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LINK

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

Summer 1968 One Shilling

For two people at least . . . it was a glorious summer

Girl with the regal air is Angela Page, an 11-year-old spina bifida girl, of Bramley, Rotherham.

Angela put away her irons and surgical shoes and proudly wore her first pair of pretty white shoes when she was chosen as Girl Guide May Queen.

Two weeks later, on May 18, she was invited to the Festival of Queens by the Salvation Army at Wombwell, Barnsley, and proudly wore her coronet and gown again.

Angela has mild hydrocephalus as well as spina bifida. Her mother is a committee member of the Don and Dearne Association.

Angela's triumph did not end with being a queen, she joined other models on May 23 and modelled 10 dresses and a trouser suit in aid of the Association.

For Angela and her family May was a month which will always be remembered.

* * *

Paul Hodkinson was happy as a sandboy playing on the beach in the sunshine.

Two-year-old Paul has had five operations including a valve insertion at five months and a closure operation within a few hours of birth.

When this picture was taken his parents were waiting for him to go back in Queen Mary's Hospital, Carshalton, for a second hip operation—both his hips were dislocated.

Paul is very active and propels himself around at great speed on his bottom. To relieve pressure and prevent sores his mother has shaped a piece of foam rubber to go between his legs, over his hips, tying with tapes around his waist.

Paul lives at Smallfield, near Horley, Surrey, with his three teenage sisters and his parents.

LINK

SUMMER Vol. 1 No. 8

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Editorial:

Overcoming the ups and downs

It is with disappointment that I take over as editor of *Link*—disappointment because illness has prevented me from bringing out an earlier edition than this.

Link has done a wonderful job so far, thanks to the determination of Stephen Hinchliffe in getting it off the ground in the first place.

Whenever I talk to anybody about spina bifida the theme of my conversation never veers far from the need for money and more money. The fact that this magazine is late is just another indication of our need for funds, because *Link* is an essential part of the work which our organisation must do and it should appear far more regularly than it has done so far.

This will only be possible with a full-time, paid editor.

I, like Stephen Hinchliffe and all of our members, do this work in my spare time. My ambition is to see *Link* become a monthly magazine, with more pages, with advertisements so that it can finance other essential publications.

We "experienced" parents must remember those awful, harrowing first days of uncertainty and determine to lessen what seems to be a tremendous blow to new parents.

A monthly *Link* would go some way towards this. So would booklets which anticipate all the thoughts, worries and fears which present themselves to a parent who knows, without yet understanding, that the new baby has spina bifida.

But contributions from parents of children with spina bifida and hydrocephalus cannot be consistent. We all have our ups and downs, our spells in hospital when voluntary work must take second place to giving constant support to a sick child.

Unfortunately these ups and downs reflect on *Link* more than any other product of A.S.B.A.H.

It is essential that money is found to ensure constancy in everything which A.S.B.A.H. sets out to do.

It is equally essential that the parents do not relax completely and leave all the work to the professionals or else the real meaning which brought A.S.B.A.H. into being will be lost.

Solving that Big Problem of the Nappy

Nappies are a problem with which all mothers have to contend. But for mothers of incontinent children the phase may seem never-ending.

A new type of disposable nappy is now on the market and it is particularly suitable for use on spina bifida children.

The Sof'down is now being used in several hospitals and paediatric units around the country. Among them are Sheffield Children's Hospital, Alder Hey, Great Ormond Street, Bristol Royal Infirmary and Tunbridge Wells Hospital.

The main advantages of the Sof'down are cheapness and convenience.

The Midwifery Superintendent at Selly Oak Hospital, D. Megan Meade, has found the tie pant which is used with the Sof'down "unbelievably simple, inexpensive, and an effective way of keeping the nappy firmly in place."

Pins are not needed with the bikini-style tie-pant which is just tied in a bow for security.

The nappies are disposable and the tie pant can be rinsed, sterilised in Milton and used for at least a week.

Less replacement

The bikini image helps to eliminate the "baby nappy" image for older children and the tie pant will fit children up to five years old.

Selly Oak Hospital found that the cost compared favourably with the cost of textile nappies, laundering, losses and replacements. It also solved the problem of maintaining supplies from the laundry at week-ends and Bank Holidays and reduced the laundering of cot sheets and gowns when used properly.

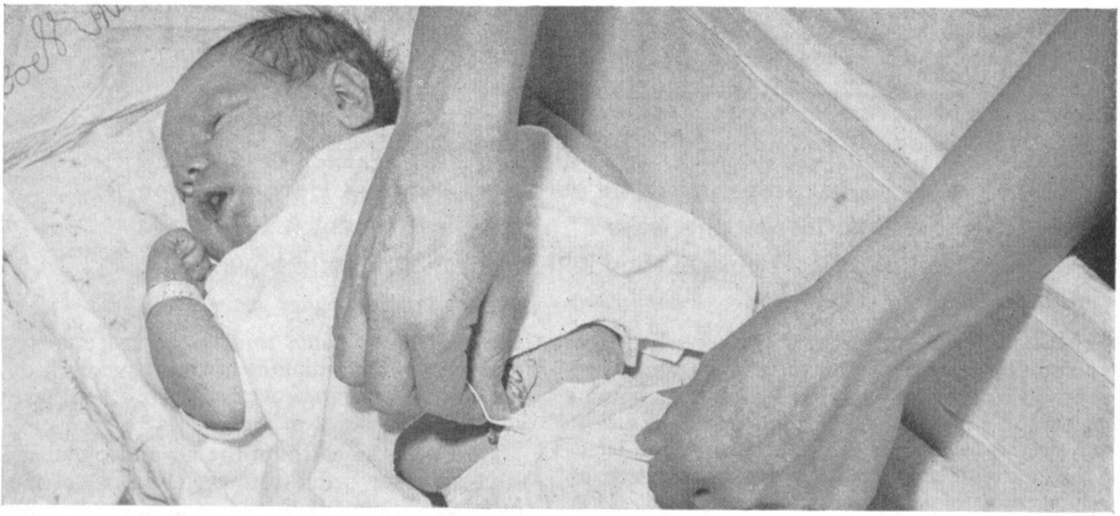
A spokesman for Lewis Woolf Griptight, who make the nappy, said: "We understand that frequency of replacement of plaster casings due to wear and tear is much less with the Sof'down method than with other methods. So trips to the theatre are reduced."

The firm are offering special reductions to A.S.B.A.H. members. The Sof'down is available in two sizes, Standard for older babies, Small for the new born.

For 10 packets of 20 nappies and eight tie pants (estimated as one month's supply) they will charge our members 36s. 9d. post free compared with the normal retail price of 47s. 4d.

Arrange nappy around baby's form, leaving ends free.

A larger pad is to be developed for adults and older children. Anybody who wants details of this development, or supplies of existing sizes, should write to Mr. R. S. Hurst, Lewis Woolf Griptight Ltd., 144 Oakfield Road, Selly Oak, Birmingham 20.



Holding ends firmly, tie in a bow (above). For older children (below), tie at the sides—ideal for "frog" plasters.

Let's play ball

Are you "on the ball" in helping your child to develop hand and eye co-ordination while he enjoys himself? Here are some novel and interesting ways of playing ball in which the whole family can participate, they will strengthen muscle power too.

Most children, on reaching the age when they can run about and play on their own (somewhere from 18 months to 3 years old) develop a natural ball sense. They learn to handle a ball, to pick it up, drop it to make it bounce, throw it, and later, probably with some help from older children or adults, to catch it.

This natural phase of development besides giving much pleasure, helps in the co-ordination of hand and eye, gives good exercise to the arms, and promotes general mental alertness.

Because many young children with hydrocephalus and spina bifida are confined to a wheelchair most of the time, it doesn't mean that they shouldn't get their fair share of *active* play—it may be with a tray of sand and a small spade, or perhaps a bowl of water with various objects in it to float, or fill and empty, or more active still the ball games we have already mentioned.

This form of play has to be a little more organised than it would normally be, because it needs to be introduced to the child rather than the child discovering it as he goes along—but once introduced the progression should be spontaneous and natural.

A few ideas

Here are a few ideas on games and how to present them—first for sheer enjoyment, but also to help normal development, and as one more way of preparing a child to live the fullest life possible later on—nowadays there are many sporting activities open to children and adults in wheelchairs or wearing calipers.

Choose a large, brightly coloured frido ball to begin with—not too hard, but not so soft that it will not bounce. Teach basic throwing and catching first. Throwing should be with the ball held in both hands close to the chest and thrown straight out from that level by stretching out the arms as the ball is thrust away.

If catching is found difficult, see that the child holds the hands in the right position and watches the *ball* rather than you. Make a joke of a dropped ball, but at the same time encourage a correct movement, a few minutes of this game each day will soon show improvement and then many variations can be added.

Throwing the ball into the air and catching it so many times before throwing to a companion, throwing with the ball held in both hands raised above the head, or in alternate hands, and later, bouncing and catching over the side of the chair is a very exciting thing to achieve for the first time. Please try and persuade the child to do this equally on both sides of the chair. It is not so good for the back muscles to lean to one side all the time.

Easy to make

After these first skills with a ball have been mastered, there is no end to the fun to be had from games played not only sitting in a chair, but on a mat on the floor.

The mat must be small so that balls can be bounced on a hard surface round about. Smaller balls can be introduced. These can be thrown against a wall, or a board on which a target has been drawn, into a bucket or waste paper basket. There is nothing like a good game of skittles, which, made in plastic, are cheap and colourful and light.

As a change from balls a few bean bags are always very popular and easy to throw and catch. They are easy to make, too, a few little bags in brightly coloured calico or heavy cotton, about six inches by four inches, filled about two-thirds full with flat dried beans and stitched up. These make a most satisfactory rattling noise when thrown at any sort of target.

If for any reason the child is not comfortable sitting up out of the chair for any length of time, it is sometimes better to have a change of position by lying on the tummy and playing for part of the time.

In this position the child can hold the ball with both hands against the chest and roll it along the floor by thrusting the arms away, or the ball can be batted backwards and forwards first by one hand then by the other. Skittles too can be played in this position.

These games, and many others which can be invented between you, can be played with other children, or with adults, but it is important for a child to be encouraged to play alone for some of the time—he must have the chance to develop his own creative games and enjoy the pleasure of being able to do something himself. But try not to be too far away when all the balls may have been thrown out of range! Nothing is more frustrating to a small child than a ball, in sight, but out of reach under the table or chair.

Just one caution, too. Some children with spina bifida have a tendency to get fractures of the legs more easily than other children, so see that all the furniture is moved out of range in case the child reaches suddenly for a ball and the legs are swung against something hard.

Many parents will no doubt already have played similar games with their children, but for those who haven't thought of it, or perhaps haven't realised that their children are capable of such activity, let this be the start of many happy hours of play.

PARENTS WHO WERE IN LUCK

Following our "case histories" in the previous issues, we find that people are anxious to share their own experience of giving birth to a spina bifida child. Here is another story from a mother who wishes to remain anonymous.

After reading the last issue of *Link*, I realize more than ever how lucky we were to get our youngest daughter treated so quickly when she was born.

When I had my fourth child, 4½ years ago, I had her at home. Our doctor, the senior partner of the practice, was off duty and by chance the young partner popped in to see what was going on. This was a few minutes before our daughter was born so he stayed on.

How lucky we were.

After my daughter was born and he had finished with me, he left the midwife to see to Claire while he went out to phone the local consultant at his clinic.

While he was out, the senior doctor came in, had a look at Claire and said that he would leave her for a few days to see how she progressed. Thank goodness this was too late.

The young doctor had just caught the consultant who was then on his way.

When he arrived at the house, my daughter was taken into another room and after a while the consultant explained about her affliction and told us what could be done to help her. It was left to us as to whether she would have anything done or not.

Of course, there was no question about it Transport was arranged and Claire was taken to Sydenham Children's Hospital about 3½ hours after her birth.

Everything happened quickly and everyone acted normally. Nothing like "she will die" was said.

We had three children before Claire. I had two miscarriages after our third child, which was disappointing as we wanted a large family. We didn't think we would be able to have any more children. Then I found I was having another. All was well until suddenly I completely changed.

I didn't want the new baby and was convinced that there would be something wrong with it. I drove my poor long-suffering husband "mad" for months, saying that there would be something wrong, that I wasn't going to keep the baby if I succeeded in having it, and that I wasn't going to saddle myself with a handicapped child.

There was no reason medically for feeling like this, and as far as I knew everything was going as it should. The midwife, herself the mother of five young children, was wonderful. She pointed out that we had had three normal children and there was no reason why this one should be any different. But it didn't make any difference to me.

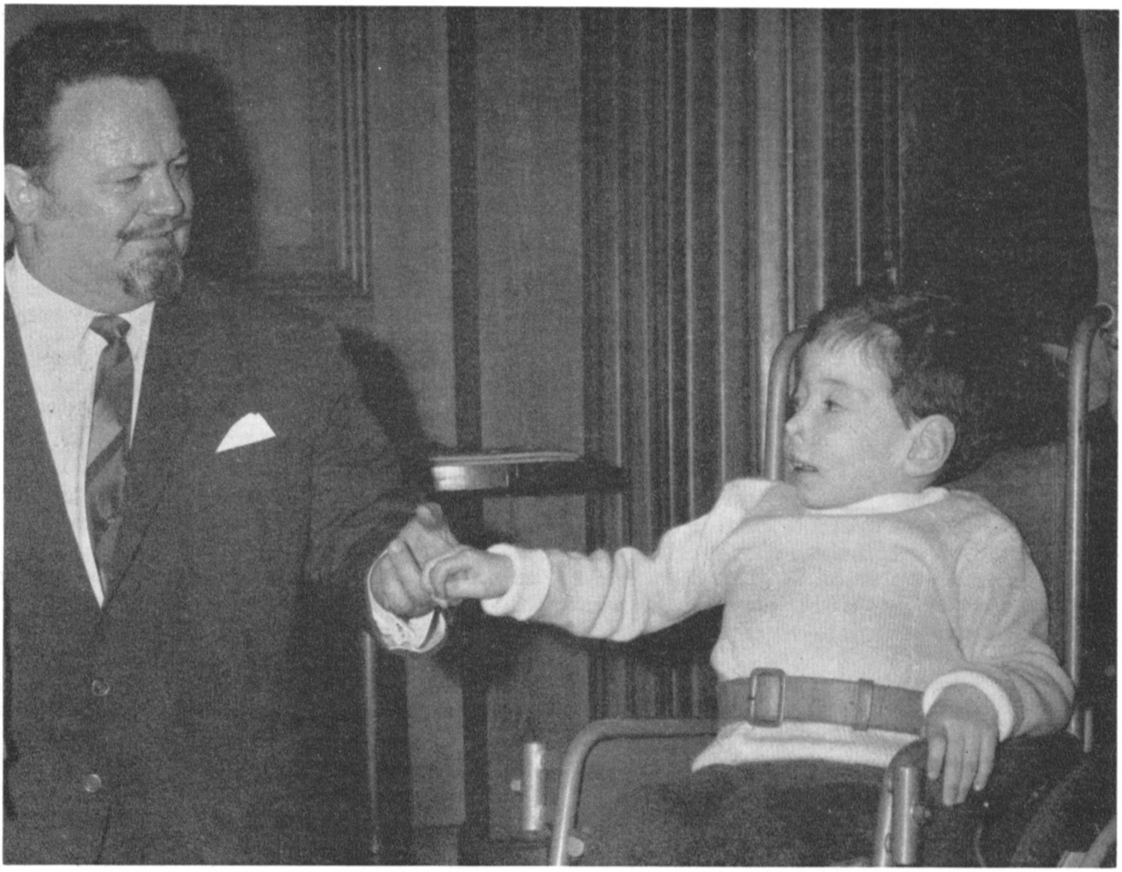
But when Claire was born, and I found out what was wrong with her I changed again. She was mine —and that was that.

She is a gorgeous little girl, and we wouldn't be without her. When I look back I still can't understand why I should have felt so strongly about there being something wrong, but I have since met two other mothers who felt the same way.

I just hope they didn't get themselves into the state I did.

Our cover

The children played their part in launching A.S.B.A.H. Our cover picture shows Ian Pointer sitting next to Kim Steadman. Behind them are Gillian Williams, Harry Secombe, Zem Rodaway. Hiding behind a teddy is Faith Seward, leader of the adult group, with Andrew Hinchliffe in his wheel-chair.



A.S.B.A.H'S. BIG MOMENT

These pictures were taken at our Press Conference in March—our big event of the year and the culmination of months of hard work by our officials.

Comedian Harry Secombe kindly agreed to join us in explaining our concern about spina bifida at the launch. And he displayed unending patience in posing for these pictures with the children who attended.

Speakers at the conference were Mr. Robert Zachary, our chairman, who explained the surgical and medical problems of spina bifida children; Mr. Allan Field of Coney Hill who spoke about education; and Mrs. Mavis Cotsford who presented the parents' point of view.

Parts of the speeches were later broadcast on Woman's Hour.

Our pictures show:

Top left: Harry Secombe chats to Andrew Hinchliffe.

Bottom left: General view of the Press Conference.

Right: Gillian Williams with Mr. Secombe. She stood by his side during most of the photographic session which preceded the conference.

LOOKING BACK ON SPINA BIFIDA

A mature spina bifida patient discusses life without the advantages of today's scientific and medical advances . . . and wonders what his lot might have been had he been born today instead.

By S. J. Teideman

This year, I am celebrating my 60th birthday. This is an event that would have surprised the doctor, who looked at the meningococyle the size of a golf ball pushed out from the dorsal region of my vertebral column, and told my mother: "There is just a chance for your baby if he is rushed to hospital straight away. But don't be too disappointed if you don't see him back'"

Sixteen hours later, I was undergoing a spina bifida operation at the nearest hospital.

When it was known that I had survived the operation—I was brought home that same day—the pundits declared that I would never be able to walk.

But, thanks to encouragement from relatives and friends and, I feel sure, the fact that I had a perfectly formed brother 18 months younger, I began walking when I was three years old.

Grossly deformed

A year later, I was able to get about quite well on my two misshapen legs, progressing with the outer edge of my foot pressing on the ground after the manner of an ape. My left leg was far more grossly deformed than my right one, and my mother took me to our family doctor to see if anything could be done to straighten my legs.

The doctor could only suggest an operation to break the bones and reset them, a cure that sounded rather too drastic to my mother and father, who declined and no doubt took into consideration the assurance of the doctor that I would not notice my disability in walking very much as I grew older.

Calipers were not suggested for me and I have never worn these appliances.

I and my brother started school together. My school days were far from being unhappy but it was rather galling to see my brother making greater progress than I was.

He was good at outdoor sports, and later at a London secondary school, became captain of the school soccer 1st XI.

He was also captain of the college soccer XI during his training as a cadet at the R.A.F. College at Cranwell.

I failed my examinations and finished my schooling at a private school, where my school reports often referred to me as a "plodder". I enjoyed English literature, history and geography and hated mathematics. I also studied natural history as what might be termed a spare time job and also took this subject as an extra in my final school examination, without having had any proper tuition in it.

I obtained what was termed a "weak pass" in natural history and passed in all other subjects I took except the three mathematics subjects then commonly taught—arithmetic, algebra and geometry.

So, according to the rules, I failed my Cambridge Senior Examination and so was unable to matriculate as my brother did later.

I left school at 18 with a burning desire to become a writer. I wanted to become a journalist but my parents dissuaded me from this idea by telling me that I would not be able to rush about which I would have to do as a reporter. I tried to get an opening in several offices without success. I am certain I would have secured a post with a large insurance company if they had not insisted on a medical check. Directly they knew I had had an operation for spina bifida I was turned down although they were satisfied with me otherwise.

Active part

Eventually, I became an office boy in the family business of which my grandfather was one of the founders. I spent my time there dreaming and writing poetry rather than in attention to my work. I felt that I was only there on sufference.

But I became less shy during this office-boy period, due to mixing with people at dances, in which I could take an active part and, above all, to taking part in amateur dramatics.

I was sacked from my job in 1929 when staff had to be cut because of a disastrous fire. I was in and out of jobs—mostly out—until, during 1931, I was put in charge of a small village shop in Kent, where all I achieved was the status of the "star" of the local fifth-rate amateur dramatic society. I was less than a year at this shop.

In September, 1932, I began trading as the owner of a new shop at a Sussex seaside resort, selling hardware. I lived over the shop with my parents until 1938, when they moved to another part of the town (my brother had been killed in an air crash during my stay in Kent).

I married in 1940, and my wife and I did our bit during the war in the A.R.P. service as voluntary workers. I was rejected for military service because of "severe double pes cavus".

After consulting a doctor about the possibility of having a family, my wife gave birth to a son in 1946, and a daughter in 1949, both of them perfectly formed.

Rare condition

I gave up my business in March, 1951, and now, with my son and daughter away at university and training college respectively, my wife and I live precariously on National Assistance and the little I earn as a freelance journalist.

I have tried in vain to find out some details about the operation I had on the day I was born. I have contacted the hospital but they cannot trace any records going as far back as 1908. The surgeon who operated on me died as long ago as 1922.

I was brought up to believe that spina bifida was an extremely rare condition and one doctor went so far as to tell me that it is so rare that it is unlikely to occur twice in the same family! Of course I know differently now.

I was amazed to learn only a few years ago the truth and the spectacular advances made in recent years in spinal surgery and care of spina bifida children. I wonder how I would have fared had such facilities as are now available been possible in pre-1914 days!

Search for knowledge

Dr. John Lorber is carrying out a survey into adult spina bifida patients who become parents. "Not enough is known about the risk which a spina bifida adult runs in having children," he told *Link*. "We want to increase our knowledge."

It would help Dr. Lorber, and our growing children, if spina bifida parents would send details of their children to him. Also details of the location and extent of their own spina bifida. His address: Children's Hospital, Sheffield.

Education Survey

Mr. Ivor Jones, new chairman of our Education Sub-committee, is carrying out a project to discover the educational opportunities available for spina bifida children.

Only if ALL parents fill in his questionnaire can the study be meaningful. Please co-operate. Even if you are happy with your child's treatment you might help another child to improve his educational opportunities by giving details of your own. Return the completed form to him at 73 Berkeley Road, Shirway, Solihull.

Please tick the appropriate box, delete that which does not apply and answer the remaining questions.

Boy ☐ Girl ☐

Birth place (town) ....

Present home address ....

....

Is he/she at: Home
Residential school

Child's age:
Under 12 months ☐
1—2 ☐
3—4 ☐
5—6 ☐
7—8 ☐
9—10 ☐
11—12 ☐
13—14 ☐
Over 15 ☐

Does he/she attend:
Pre-school play group ☐
Nursery ☐
Infants school ☐
Junior school ☐
Secondary school ☐
Special school ☐
Hospital ☐

Does child have home teaching? Yes/No

How many hours weekly? ....

Does child have hospital teaching? Yes/No

Please give details if you pay in whole or part for your child's education

....

....

....

Do you feel that your child is receiving the best possible education for his mental and physical abilities? Yes/No

Comments and experiences will be welcome on a separate piece of paper.

Take a tip — be a slut

Madam, are you a slut? Or a slave?

Think before you answer for a slut is no longer the social outcast she once was.

On the whole she gets much more fun out of life than her over-houseproud sister.

Katherine Whitehorn, of the *Observer* newspaper, admits to being a slut and so do many other women who lead busy lives.

Often they use the word "slut" rather carelessly for they are neither slovenly in appearance nor slummy by habit.

What they really mean is that they have got this housework business in its right perspective.

They skip unnecessary chores and are not over-zealous in performing essential ones.

Mothers with handicapped children to care for will find their lives much easier if they adopt a more carefree attitude towards their household chores.

It means turning a deaf ear sometimes when a friend who enjoys being a martyr to her family remarks on how much nicer a meal looks served on a table cloth.

Learn to smile

But you will find that hides, like arteries, harden with time. A slut learns to smile and sing under insults and difficulties.

What use is a table cloth, for instance? It may be decorative but it is also dangerous when small children pull themselves up by it. Gay table mats are just as attractive, are impervious to spills and clean with a wipe. You can even wipe them with Milton to be really hygienic.

Ironing is time consuming, so bear in mind "what the eye doesn't see". One mother of four religiously irons the whole family's underwear. She says it doesn't take more than a minute to iron a vest. But multiply this by six, add other items of underwear, allow for regular changes and she is wasting nearly an hour a week.

My undies are unashamedly wrinkled. So are my husband's and my child's. Who will see them unless we are involved in a road accident? And in that event I trust the hospital staff will be too busy saving our lives to notice our lowered laundry standards.

Bed-making too uses up a lot of energy—whoever designed this chore as a woman's work MUST have been a man.

A little forethought when buying bed linen can reduce your load. Fitted sheets need taking off only to be changed. They are now available in nylon which looks and feels like cotton and does not need ironing.

Resolve to buy these when your sheets next wear out.

And if your blankets are wearing out think twice before replacing them. Duvets are labour-saving. They are down-filled quilts which originated in Scandinavian countries. Only one is needed for each bed. They cost from £7 each single bed size, and apart from being warm they really are labour-saving.

When buying large electrical appliances think which you really need most. A fridge cuts shopping to the minimum whereas many home washing-machines are not as labour-saving as launderettes.

My twin-tub needs constant attention because the clothes need changing from tub to tub and rinsing. At the launderette, I can hand my bundle to the assistant while I do the shopping or sit peacefully while the automatic machine takes care of my load. I use this time to read to my child, if she's with me, or to myself if she's not. A girl friend has got manicuring in a launderette off to a fine art.

The £80 I spent on my washing machine would have been better spent on a fully automatic model or, even better, a fridge with a large deep-freeze.

Natural labour

Deep-freeze is increasing in popularity. There are now shops in London which hire them out and sell food in bulk at great savings.

In hard-water districts you can save the bath-cleaning back-break if every member of the family adds a softener like Calgon to the water.

Don't overlook your natural source of labour.

Our children need to feel useful and it does them no harm at all to polish shoes, dust the house, polish the brass.

Don't feel guilty. You are doing your child a double favour. He is learning to be helpful and you are remaining good-natured enough to play with him when you have finished your reduced number of chores.

And what can you do with all the time you are saving? Perhaps you might like to spend it on raising money for A.S.B.A.H.!

From our next issue, we plan to run "tips column" to help you solve your problems—or to help you raise funds for A.S.B.A.H.

News from the groups

Manchester and District

This branch donated a desk-unit computer to the Medical Genetics Department of Manchester University in May. The computer was handed over at an official presentation by Dr. Epstein, the branch's President.

Don and Dearne

This branch raised £174 at a ladies v. men football match in March. Mr. Arthur Holland was referee. In May, spina bifida children acted as models in a fashion parade to raise more funds for the Association.

Devon and Cornwall

A flag day held in Plymouth City Centre aided by local grammar school boys raised £53. A Grand National draw, with 6,000 tickets sold, realised a profit of £50. Mr. Pitts of Torrington sold 1,100 tickets himself.

Another £20 was raised at a jumble sale in April. The bowlers at the Wyvern Bowl, Plymouth, have adopted the branch as their charity and raised £48 for funds at a tournament, chicken shoot and challenge day.

The Plympton Round Table have chosen the branch for their 1968 project and were planning a summer fair in aid of spina bifida.

Sussex

This association have started collecting knitted woollens to raise funds. A small note to housewives has been printed asking for jumpers, twin sets, babies' woollies, woollen underwear, jersey wool dresses, pullovers and old white wool blankets.

"Condition is immaterial as long as they are reasonably clean," says the notice.

After collecting the woollens the Association sell them to Sendus-wools Ltd. of Dewsbury Road, Ossett, Yorkshire. Other branches might be interested in contacting this firm and starting similar schemes.

Finding a suitable site for the branch's caravan has proved a problem. Despite inquiries through many channels the van remains in the garden of its previous owner. It must be moved early in the autumn. But to where? Can any other branch help?

A lot of publicity and a little profit resulted in S.A.S.B.A.H., N.A.S.B.A.H. (Surrey) and the Southampton Association joining forces with a stand at the South of England Show. Many leaflets were distributed at the enterprise, early in June.

Whitby

Money raised at a "nearly new shop" at Baxtergate, Whitby, has been used to launch a welfare fund at national level. The shop sold hats, coats and dresses all at bargain prices, and raised £200.

Mrs. Christine Stephenson, a doctor's wife, was largely responsible for the effort and she and seven other women acted as shop assistants. They organised a baby sitting rota to care for their total of 20 children while they worked.

Members in need of welfare help are invited to apply to the welfare fund which is being run to respect privacy and prevent embarrassment.

Leicester

The Richard Fund benefited by £280 from events held in Leicester earlier this year. A rummage sale, annual tombola and dance and golf competition contributed to this figure.

Sheffield

Singer Frankie Vaughan raised £34 when he made an appeal for funds at Greasborough Social Club earlier this year. A charity football match, involving a Tommy Docherty All Star Eleven, arranged by Mr. and Mrs. Troop of Rotherham, raised £150 between the local branch and the Spastics Society.

A jumble sale raised over £60. And spina bifida boy John Antonsziewiez, 17, raised £40 with a sponsored cycle ride from Sheffield to Doncaster.

Huddersfield

Members helped to organise the 1968 Huddersfield Marathon Walk in which 2,514 walkers of all ages, mostly young people, started a 30-mile walk of the town boundaries. The course was completed by 1,800 and a half share of the proceeds was earmarked to provide a chalet at a northern holiday resort.

EDITOR'S NOTE: Owing to delay in publication we regret that there may be omissions in Branch News.

However, I hope that secretaries will continue to send information to me because this is an essential feature for passing on ideas and keeping members informed of local activities.

It would help our limited resources if secretaries, where possible, could type their reports in double spacing on one side of the paper only. Do not be deterred if this is not possible—and please let us have any photographs which might be suitable for inclusion.

Overseas news

Links with overseas associations are continuing to be forged by A.S.B.A.H.

Our medical advisors, in particular, are largely instrumental in building up this "entente spina bifida."

Dr. J. Lorber and Mr. W. J. Sharrard recently visited German universities in Dusseldorf, Bonn, Munster and Heidelberg. During their tour they presented lectures, saw patients, and acquainted the Germans with the work which is being carried out in Britain for patients with spina bifida and hydrocephalus.

Contact was made with the German Ministry of the Interior who deal with handicapped children as well as with a lay person who is the secretary of the local Hydrocephalus Association. As a result of the visit it is hoped that there will be increased activity in Germany in building up a national association for parents of spina bifida children.

The Independent Order of Foresters nominated Surrey branch as their charity for 1967. Earlier this year the Court Mountain Ash of the Order presented the Surrey group with over £300 worth of equipment.

Our picture shows Mrs. Irene Button, the Court's charity committee chairman, presenting the gift to Elaine Couper, six year old daughter of the group's chairman, at the Court Mountain Ash Charity Ball.

Included in the equipment were SHASBAH trollies, infant crawlers and wheelchairs.

School vacancies

The Lord Mayor Treloar Trust have announced a number of vacancies at their new boarding grammar school for handicapped girls at Alton, Hants.

Link readers may remember a recent feature on this excellent school which admits girls from the age of 11 up to a leaving age of about 20. Further information is available from A.S.B.A.H. headquarters.

Stamps, please

Those used stamps are worth money to the Richard Fund. Please send them to Mrs. J. Lorber who will convert them into cash to finance research in Hydrocephalus and related disabilities. Her address is: 305 Ecclesall Road South, Sheffield.

LETTERS FROM OUR READERS

I watched with great interest the T.V. programme on spina bifida. I thought you might be interested to know that exactly 50 years ago I gave birth to a baby girl with a severe dorsal spina bifida.

The ordinary doctors seemed to know nothing about it except to tell me she could not live long. I wrote to a number of London hospitals and received only one favourable reply—from the Royal Free. I was asked to take the child along to see the specialist.

She was six weeks old and was an in-patient for a week. I was told to take her home for three months when they would operate, but to return her to hospital at the first sign of the tumour weeping.

After three months I took her back. Sir James Berry operated and his wife was anaesthetist. The operation was successful and after two weeks I took her home. I was told she may never walk, never use her arms and might be an imbecile.

She grew into a lovely child. She walked and later could dance, swim and do anything any ordinary child could. She passed her examinations and became a teacher. She has two "perfect" daughters—aged 15 and 13. I thought other mothers might be given hope by hearing my story.—Mrs. H. P. Matthews, Hull.

Unforgettable

I had the great pleasure of taking my small son, who is now nearly six years old, as a representative of spina bifida and hydrocephalus children, to the opening of the new Congenial Anomalies Research Unit which is in the Thornbury Annexe of the Childrens Hospital at Sheffield.

It was an unforgettable experience to see Sir Isaac Wolfson and other Sheffield dignitaries tour the various rooms and hear of the research which is to be carried out there to help children handicapped as my son.

My proudest moment was when my little boy presented Sir Isaac Wolfson with a momento of the opening. Although my son has to have a wheelchair, he is now at a local school and progressing extremely well and my pride was that Mr. Zachary, Mr. Sharrard and Dr. Lorber with some of their colleagues were there to see him. I feel sure they were as proud of him as I, because due to their skill and kindness he was able to play a small part in the opening of the new Research Unit.

I would like to take this opportunity through our magazine, and I am sure all parents are with me, in thanking everyone at the Sheffield Children's Hospital, also Mrs. Lorber who works extremely hard for our children. Every success in their future research at the new Unit.—Proud Mother.

Book review

The Legend of Linda Martel, by Charles Graves (Icon Books Ltd., 35/-), tells the remarkable story of a child in Guernsey. Paralysed by spina bifida, she died aged five in 1961, having apparently cured a number of people of various ailments some, but not all, of a psychosomatic type such as acute headaches, backache, asthma, etc.

The story is told in part from tape recordings made by those who benefited from her help, and in part from the author's own enquiries of her family doctor, the paediatric surgeon, the local M.O.H. and others who knew her.

This is not the place to discuss "spiritual healing", but one expert in this field remarks how unusual it is to find so young a child with healing powers so well developed. What is made abundantly clear in this book, however, is the extent to which Linda felt herself consecrated to this work, and the effect she undoubtedly had on those around her. No life need be lived in vain, no matter how handicapped or how short that life may be. There is no doubt this latter-day Bernadette inspired and helped many hundreds of people, over a thousand of whom attended her funeral. Despite some repetition, this book makes absorbing reading.—F. G. Armour.

Help a student

Student Ivor Humphris has chosen spina bifida as the subject for a research paper on which he is working at present. He is particularly interested in the educational opportunities available for these children.

He would like to hear from any of our members about achievements and possible frustrations in obtaining appropriate schooling for their children.

"I would be delighted to hear from any children attending local or residential schools telling me of their experiences and progress," said Mr. Humphris. Teachers, too, are invited to write to him. His address: 19 Shelley Road, Oxford.

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