmary.

OUR READERS WRITE

AMAZING AND AMUSING

● I should like to thank all readers who wrote to me after my letter was published in the Autumn issue of *Link*.

When Yvonne left hospital she started school in Penarth as a day pupil. She has matured so much during the past few weeks and the difference is both amazing and amusing. She takes a great deal of interest in her appearance, (pimples on her face are treated with a face pack). She wants to know when she can have a boy friend (she is nearly twelve) and at what age may she smoke!

She wears short dresses and worries if her panties show. I am so glad I am now able to write on a happier note. My thanks again to everyone.

MRS. THERESA PRICE,
15 Porlock Road,
Llanrymney, Cardiff.

In the Summer 1969 Link we published a picture of Victoria Becker on her first birthday. Here she is now on birthday number two.

ALISTAIR'S DAY OUT

● I am not a mother of a spina bifida child, but may I offer this contribution? My first contact with a boy with spina bifida occurred in 1954, when as a pre-nursing student, I worked in the convalescent home of an orthopaedic hospital.

This boy was 13 years of age, and had not benefited from the early surgery that most babies today have. Nursing him made a permanent impression on me, for he was, I felt, severely afflicted, and needed love and help.

At this time, a friend of my family had a baby girl with spina bifida, and the child did not receive the early help that is so important. Her parents tried very hard, but had little encouragement. However, this girl is now 16 years old, has just left a special school, and is bright and much loved.

These contacts, with many others made later, especially during Orthopaedic training, gave me a desire to help such children whenever I could.

As my fourth child reached 2 years of age, I was able to contact a family with a boy of three with spina bifida. This family welcomed the little help I wanted to give, and Alistair has come for the past eighteen months or so to spend a day a week with my family. Although he has no movement in his legs, the early operations that he has had have been successful. He is entirely different to the children I met in earlier years.

I hope we have been able to help Alistair; certainly he has helped my children, and in the way children often do, they accepted him and counted him as one of themselves, and helped in unobtrusive ways when necessary. He now comes to Sunday School, and greatly enjoyed the Christmas party.

May I offer some assurance to parents who may be confused and shocked at finding their child has spina bifida? I haven't got that personal experience, but I do know that "man looks upon the outward appearance, but the Lord looks on the heart".

Your child may have more hurdles to cross than a normal child, but I believe that if guided rightly this will only serve to make him richer in experience.

Alistair will soon be going to school, but I hope our friendship will be a lasting one, and that in time I can be permitted to help others in a similar way.

MRS. JENNIFER MUIR,
West Lothian, Scotland.

Notice to all Association Secretaries

Copy for each issue of Link should reach the Editor at 112 City Road, London, E.C.1, not later than one month prior to publication of each issue.

This is usually in the second week of the following months—September and December. This means, therefore, that all copy should be in by the second week of August and November.

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 manoeuvreable 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

MORE ON THE SHREWSBURY SPLINT

By MISS D. B. WOODS, M.C.S.P.

KATHERINE ELLIOT SCHOOL, MONKMOOR, SHREWSBURY

● As a member of A.S.B.A.H. and a Physiotherapist concerned with the treatment of Spina Bifida children in Shrewsbury, I was pleased to read Mrs. Menary Smith's letter, and to note that she is finding the "Shrewsbury" Splint a useful one in which her daughter is doing so well. We have a number of children using these Splints from an early age and all are leading an active and enjoyable life in them.

TRAINING ESSENTIAL

I was, however, dismayed to learn that some parents are disappointed in this Splint—apparently through lack of instruction as to their use or the method of training. It is, in my opinion, most essential that these children, with their parents, should be shown, by a Physiotherapist, the easiest ways of training in the use of this Splint. I thought, therefore, that parents might find the following points helpful if they have a child in this Splint.

CONFIDENCE

Firstly, it is most important for the child to feel completely confident in the standing position—let the child stand between bars or chairs—somewhere where they feel they can steady themselves if necessary. Then encourage them to take their hands off and perhaps give them a ball to throw or a bat to hit with, or place their hands in various positions, i.e. on top of their heads, etc. This can then be done "out in the open" away from supports and this should teach the child confidence in standing fairly quickly.

GETTING THE FEEL

For walking training, I often let them start to walk between bars or pushing a Rollator to let them get the feeling of how the footplates work. Fairly soon after this, by holding on to the back of the top strap or lightly on the top of the shoulders we encourage the children to swing their arms vigorously from side to side—I sometimes give them something light to hold in each hand—and from then on, I think each child develops their own type of movement, in the same way in which we all develop individuality in walking. On the whole we don't use the method of holding the child's hands in front, as the movement of pulling results in the wrong action of the shoulders and trunk. However, obviously with some children this has helped, and they have developed the correct movement.

MODIFICATION

I sympathise very much with the mothers who have been left on their own to cope with an entirely new type of Splint, as not only is the training important, but also very often a Splint needs modifying if difficulty in motivating or balancing it is experienced, particularly as the children grow taller, fatter, or if deformities increase—all these need attending to by someone with experience of Splints and the physical treatment of these children.

SELECTIVITY

I would also add that although nearly all our Spina Bifida children with paralysis below the waist use these Splints very satisfactorily it is still necessary to be selective in the choice of children for whom the Splint is prescribed.

I also understand that in some areas Splints are being manufactured where the only similarity to the "Shrewsbury" Splint is the footplate, and therefore they are not true "Shrewsbury" splints—these may present difficulties of which I have no knowledge.

MISS D. B. WOODS, M.C.S.P.,
Katherine Elliot School,
Monkmoor, Shrewsbury.

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