29

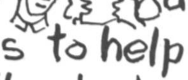
Link

Nov/Dec 1973 5p

Association for Spina Bifida and Hydrocephalus (ASBAH)

Best wishes for a happy Christmas

a fairy story with a happy ending

Once upon a time there was a little roo called Kanga. He hopped to the edge of the wood  where he saw a big house  He looked into the house and saw there were lots of nurses  with children, the nurses were saying that one of their biggest problems was incontinence Kanga  did not know what this meant so he asked and they told him that it made the children  very sore and caused the nurses lots of work. Kanga had some clever friends who worked in a Hospital laboratory  so he asked them to help. Next week he came back to the house  with some special pants  he had invented. When the nurses tried them on the children they were very pleased  because they were very comfortable and easy to change Kanga's friends  are now working on other problems to help children — but if you would like to know more about the pants that Kanga's friends invented please write to Kanga at...

LEWIS WOOLF GRIPTIGHT LTD.
Pershore, Worcs WR10 2HW.

Vol 1 **No. 29**

Association for Spina Bifida & Hydrocephalus (ASBAH)

National Office:
Devonshire Street House,
30 Devonshire Street,
London W1N 2EB
Tel: 01-486 6100 or
01-935 9060

Patron: HRH The Princess Richard of Gloucester.

ASBAH Chairman:
Mr. R. B. Zachary, FRCS
Hon. Treasurer:
Mr. E. S. Gower, FCIS, FHA

COVER STORY: Lynne Skinner, 9, full of the joys of Christmas.

The photograph was taken by Richard Draper at the children's Christmas party held by Barnet and Brent ASBAH group last year.

Correspondence to ASBAH:

General Secretary:
Miss M. E. Oughtred
Appeal Secretary:
Mrs. Kate White
Liaison Officer:
Mr. H. D. Macfarlane
Finance Officer:
Mr. F. G. Armour, FCA
Appliance Officer:
Miss F. A. Birkett
Link Editor:
Mrs. Susan Gearing

ASBAH'S 1974 Conference see page 7.

Editorial

Education is supposed to be a preparation for life. It is a costly business, particularly for handicapped children if they are attending special schools. Yet despite the years and money spent on getting them started off in life, thousands of handicapped school-leavers find that there is little for them beyond school—except perhaps frustration and boredom.

This situation is brought to light in the long-awaited four-year study by the National Children's Bureau, entitled "Handicapped School-Leavers". The study revolves around a carefully selected group of 788 handicapped school-leavers, and it aims to look at their experiences, and the facilities they found for further education, training and employment.

Most of the young people left school at the statutory age of 16, and 83% were considered by their head-teachers to be suitable for further education and/or training. In fact, only about one-third received it—mainly it appeared because of the lack of suitable provision.

The report revealed a disturbing picture of unemployment and low wages and of school-leavers wasting away at home when they were considered to be suitable for education or employment.

One of the report's recommendations is that there should be a well co-ordinated and flexible system whereby a school-leaver receives proper vocational assessment and guidance, and that he should be the statutory responsibility of a Further Education Department for two years after leaving school. A Further Education Officer would make good contact with the school, the leaver, and his family well before he leaves.

The report also says that along with the Further Education Officer there should be a specially identified social worker—perhaps attached to the school—liaising with the pupil, and with involved people such as careers officers, medical staff, rehabilitation officers, etc.

This report should be of special concern to ASBAH members as more and more spina bifida and hydrocephalic school-children are reaching 16.

More attention is now being focused on schooling—ASBAH's new film deals with education—and this is to be welcomed. At the same time, we must also devote much time and energy to improving life and work situations *after* school.

ASBAH is financing an assessment service for school-leavers in Sheffield as reported on page 14.

The National Association can often give advice. It is essential to know of the problems in order to know what services to press for.

Future issues of Link will deal with all aspects of further education, training and employment, starting with an article on Assessment Centres in the next issue.

News from the groups

A surprise package!

When Mr. Ralph Chawner, Secretary of the Warwickshire Association, received a package postmarked Chichester—he does not know anybody in Chichester—at the height of the letter bomb alerts he was, to say the least, concerned.

On the principle that it is better to be safe than sorry he contacted the local police. Later when the Sutton Coldfield police opened the parcel they found a £500 anonymous donation—one hundred fivers.

This donation brought a series of anonymous donations in the area up to the £2,500 mark.

In the swim

Kent: The Association has organised weekly swimming sessions for spina bifida children and children with other handicaps at the new public swimming baths in Maidstone's Mote Park. The sessions are held on Friday evenings between 6-7 p.m., and the children have exclusive use of the two learner pools. About 20 families are so far taking part in these sessions. They have been made possible thanks to the generosity of Mr. Pastry who has paid the cost of the first season. Kent Association has tried, so far, in vain to get financial assistance for future swimming seasons from the local authority.

The Association received £7 thanks to the efforts of Stevie, 13, and Stuart Wells, 11. They raised the money with their own garden fete. It was their second attempt. Last year they gave the money they raised to their friend, Kim Buckingham. Kim is now seven and has had five operations. But she is coping well and after the holidays began attending a Margate junior school.

Workers buy chairs

Chesterfield: Ladies working at Robinsons and Sons in Chesterfield have raised sufficient money to buy two chairmobiles for members of the Chesterfield Association. These were presented at a party and each spina bifida child received a gift.

Mr. Ralph Chawner and "fists full of fivers"

Photo: Birmingham Evening Mail.

Well done!

Bournemouth: "Ding-dong bell, pussy's in the well" was the title of the float which won the Bournemouth and Christchurch Association the prize for the best general tableaux in the Bournemouth carnival. And to make sure they were spotted by the local press the entrants had made their cat and well out of local papers.

It's worth asking

Sussex: Some useful advice from the Crawley group. A member was attempting to pull her son backwards, in a pushchair, up the stairs in a Marks and Spencer store when a member of staff offered the use of the lift. She was told to always ask for this facility. This service may be available in a lot of stores—it is worth asking.

Keeping their eyes open

Southampton: Children, aged between five and thirteen, had a special reason for keeping their eyes open. Organised by Beverley Wateridge they had been sponsored for the number of hours they could stay awake between 7 p.m. and 7 a.m. And they raised £51 for the Local Association.

News from the groups

A beach hut of your own

Two well-equipped beach huts in a good position at Cliftonville, Kent, will be for the exclusive use of families with spina bifida children—and what's more there is no charge! The huts will be available from Easter to October 1.

The huts were provided by the Magpie Appeal, and great care was taken to site them in a convenient spot.

The huts, which are adjacent, are at Hodges Gap, Cliftonville, at the beach end of the long promenade, just below a restaurant called "The Bungalow". Apart from being near the beach, they are also very close to a swimming and paddling pool. A useful shop, toilets, refreshment huts, and a St. John Ambulance Brigade hut are also nearby. There is a footpath slope down to the huts from the top, and families will also be allowed to drive down the road near to the huts to allow handicapped children to get out.

The huts are next to the Beach Superintendent's hut. He has the keys.

One hut is equipped with a small kitchen, with cooking facilities, cutlery, plates, etc. and will be stocked with tea, sugar and soft drinks. The other hut has an Elsan toilet and has a dividing curtain for changing. There are coat hooks, etc. Both huts are carpeted.

TV tapestry

Greenwich: The group said thank you to the Thames television programme "Magpie" for their Christmas appeal by presenting the programme with a specially made tapestry. Marie Murphy made the tapestry and together with Diana Filmer, Dave Randall and a group of children presented the gift during a programme late in August.

A measure of freedom

Scotland: Fourteen-year-old Margo Whiteford has been given a new battery-driven Braune power chair by the Eastern Branch. The chair is driven by 12-volt batteries and these give enough power to travel six miles. For Margo it means the freedom to go out alone for the very first time.

First step!

Barking: The Friends of ASBAH in Barking and District which started in February this year held its first Sponsored Walk in August—a 30-mile trek from Dagenham Civic Centre to Southend Pier. More than 20 walkers took part, and 15 of them managed the full 30 miles. At the time of going to press the result was expected to be about £200.

£10,000 boost for fund

◀ Nurses (left) keep a careful watch on a spina bifida baby at Morriston Hospital in South Wales. A major appeal is in progress at Morriston to build a special unit for spina bifida children.

It is an effort which received a tremendous boost in August when the Alcoa firm gave £10,000. It brought the total up to £23,000 and the target is £100,000.

Photo: South Wales Evening Post.

The Family Fund

Many readers of Link will know that last Autumn the Government, aware of the strain which a disabled child is on a family, voted the sum of £3 million to help such families. The Joseph Rowntree Trust was asked to administer the grant, and the name "The Family Fund" was chosen.

From April to August applications were limited to those with children aged between 10-15 inclusive. Now parents or foster parents with a severely congenitally handicapped child of any age up to 16 may apply.

The aim of the Fund is to relieve stress. There is no formal means test, though the economic and social circumstances are noted in deciding if an application qualifies for help.

The Fund is designed to complement the services of statutory (e.g. Social Services) and voluntary (e.g. ASBAH) bodies. It is administered with as much speed and flexibility as possible. Usually a social worker will call on the family to discuss their needs. Help may take the form of goods, services or a grant of money for a special purpose. A loan may also be made or the help of the Fund given whilst a family is waiting for some other payment or service to be arranged.

So far help has mainly taken the form of assistance with transport, holidays, clothing, equipment, house adaptations and unusual aids. Above all, however, the Fund want to know what families feel they need, and it is anxious to consider new and unusual ways of helping.

Those with severe spina bifida and/or hydrocephalus are likely to qualify for consideration on medical grounds. Obviously it is best to apply for help with some specific problem or area of need, particularly if outside the scope of normal Local Authority provision.

Applications should be sent to the Secretary of the Trust: Mr. Dennis Hitch, The Family Fund, Joseph Rowntree Memorial Trust, Beverley House, Shipton Road, York YO3 6RB.

The General Secretary of ASBAH will gladly advise or help, and can sometimes send a letter of support to the Fund.

Letters

In the last Link a correspondent raised the issue of access to public places criticising the organisers of the Ideal Home Exhibition for the restrictions they imposed and the way in which they were worded.

Now Kenneth Corney, Exhibition organiser, replies to the criticism:

"The actual wording on our publicity posters read: 'Dogs, prams and pushchairs of any description not admitted. Free pram park provided. Wheelchairs admitted on certain mornings but only by prior arrangement with the Organiser.'

"In short, dogs are linked with prams and pushchairs since all have to be precluded completely under GLC regulations. Wheelchairs are mentioned separately because they *can* be admitted at agreed times. I do not honestly see that this should offer any offence to people in wheelchairs; but if you do, please let me know how you would suggest re-wording it. But you might bear in mind that we also get the criticism, 'If you can admit wheelchairs, why not pushchairs?'

"We were the first major public exhibition in London to obtain the concession from the GLC to admit wheelchairs. But we, as Organisers, are still held responsible for the safety of all visitors. We have to decide when we think, from the pattern of attendance, the exhibition will be the least crowded. For undoubtedly, in the event of a fire or explosion a quick evacuation of the buildings is imperative. A wheelchair mixed up in a hurrying crowd making for the nearest exits could be a considerable hazard. We choose the least crowded mornings in consequence, but the GLC decide the number of chairs we may admit at any one time.

"I do think that we are doing what we can to help in all the circumstances. . . . "

Kenneth Corney

ASBAH Spring Conference

5-7 April 1974, The University, York

Following the support of the Conferences in 1972 (at Keele) and 1973 (at Reading), plans are in hand for a third Spring Conference to be held in York in 1974.

The theme of the Conference will be living accommodation, including:

- a Housing the family–adaptations, bungalows, sources of help.
- b Housing for the young adult.
- c Homes for children with no family support or needing short-term care.
- d Long stay care for the severely disabled.
- e Holidays–for the family, the child, the young adult.

Speakers will include members with experience to share, as well as those professionally involved.

A programme and further details will be available later in the year and will be sent to all Local Associations and to individuals on request.

New Film 'Growing Together'

(16 mm. Colour. 40 mins.)

Growing Together', a new film commissioned by ASBAH on the subject of education was shown at the Annual Meeting in September.

It was made by Kestrel Films, which some of you will remember is the company which made the feature film "Kes".

The film shows three spina bifida and hydrocephalic children–one attending an ordinary day school, the other a special day school, and the third girl attending the special unit of an ordinary school.

'Growing Together' should be of interest both to Local Associations and to colleges of education.

By the end of November copies should be in the Library, Concord Films Council, Nacton, Ipswich, Suffolk, and can be hired from there.

Copies may also be purchased. Full details will be circulated to Local Associations very shortly.

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

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

THE SHASBAH TROLLEY FOR HANDICAPPED CHILDREN

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

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

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

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

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

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

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

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

We live for today and we make the most of all our todays

Margaret Elton of Wellingborough writes:

My husband, David, and I were quite used to pain and suffering and the hardships it caused, by the time Rachel arrived. David had already spent most of the first few years of his life battling against illness, and he had also had a major lung operation. He was a registered disabled person.

We had decided to have a small family quickly so that I could get back to work if necessary. The two girls arrived within 16 months of each other and we decided to try again for a boy. We got our boy, a lovely healthy boy. He was a model baby and that was the happiest year I remember.

Then disaster struck. I was rushed into hospital and was there for several weeks. I was so weak when I came home that it was the following April before we were ready to be a family again. During that depressing six months my father-in-law had died, aged 57, and my eldest daughter had spent several weeks in hospital with bronchial pneumonia. But David's chest had not been as bad as usual, and except for a few weeks he had worked . . . the first winter for several years.

I was very depressed. My baby had grown up, and although he was a very handsome, blonde, suntanned, boy—I wanted a baby. We were very encouraged by David's improved health, and so I talked David into "four children taking up no more time, effort and money, than three". I was happy again. I was pregnant again. David had had another "not-too-bad" winter.

Rachel arrived on June 24th and our other children were three, four and five. Rachel was spina bifida. I just simply couldn't believe it . . . hadn't we had our share, I thought it was some sort of punishment for being so happy and having such a beautiful family, and yet wanting another.

To make matters worse we were so numb and in a constant daze that we hadn't thought of family planning and it was only a few months before I realised I was pregnant again.

That winter was long. David was ill, Rachel was in and out of hospital, we couldn't make ends meet and I couldn't work because I was pregnant. Just before Rebecca was due a friend of David's asked him if he would be interested in driving instruction. It seemed a God-sent opportunity, but how could we live on £12 a week. Our mortgage was nearly £8 a week.

Rebecca was born on September 5th and I started work on September 30th . . . for a few months, just to give driving instruction a fair try. It worked; David was well—the job suited him and funnily enough I found that my job kept me sane, and mother-in-law enjoyed having the babies.

After that first winter I gave up full-time work for part-time temporary work so I could be at home in the holidays. It fitted in amazingly, and when Rachel was in hospital I could afford to go and see her. I was always short of time and we were having to exercise her legs every day, and the housework, washing and ironing seemed endless.

Brighter outlook

When Rachel was 2½ she had an ileal loop and her feet were sorted out so now at last her feet were almost flat to the floor, which meant we could start to help her to walk and stand.

A few weeks later Rachel's health visitor got her into a pre-school playgroup for normal children. This was just in the mornings, so I worked during those hours and paid the playgroup fees out of my earnings. I felt I had a much brighter outlook than most mums with a problem child, because I was able to get away from it all for a few hours every day. At this time my mother-in-law still looked after Rebecca while I worked.

The playgroup was a marvellous idea. When Rachel first went there she was only crawling. Within a staggering six months she was walking with her calipers and crutches and in 12 months was climbing a 10-ft. climbing frame just to be "king of the castle" like the other children. And all this time, although her valve had been fine, we were still coping with continual urine and bladder infections even though her waterworks had been diverted.

In the meantime, when she was three, Rachel's little sister, Beccy, had started at the playgroup. David was happy with his driving instruction and I

Mrs. Margaret Elton and Rachel
Photo: Northamptonshire Newspapers Ltd.

had found a job with a local firm who would let me work whatever hours I liked.

We bought an old car for me soon after Beccy started at the playgroup. Now I was mobile. Everything was so much easier. Rachel's legs were improving so much that it was noticeable.

Rachel was assessed for educational purposes, and much to our relief we were told she was suitable for normal education. Thinking our problems were over, I very confidently rang the headmaster of our local school to put her name down. The headmaster was horrified. His classes were 40-plus and he didn't feel that he could cope. Not only that! When I wrote to the County about her future, they could see no problem. As far as they were concerned she was a normal child.

Most of the children from the playgroup went to a small school, with small classes, in the older part of the town, because they lived in that area. On the off-chance I went to see the headmistress. She already knew a lot about Rachel and was very keen to have her. She seemed the ideal person. Her ideas about the education of such children seemed so sensible to us. Once again we thought our problems were over. I wrote to the County to tell them that Rachel was now fixed up in another school. Their reply was a shocking blow. They wouldn't let her go because it was not the school for our zone and since for educational purposes she was now classed as normal no preferential treatment could be given. She would have to go to the local school. Unfortunately the headmaster at the local school had not changed his mind.

Doing well

For several months the letters went back and forth and by this time the hospital, the playgroup, the little school, and even local politicians were all involved in the battle with the county. Eventually, two weeks after the term had started, without Rachel, we received a letter saying that she could in fact go to the school of our choice. We were delighted.

She has now been at school for four terms and considering that she lost a lot of time earlier this year when she went into hospital to have her valve revised and her bladder removed, she is doing quite well. Beccy will be leaving the playgroup and starting "big school" in September when she is five. The older children are "very, very old" now, Louise has reached the great age of 11½, Claire is ten and Christopher is nine. I am still working and the older girls help a bit at home to keep things running smoothly. My husband, David, is now a fully qualified driving instructor and the five years since he changed his job have been fairly healthy years for him.

What of the future? Well I don't really think about the future, or even if there is one. I have learned to live for today. I feel that the damage already done to Rachel's kidneys offers no guarantee for the future anyway. We live for today and we make the most of all our todays.

Health matters

Skin sores: prevention better than cure

Due to lack of sensation and poor circulation people with spina bifida are highly prone to develop pressure sores. As always, prevention is better than cure, and most pressure sores can be prevented. At as early an age as possible spina bifida children should be made aware of this and taught to notice any red areas that could become pressure sores. With the use of full length mirrors and hand mirrors in the bathroom or bedroom they can learn to inspect their bodies daily, especially backs, buttocks and feet, and thus start treatment before a sore develops. This cannot be over-emphasised.

The children and their parents should also be made aware of the causes of pressure sores. Boots and shoes that become too tight can very soon cause sores on toes and heels, so footwear should be checked regularly to be the correct size. If toes are not straightened as far as possible inside the shoe, this too can within hours cause blisters which can break into sores. Rough seams and edges on shop-bought shoes can cause the same damage and therefore children should be encouraged to wear the surgical boots and shoes they have been especially measured for. Creases and ill-fitting socks have the same dangers.

Spina bifida children should be discouraged from carrying toys, pencils, etc. around in their wheelchairs. These, if sat on, will soon cause the skin to break and a pressure sore to develop. A bag on the back of their wheelchair can carry these articles. Special back and seat cushions in their wheelchairs can prevent sores developing on their backs and buttocks. This is especially so in a child with a marked kyphosis, who should have a cushion measured for them with a hole in the appropriate place. This relieves the kyphos of pressure from the back of the wheelchair. Rough edges and creases in chair seats, on clothes and bedclothes can also cause pressure sores. Sitting and lying in the same position will also do this and so regular changing of position is important. If able to walk at all this too should be encouraged as walking will increase circulation and relieve pressure from buttocks and back.

All areas that are most likely to receive pressure will benefit from regular massage with surgical spirit, thorough drying and talcing. This helps to increase the blood supply to the areas and helps to toughen the skin. The child should be taught to do this for himself.

Incontinence is another cause of sores if frequent changing and washing is not carried out. A child that sits in urine-soaked napkins for several hours will soon develop sore skin. Washing well with soap and water at each napkin change and daily baths are very necessary aids to prevention of sores.

If pressure sores do develop then the main treatment is to remove pressure from the area, e.g. if on back or buttocks the child should be laid prone or semi-prone; if on feet shoes should be removed and the child should not walk until the sores have healed. Early sores where the skin is only broken usually respond very well to the application of tincture of benzoin. Once they become more than this then medical attention is necessary. There are many forms of treatment for pressure sores and many methods may be tried before a successful treatment is found for the particular sore.

Where there is lack of sensation extremes of temperature to the skin should be completely avoided. The child will not know if, for instance, a hot water bottle is too hot. Burns occur much more easily than when sensation is present and therefore the child should not be allowed to be exposed to fires and intense sunlight. Bath water should always be checked by an adult before the child gets in the bath. The same applies to low temperatures—legs should be well wrapped in cold weather.

Pressure sores may take only hours to develop, but could possibly take months to heal. The importance of prevention cannot be over-emphasised.

L. J. Bradley SRN
Mossbrook School
Sheffield

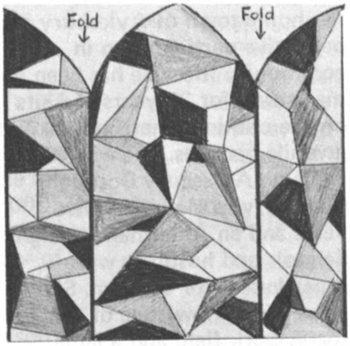
Family page

Christmas cards you design and make yourself could make a very good start to Christmas for your family and friends. Here are a few simple ideas . . .

Made for Christmas

Cut and fold a piece of thin card or heavy cartridge paper to the size and shape you want for your Christmas card, and draw a simple design on the face—a candle, a bell, a piece of holly, a Christmas tree, or something similar. Trace round the outline of the design with Gloy Children's Glue, applied with a matchstick or cocktail stick. Sprinkle Gloy Glitter—in any colour you choose—on to the card so that it sticks to the glue. Shake excess Glitter on to a sheet of paper and return it to the container. Next, fill in the various solid areas of the design by "painting" them with Children's Glue and sprinkling them with Glitter of the appropriate colour. *Remember*—complete the use of one colour before going on to the next, or you won't get a clear design. It is best to keep to about three colours, for the most effective results.

* * * * *



A stained-glass window makes an attractive Christmas card shape (see above). Cut it out of thin card or heavy paper to the size you want.

Draw the black lines using a ruler, and fill in the shapes by sticking on small pieces of shiny coloured paper. Ideal for this purpose is Gloy Coverlon—self-adhesive, see-through plastic film in red, blue, yellow, green and clear (obtainable from good stationers like W. H. Smith). Any shiny coloured paper will do, of course, if you can't get Coverlon. It isn't necessary to fill in all the shapes with paper. Leave some with the plain white card showing through. Fold the two outer sections across the centre one, and write your greetings on the back of them. When unfolded a little the card will stand erect.

Snowman melts in the mouth

Here's a simple idea for a decoration to brighten up the Christmas party table . . . Marshmallow Snowmen.

You will need white marshmallows, two toothpicks, currants, glace cherry or a red sweet; small round sweets, ribbon and black paper.

Take a toothpick and on to it slide three lumps of marshmallow—a fat one for the body, and one for the legs and one for the head. Stick another toothpick through the body from side to side and put a small piece of marshmallow on either end of it to make the arms. Push currents into the head for eyes and nose, and a piece of glacé cherry or red sweet for the mouth. Stick small round sweets into his body for buttons. Tie a ribbon round the snowman's neck as a scarf, and make him a hat with a cone of black paper.

Appeals and publicity

Mrs. Kate White

Link thought that readers might like to get to know Mrs. Kate White—"our Kate"—a little better.

She has been Appeals Secretary since October 1971 and her job is to organise and co-ordinate fund-raising and publicity events.

Mrs. White is well known in her home town of Aylesbury for her active participation in community life. She has been a magistrate for 22 years and sits on the criminal, matrimonial and juvenile benches. She was 19 years on Aylesbury Borough Council, was Mayor for two years and an Alderman for eight. Schools and hospitals were special areas for concern. She has a wide knowledge of the social work field and a large number of useful contacts.

Mrs. White is fortunate in having the support of her husband, who helps with her appeals work whenever he can. Incidentally, he is NOT the Mr. White who is Chairman of the Appeals Committee and in her opinion her Mr. White is slightly more handsome!

Mrs. White feels that if ASBAH is to have a future as a strong and influential organisation it must grow together more. "One voice is much more powerful than a collection of smaller voices." Although she is concerned with money-raising, she doesn't want ASBAH and its Local Associations to become merely fund-raising groups.

"The greatest work which Local Associations can do is in caring for and supporting their members," she says.

Boots, Boots, Boots

In many ways I'm very lucky, for I find in the course of my work so many instances of spontaneous goodwill for our children with handicap. It is most encouraging to find that gradually more and more people are becoming aware of the problems which the handicapped member and the whole family have to face.

A case in point is the offer "out of the blue" from a small group of soldiers in the Parachute Regiment and the Irish Rangers to undertake a sponsored walk in December, during their leave, to raise funds for our Association. Naturally, I have accepted the offer with thanks, and I hope readers whose route they will traverse will be able and willing to help me in obtaining a mammoth number of sponsors. The route originally proposed was from John O'Groats to Land's End—800 miles—but I think in view of the possibility of bad weather they may opt for a shorter distance—possibly walk the Pennine Way. There will be more details later.

Listen to Larry

Larry Grayson, the popular Comedian of the Year, very kindly consented to appeal on BBC Radio 4 on Sunday, 21 October, in aid of our Short Stay Care Appeal. By the time you read this that date will have passed and I shall hope to be submerged in envelopes.

For our children's children

We now have £40,000 in this Research Fund—two thirds of the way towards our target of £60,000. Of this approximately £20,000 has been contributed by our own Local Associations.

It has been agreed to go ahead and advertise the Fellowship, inviting senior researchers to submit theses for consideration. I hope that when we know the area of research decided upon, and can submit specific details, sizeable grants may be obtained from charitable trusts and industry to make the target by the New Year.

May I wish you all a very happy Christmas, and a good New Year.

Kate White

All in a year's work

REPORT IN BRIEF—a look at some of the main points from ASBAH's Annual Report for 1972/3.

The Report opens with the excellent news that Her Royal Highness The Princess Richard of Gloucester agreed earlier this year to become Patron of the Association.

Research

In order to promote vital research into the prevention of spina bifida and hydrocephalus a £60,000 Research Fellowship Appeal was launched during the year (at the time of Link going to press this had reached £41,000). A substantial amount was raised by Local Associations. Applications for the first holder of the Fellowship are being invited.

- Research into the basic structure of the spinal cord. This research by Dr. Barson in Manchester, and financed by the Spina Bifida Trust, continues into its second year.
- Thanks to the generosity of people all over the country £14,500 was raised last year by ASBAH for a Quantimet—one of the few electronic scanners in the country—which has been installed at the Congenital Anomalies Research Unit, Sheffield.
- A research project into the chemical analysis of amniotic fluid continued last year, financed by the Association in Edinburgh. This research is concerned with early pre-natal diagnosis of a baby with a central nervous system abnormality, and already important advances have been made in this direction.* Other units in the country are now working on the same lines so that a nationwide early diagnosis service may be available for expectant mothers who already have a spina bifida child.
- The need for special care of the eyes of those with hydrocephalus is very important, and ASBAH decided to appoint a part-time ophthalmologist for one year to work at the Hospital for Sick Children at Great Ormond Street, London.
- The Association was able to install a high-frequency recording apparatus, costing £4,500, at Hull Royal Infirmary to determine ventricular pressure in those with hydrocephalus.

Welfare

Parallel with efforts in the field of research is always the concern for the welfare of the families with a spina bifida and hydrocephalic member.

Another social worker was appointed during the year. There is ample evidence of the value of the support which the social workers can give to individual families, and it is hoped that more will be appointed.

Poignant requests continued to be received for financial assistance in various domestic crises. ASBAH worked with the local authority social services, and was able to fill many of the gaps in statutory provisions.

Equipment and appliances

ASBAH's Appliance Officer continued to visit Local Associations and Groups to keep them in touch with various aids and equipment, and to demonstrate their effectiveness. "Do-it-yourself" type equipment proved particularly helpful.

The long delays experienced by many people in the supply, adaptation or repair of essential appliances such as calipers, continued to cause frustration, and often delayed the patient's progress. ASBAH approached the Department of Health and Social Security which has agreed to investigate each case of difficulty.

Hopefully this may lead to a general improvement in the service. Efforts continued—without success so far—to persuade the Treasury to withdraw Value Added Tax from apparatus used by the handicapped. This offer has been taken up far too infrequently. Please do not hesitate to let the General Secretary know if you are experiencing difficulties. Only in this way can the Department be kept fully aware of how frequent the problem is.

The Christmas Appeal of Thames Television Children's programme, "Magpie", which focused on equipment and aids, has enriched the life of many spina bifida children.

The programmes were handled with enthusiasm and sensitivity and the Appeal brought before a

---

* Dr. John Lorber will be writing on this subject—Amniocentestis—in the next Link.

All in a year's work

wide public the name and nature of spina bifida. The appeal raised the magnificent sum of £79,000 to provide holiday chalets, mini-buses, apparatus in special schools, and equipment to help young people with spina bifida—whether Association members, or not.

Annual Conference

The subject was "The Severely Disabled Spina Bifida and Hydrocephalic" and the Conference, held at Reading University, was supported by over 100 teachers, social workers and Association members.

Training and Employment

The Association voted £10,000 to continue for a further three years the assessment service by Mr. A. P. Lonton under the direction of Dr. John Lorber. This assessment work was originally done by Dr. H. G. Parsons as research work. Based in Sheffield, the service is available to young spina bifida school leavers from all over Britain.

Liaison work

The interchange of ideas between Local Associations and the National Association is an integral part of the growing strength of our work. Mr. H. D. Macfarlane, the Liaison Officer visited many local groups, helping to sort out problems, and assisting in the formation or restructuring of Local Associations.

Appeals

Mrs. Kate White, the Appeals Secretary, and the Appeals Committee were kept very busy. All ASBAH's work is at present financed from voluntary sources. As the work expands so does the need for more funds.

ASBAH is extremely grateful to the many groups of well-wishers and individuals who sent in donations and were responsible for money-raising and publicity events whether they were large-scale national functions or "back-garden" efforts.

The Annual Report concludes with a thanks by the Executive Committee to the Association's growing number of friends.

Plans for a better tomorrow

Lord Sandford, the Under Secretary of State in the Department of Education and Science, was the guest speaker at ASBAH's Annual Meeting in September at the Royal Society of Medicine in London.

Lord Sandford drew attention to two new Government plans in the field of education—outlined in the White Paper, "Framework for Development"—which will be of special benefit to handicapped children.

- The increase in capital investment in education from its present £11 million to £19 million in four years' time. This would mean new schools, and the building of new special units attached to ordinary schools. He considered these an ideal answer to the problem of integrating handicapped children with normal children of their own age. These units enable those handicapped children who progress sufficiently well to gradually move out of the special units into the main schools. Lord Sandford hopes that the planning and design of new buildings will take account of pupils with all kinds of handicap.
- The massive increase in nursery school education to meet the needs of all children under five. This would greatly benefit handicapped children.

He also mentioned in particular the Employment Medical Advisory Service which was set up in February which should be of great help with the resettlement in employment of handicapped young people.

On a less happy note, Lord Sandford said he thought it unlikely that there would be any early changes in VAT.

Inter-association holiday opportunities

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

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

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

Lessingham, Norfolk. Well-appointed 6-berth Caravan. Sea 100 yds. Vacancies. Apply Mr. P. White, 12 Swallow Gardens, Hatfield, Herts. Tel. Hatfield 63018.

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

Mablethorpe. Self-contained 6-berth Chalet situated at Golden Sands Estates, Mablethorpe, Lincolnshire. Further details from Mr. Ken Hall, 17 Walhouse Street, Cannock, Staffs.

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

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

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

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

Wanted—a loving foster home

A three-and-a-half year old boy with hydrocephalus and quite out of touch with his mother needs a loving, long-term foster home, preferably where there are other children to give him a chance of enjoying a normal family life. Anyone interested should contact Miss P. Sheridan, Area Social Services Officer, 51 Kent Road, Southsea, Hants.

ASBAH publications and publicity

By J. Lorber, MD, FRCP: Your Child with Spina Bifida, 15p*. Your Child with Hydrocephalus, 15p*.
By O. R. Nettles, MCSP, ONC: Equipment and Aids to Mobility. A folder of four booklets, 25p complete* (Part 4, which is now available: 5p).
By Barbara Webster, SRN, RSCN: Clothing for the Spina Bifida Child, 15p*.
General information leaflets: £1 per 100.
Leaflet for young people: £1 per 100.
Posters: Double Crown: 5p each. Future Bright: 10 for 20p.
Flag Day emblems: 1,000 for 50p.
Cards for notice boards: 10 for 10p.

*(*Special rates available to Local Associations.)*

All available from: ASBAH, Devonshire Street House, 30 Devonshire Street, London W1N 2EB.

Scottish Spina Bifida Association booklets:

By O. R. Nettles, MCSP, ONC: The Spina Bifida Baby, 10p. Growing Up with Spina Bifida, 20p.
Single copies of these booklets from ASBAH (as above). Bulk supplies from: The Scottish Spina Bifida Assn., 7 South East Circus Place, Edinburgh EH3 6TJ (at special rates).

Postage on all these items is extra *outside* the UK.

Local Association offers

SB Badges. Silver and green enamel with pin fastening. Replica of the Spina Bifida emblem: 22p plus postage. (Single badges, please enclose s.a.e.) Enquiries from groups welcomed for quantities.

Apply: Mr. K. McKenzie, Badges Secretary, Salisbury and District ASBAH, 111 East Gomeldon Road, Gomeldon, Salisbury SP4 6LZ.

Badges for Children. Good quality 1¼ in. diameter incorporating the SB symbol and the words "Spina Bifida Children" in black on a green background. For sale in the following quantities: 25 badges for 75p, 50 badges for £1.40 and 100 badges for £2.65, including P. and P. Cheques or postal orders should be crossed and made payable to "SASBAH" and sent with order to: Mrs. I. Olditch, High Lea, Turners Green Lane, Wadhurst, Sussex.

Car Stickers. "Support the Spina Bifida Campaign." Transport stickers, 5p each plus postage, from Staines, Hounslow and Districts Association, c/o Mr. E. G. West, 13 Princes Road, Ashford, Middlesex. (Min. order 50.)

Ties. N. Hampshire, S. Berkshire and W. Surrey Association has ties for sale—the *SB* symbol on dark blue or dark green. The ties are washable terylene of a heavy weave and cost £1 each. Cash with order to Mr. Bernard High, 10 Woodruff Avenue, Burpham, Guildford, Surrey. Please state colour required.

Blackpool. Homely accommodation for severely disabled children and families. Well equipped. Self catering. Convenient for promenade, beach, shops. Available all the year round. All enquiries to: Mr. J. H. Lawes, 18 Kenilworth Gardens, Blackpool. Tel.: 47992.

AFFILIATED ASSOCIATIONS – Hon Secretaries

BRISTOL
Mr. R. W. Mabbutt,
20 Bramble Drive,
Stoke Bishop, Bristol.

BROMLEY & DISTRICT
Mrs. J. Moore,
102 Westwood Park,
London SE23 3QH

BUCKINGHAMSHIRE
Miss J. McDonnell,
Wyvern House,
Askett, Princes Risborough.

DARLINGTON AND DISTRICT
Miss J. Hutton,
17 North Terrace,
Gainford, Darlington.

DERBY
Mrs. P. E. Broadgate,
11 Old Lane,
Darley Abbey, Derby.

DEVON AND CORNWALL
Mr. J. Carter,
5 Culme Road,
Mannamead, Plymouth.

DON AND DEARNE
Mr. T. J. Murphy,
43 Cutts-Avenue,
Wath-On-Dearne, Yorks.

EAST ANGLIAN
Mrs. P. Symonds,
28 Leys Road, Cambridge.

HALIFAX AND DISTRICT
Mr. A. L. Crowther,
42 Marldon Road,
Northowran, Halifax.

HAMPSHIRE, NORTH/ W. SURREY & S. BERKS.
Mrs. Selby,
ASBAH,
4 High Street, Guildford.

HAMPSHIRE-SOUTH
Mr. J. A. Rae,
16 Clifton Road,
Lee-on-Solent, Hants.

HERTS AND SOUTH BEDS.
Mrs. T. A. Hammond,
65 Devon Road, Luton.

HUDDERSFIELD
Mrs. C. Carter,
32 Winget Avenue,
Cowlersley,
Huddersfield.

HULL & DISTRICT
Mrs. G. D. Brown,
233 Cranbrook Avenue,
Hull, HU6 7TX

KENT
Mrs. P. Fearn,
120 Mill Street,
East Malling.

LEEDS AND DISTRICT
Mr. G. Baxter,
77 Collier Lane, Baildon.

LEICESTERSHIRE
Mr. P. Cusack,
39, Kings Walk,
Leicester. F.E.

LEIGH & DISTRICT
Mrs. S. Goulding,
20 Pendle Road,
Golborne, Lancs.

LINCOLNSHIRE
Mrs. Clucas,
6 The Cloisters,
Humberston, Nr. Grimsby.

LIVERPOOL
Mr. P. A. Glennon,
LASBAH
1st Floor,
46 Manchester Street,
Liverpool, 1

LONDON
Mr. J. Barefoot,
23 Marlborough Road,
Southall,
Middlesex UB2 SLW

Barnet area
Mrs. V. A. Brooker,
6 Merrivale, Southgate,
London N14 4SH

Ealing area
Mr. L. R. Mower,
59 Betham Road,
Greenford, Middx.

North East (Forest) Area
Miss D. Baxter,
8 Keith Avenue,
Wickford, Essex.

LONDON SOUTH
Mrs. C. Byrne,
Flat 1,
10 Wexford Road,
London, S.W.12.

MANCHESTER AND DISTRICT
Mrs. E. Taplin,
Colonial House,
63 Corporation Street,
Manchester M4 3DT

MANSFIELD, WORKSOP AND DISTRICTS
Mrs. E. Freeman,
23 Melbourne Street,
Mansfield Woodhouse, Notts.

NORTH BEDS. & NORTHANTS
Mrs. A. Merry,
12 Crofton Close, Bedford.

NORTH EAST (Northumberland)
Mrs. E. Grant,
27 Redwell Road, Prudhoe,
Northumberland,

NOTTINGHAM & DISTRICT
Mrs. S. E. Plant,
305 Foxhill Road,
Carlton, Nottingham.

PRESTON
Mrs. D. Snaylam,
72 Priory Lane,
Penwortham, Preston.

ST. HELEN'S & DISTRICT
Mrs. N. Maddocks,
324 Warrington Road,
Rainhill, Prescot L35 9JA

SALISBURY AND DISTRICT
Mrs. J. Renshaw,
155 Gainsborough Close,
Salisbury, SP2 9HB.

SHEFFIELD
Mr. T. Robinson.
4 Longford Close,
Bradway, Sheffield S17 4LH.

SOUTHAMPTON & DISTRICT
Mrs. P. M. Trim,
20 Depedene Close,
Great Roman Way Estate,
Holbury, Southampton S04 IPQ.

STAFFORDSHIRE
Mrs. J. Davies,
8 Oakhill Avenue,
Oakhill,
Stoke-on-Trent, ST4 5JN

STAINES, HOUNSLOW AND DISTRICT
Mr. M. Loosley,
32 Viola Avenue,
Feltham, Middlesex.

STOCKPORT
Mrs. S. Silver,
1 Brookside Avenue
Offerton,
Stockport, Cheshire.

SURREY (NASBAH)
Mrs. C. J. H. Phillips,
304 Croydon Road,
Wallington, Surrey.

SUSSEX
Mrs. B. Sutcliffe,
26 Weald Road,
Burgess Hill, Sussex.

SWINDON AND DISTRICT
Mrs. J. Trembling,
13 Tennyson Street,
Swindon, Wilts.

TRAFFORD
Mrs. J. W. Shawcross,
22 Manor Park,
Urmston, Manchester.

WARRINGTON & DISTRICT
Mr. S. J. Charlton,
36 Park Avenue,
Latchford, Warrington.

WARWICKSHIRE
Mr. R. W. Chawner,
18 Finch Drive,
Sutton Coldfield, Warwickshire.

WESSEX
Mrs. J. Wheller,
5 Wyke Road,
Weymouth, Dorset.

WIRRAL
Mrs. S. Keeler,
7 Church Road,
Upton, Wirral.

WORCESTERSHIRE
Mr. W. J. Webster,
36 Fairfield Lane,
Wolverley, Nr. Kidderminster.

YORK
Miss F. M. Seward,
45 The Paddock,
York, YO2 6AW

NORTHERN IRELAND

BELFAST & DISTRICT
Mr. J. H. Blackwell,
132 Orangefield Cres.,
Belfast BT6 9GT

SCOTLAND

SCOTTISH ASSOCIATION
Mrs. G. McIntyre,
General Secretary
7 South East Circus Place,
Edinburgh, EH3 6TJ

WALES

MID WALES & BORDER COUNTIES
Mrs. D. Brayne,
5 Woodcote Way,
Monkmoor, Shrewsbury, Salop.

NORTH WALES
Mr. P. H. Galloway,
The Flat, The Plassey,
Marchwiel, Wrexham.

SOUTH WALES
Mrs. D. Cox,
28 Cromwell Road,
Bulwark,
Chepstow, NP6 5AD

OTHER LOCAL ASSOCIATIONS

Bournemouth, Christchurch & District
Mrs. V. J. Spiers,
4 St. Merrins Close,
East Howe, Bournemouth.

Blackpool & Fylde
Mrs. D. Sharpe,
33 Moorway,
Poulton, Blackpool.

Bolton & Bury
Mrs. M. Fagan,
750 Walmersley Road,
Bury, Lancs.

Burnley
Mr. J. McFarlane,
50 Moorland Road,
Burnley.

Cannock & Walsall
Mrs. C. Phillips,
11 Seymour Road, Ocker Hill,
Tipton, Staffs.

Chesterfield
Mrs. K. M. Tomlinson,
56 Brooke Drive,
Brimington Common,
Chesterfield.

Consett & District
Mrs. M. Holmes,
30 Watling Street,
Leadgate, Co. Durham.

Dudley & Wolverhampton
Mr. B. Attwood,
1 Autumn Drive,
Lower Gornal, Dudley
Worcestershire.

Essex
Mr. J. T. Saunders,
2 The Ruskins, Rayne,
Braintree, Essex.

Gloucester North
Mrs. B. Symonds,
9 Collum End Rise,
Leckhampton,
Cheltenham, Glos.

Greenwich
Miss Sandra Tucker,
38c St. John's Park,
Blackheath SE3 7JH

Isle of Wight
Mr. D. J. S. Sprake,
Springfield, Town Lane
Chale Green, Ventnor.

Lincoln
Mr. A. Goulding,
242 West Parade,
Lincoln LN1 ILY

Lunesdale (Lancaster)
Miss P. Crook,
Brananlor, Ball Lane
Caton, Lancaster.

Rochdale
Mrs. K. Fidler,
18 Fairway,
Links Estate,
Castleton, Rochdale.

Spenborough (Yorks.)
Mr. H. Lodge,
38 George Street,
Cleckheaton, Yorks.

Teesside
Mr. W. J. K. Wilson,
29 Adcott Road, Acklam,
Middlesbrough TR5 7ER

Wigan & Chorley
Mr. J. A. Hughes,
20 Kennedy Close, Standish,
Nr. Wigan, Lancs.

NORTHERN IRELAND

Ballymena
Mrs. E. Kenny,
The Bungalow,
Teesham, Ballymena.

Lurgan & Portadown
Mr. P. A. Smyth,
Marymount,
North Circular Road,
Lurgan, Co. Armagh.

Mid-Ulster
Mr. J. R. Stafford,
26 Killymerron Park,
Dungannon, Co. Tyrone.

CHANNEL ISLANDS

Mrs. U. Emmanuel,
Mont a l'Abbe,
Manor Farm,
St. Helier, Jersey, C.I.

EIRE

Enquiries to:
Mrs. M. Kinsella,
66 Martello Hill, Carrick Estate
Portmarnock.

OVERSEAS subscribers to "Link" are in many parts of the world and are growing in number.

Printed in Great Britain by The Whitefriars Press Ltd., London and Tonbridge