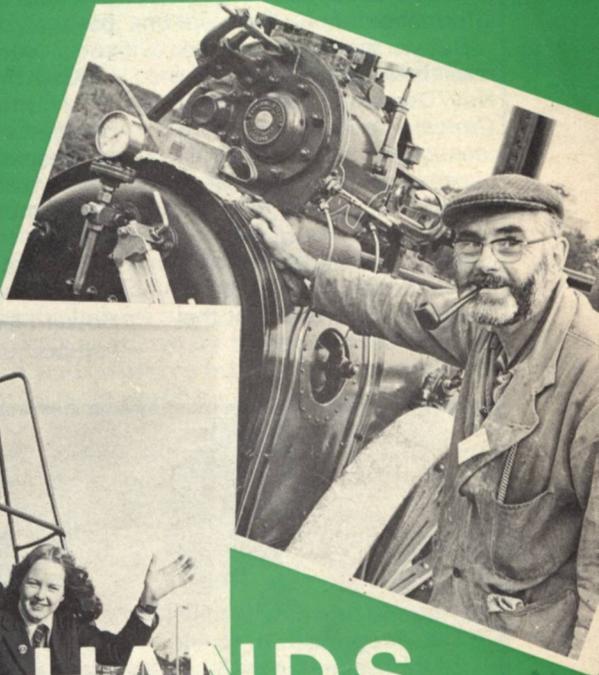


# Link

Jan/ Feb 1975 5p

Association for Spina Bifida and Hydrocephalus (ASBAH)



## HELPING HANDS



## Letters

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### WE WERE SHATTERED

We are always pleased to receive our copy of *Link* which we find full of positive articles and useful information.

But we were shattered to read the article in the Nov/Dec issue entitled *Growing up*. Even if modern teenagers could accept the patronising attitude of the writer, I shudder to think what they would make of the content, with its advice to have a 'lovely chat' about 'feelings' so private that they can only stand a veiled reference.

And who is to be chosen for this lovely chat? Not parents (too embarrassed) nor teachers (too cross). Who else but the youth club leader or social worker!

After the 'lovely chat' does Mrs. Elyan really expect teenagers to see their grown up people smile at them with a new twinkle in their eye, which means "Ah, growing up".

One wonders who should be growing up?

**Howard Newton**  
Farnborough, Hants.

**Editor's note:** It is always difficult to strike the right balance to please everyone in an article of this kind. Some people have said they thought it was a good and useful article. Mr. Newton obviously does not agree. Mrs. Elyan points out that one cannot itemise specific problems in a magazine as these are personal to the individual concerned. She also comments that the aim is to encourage young people to talk about their problems at a very early age and consequently this article was written with the younger ones in mind — in general for the 10/11 year olds — rather than for the majority of teenagers. *Link* will consider carrying an article for older teenagers at a later date.



#### **THE SHASBAH TROLLEY FOR HANDICAPPED CHILDREN**

Patent applied for in

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**Standard model** for children one to five years old costs £11.00 plus carriage.

**Large model** for children five to ten years old costs £14.50 plus carriage. Overseas prices on application.

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

All enquiries to: Mrs. K. Charrett, 46 Tillbrook Road, Regents Park, Southampton.

Telephone enquiries: Totton 3365 (Mr. Mortimer)

## BOOKS

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### Outdoor pursuits for disabled people

Norman Croucher, the author, is perhaps the best advertisement for his own book. Despite having two artificial legs he is an experienced mountaineer—he has climbed the Matterhorn!—no less and showed limitless energy in travelling all over the country in the preparation of this book.

It contains valuable information on all kinds of outdoor sports which disabled people might care to attempt and enjoy—ranging from sub-aqua diving and angling to gliding, camping and riding. There is a great deal of factual information as well as good sound advice. Points on safety limits, special equipment, lists of instructors and organisations are included. Price 75p from Disabled Living Foundation, 346 Kensington High St., London W14 8NS.



Link No. 36

Association for Spina Bifida  
& Hydrocephalus (ASBAH)

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HRH The  
Duchess of Gloucester

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Link Editor:  
**Mrs. Susan Gearing**

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## Editorial

Readers will have learned of the Government's intentions following Lady Sharp's report on *Mobility for Disabled People*.

The proposal that the disabled passenger, for the first time, should receive consideration for financial help must be very welcome news to parents, and it is suggested that the new allowance will be available to those with children from age five.

The new allowance is to be phased in gradually to cover different categories of disabled, and there will undoubtedly be much debate over who is to receive consideration first.

**Good news so far, but what is certainly not good news is the proposal that the £4 a week allowance be taxed. Vigorous representations are being made to see that the allowance is tax free, since its whole purpose is to enable all disabled people to overcome their lack of mobility as far as possible. Let us hope that the representations are successful.**

The whole allowance does need to be thought of in its broadest context. Its aim is to provide the means for improving the general mobility of the individual disabled person. The answer may not always be to have a car. For instance in these days of shopping precincts a taxi, two or three times a week, might be more suitable, and be a more economical use of the allowance. Or it might be more sensible to contribute towards the running cost of a car owned by a relative or friend. Alternatively a powered outdoor wheelchair might best meet an individual's needs. Fortunately advice on how to make the best use of the allowance is to be made available.

*Link* will continue to keep you in touch with developments as the Government begins to turn its good intentions into what we hope will be good legislation.

**What is the role of a local Association Chairman? Should he spend valuable time sorting out jumble for the Spring sale or getting the right number of chairs and tables assembled for a meeting? It can be all too easy for a Chairman to get saddled with these chores, particularly if his predecessor took them on.**

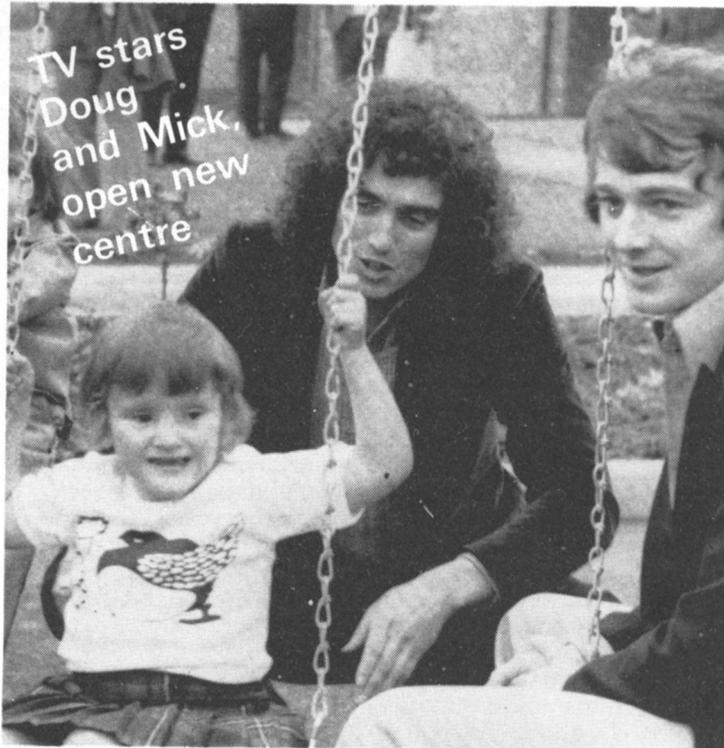
The important question of what the Chairman's role really should be was aired by a group of Local Association Chairmen at one of the individual discussion groups at the ASBAH One Day Workshop held in London in November.

It was generally realised that to be of real use a Chairman should concentrate on being a helmsman, someone to keep control and to see that the Association remains on course. It was also felt that he should be very outward looking, and take time to get out and about and establish valuable personal contacts within various local authority departments, with social workers, with schools and influential members of the community.

Only by becoming a real and recognised part of the community will a Local Association be able to make full use of the resources of the area. It is obviously important that the real role of a Chairman is recognised not only by the Chairman himself but by his Committee and the members of the Association.



# Local Association News



TV stars  
Doug  
and Mick,  
open new  
centre

Doug and Mick, ASBAH's good friends who are the popular personalities of ITV's *Magpie* opened in November a new £57,000 centre built by Teesside Association.

The centre in Tollesby Road, Middlesbrough provides recreation and play facilities not only for spina bifida children and teenagers but for other handicapped young people in the area. The organisers hope that able-bodied children will also be encouraged to use the centre. The building includes a gym, snack bar and varied play facilities and will be staffed by two paid playgroup leaders, with the help of volunteers.

The £57,000 was raised by the Teesside Association. Local clubs and associations of all kinds contributed. The centre also received an Urban Aid grant.

Mr. Norrie Roy, a member of the management committee said he hoped that in particular teenagers, both handicapped and able-bodied, would make full use of the centre's facilities.

photo: The Northern Echo.

## What's in a name?

A few thoughts on our name from Miss Dorothy Baxter, Honorary Secretary of the North East London branch of the London Association (reprinted from their Newsletter).

After listening to all the commentary given out by various media at the recent Charity Football Match my opinion has been confirmed that "our" name is very complicated for the general public to use fluently. We know: but can you imagine the thoughts of an outsider on seeing our title!

The Spina bit is all right because it is similar to spine, but what happens when you come to Bifida? Are the i's hard or soft? Hydrocephalus causes the greatest problems—hydro is easy. Is the c hard or soft? Ph stands for f. All this makes one hesitate and it soon becomes "this good cause".

I think we must all become "name droppers" and say Spina Bifida and Hydrocephalus whenever we can so that, in time, it will just roll off everyone's tongue.

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The Editor welcomes your news and views. All copy should be sent to Mrs. Susan Gearing by the 30th January at the very latest, for the March/April LINK.

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# Local Association News

## Down the river

**Barnet & Brent.** Other Associations might be interested in the success of Barnet and Brent's outing down the Thames which they tried for the first time last year. A very spacious launch was hired from Thames Launches Ltd. at Charing Cross pier. It had plenty of room for wheelchairs. There was a much used kiosk on

board serving drinks and light refreshments. Getting on board proved rather difficult because of the steep steps, but apparently it would have been easier at Putney Pier. The launch went down to Tower Bridge and the Tower of London, and there was a two hour stop at Richmond. The whole trip appealed to young and old alike.

## Children help

**Staffordshire.** Donations of any amount are warmly received by Local Associations, although sometimes it is only the larger sums of money that receive publicity. Staffordshire wanted to say a special thank you to nine children aged between 5 and 12 who worked very hard over several weeks to raise £21 for the

Association. The children who live in and around Stoke on Trent enlisted the help of parents and grandparents to make their jumble sale and raffle a real success. The £21 cheque was presented to a young member of the Association, two-year-old Simon Foster who has spina bifida.

## Christmas present

Just in time for Christmas, spina bifida children at Cheyne Hospital, West Wickham, Kent have at last got their long awaited playroom.

The £6,300 playroom wasn't completed in April as planned because of delays in obtaining building supplies, and shortage of funds.

## Holiday success

**Chesterfield.** Secretary, Mrs Tomlinson reports that the first season of the holiday bungalow at Bridlington has proved very successful, with every week booked by the Association families from Spring Bank Holiday to Mid-September.

## FRONT COVER

Some of ASBAH's supporters: Margate Inner Wheel at a Halloween Party in aid of ASBAH. Mr. Angus MacLellan at a Model Engine Exhibition at Stroud, Gloucs. Girls of Ian Ramsay School, Stockton with the climbing frame they renovated and gave to Teesside Association. TV star Doug Fielding (PC Alex Quilley) with the raffle prize he won when taking part in a football match in aid of ASBAH organised by the Foresters at Maidstone. Six Darlington children who raised £77 at a Garden Fete and gave it to Darlington Association. Photos: East Kent Times, Stroud News, Evening Gazette, Middlesbrough, Maidstone Gazette, Northern Despatch, Darlington.



Cub Scout Mark Warton of Barrow-in-Furness receives a Gold Arrow Award for outstanding merit. Eleven-year-old Mark who has spina bifida and hydrocephalus has now moved up to the Scouts. photo. Barrow News and Mail



# Research - the experts' findings

by  
Gordon Brocklehurst, M.Chir., MB FRCS, Consultant Neurosurgeon.

The 18th Annual Meeting of the Society for Research into Hydrocephalus and Spina Bifida was held in June 1974 at Gothenburg in Sweden under the presidency of S.A. de Lange, and with Dr. and Mrs. Hugo Andersson and their colleagues from the University of Gothenburg as the hosts.

The answer to the basic question of whether or not this meeting significantly advanced our knowledge of spina bifida and hydrocephalus in a direction which will help patients and parents is a 'yes' but a small 'yes'.

Dr. Cedric Carter from London gave the 1974 Casey Holter Memorial lecture entitled "*Clues to the aetiology of neural tube malformations*" by surveying in depth and breadth the many factors which can be included under the terms genetic and environmental, all of which have been shown to have some significance in the occurrence of spina bifida babies. The conclusion is that no single one can at present be regarded as the main causative factor and we cannot provide a single answer to the problem of cause and prevention. On the other hand we now have sufficient information to give very detailed genetic counsel to parents in families who

already have had some infants with spina bifida or anencephaly, and such parents should certainly seek this advice from some well-informed genetic counsellor.

### Ante-natal diagnosis

Related to this is the place of the investigation designed to determine alpha-feto protein levels in the fluid which surrounds the developing baby inside the mother's womb. This fluid can be extracted by the obstetrician and if the examination is made at the 16-18 week stage, there is a high correlation between an abnormally high level of this protein and abnormalities such as anencephaly or severe spina bifida. A pregnant woman with a previous family history of the condition might therefore be in a position to receive advice about her current pregnancy and to make some suitable plans. The correlation between a raised level of this protein and anencephaly is high even as early as 15 weeks, but spina bifida cannot be so easily detected at this stage, and may not be detected at all if it is one of the so-called closed spina bifida lesions. However, clearly this test is an advance in the direction of preventing another abnormal pregnancy from coming to term when there is already a strong

family history of spina bifida or anencephaly. The risks and limitations of the test at this stage are such that it is hardly justified as a screening test for all pregnant women. Only a few centres in the country have these facilities for making this analysis of amniotic fluid, but specimens can be sent to these centres and an answer obtained relatively rapidly.

The meeting learnt from Professor Emery and his colleagues more details of the abnormal structures of particular parts of the brain in spina bifida infants, and one of the finest contributions was a study of the breathing abnormalities in spina bifida/hydrocephalus infants and their relationship to the brain malformations by Dr. Wealthall of Sheffield. Some good practical advances in the management of the bladder problems of spina bifida children by Mr. Forrest, Dr. Duthie and Dr. Stark in their study of the use of indwelling catheters which has previously been regarded as a rather unsuitable method. They showed that with proper supervision the indwelling catheter can be very useful and help to control the urinary tract problems as well as answering the social implications of incontinence.

(Continued)



## Health matters

In the treatment of hydrocephalus much more interest is now being taken in measuring pressure inside the head over a period of time in order to assess whether hydrocephalus is progressive or not, and endeavours are being made to re-introduce operations to deal with the hydrocephalus which do not involve the placement of tubes from the brain to the heart or peritoneal cavity, but try to restore a more natural distribution of fluid in and around the brain.

### Family stress

Studies of the effects of having a spina bifida child upon family life continue and confirm the obvious impression that there is a great deal of extra family stress involved. Dr. Tew and his colleagues from Cardiff, using various methods of assessing family life, showed that the families with spina bifida have over twice the amount of signs of family

stress. Furthermore, an analysis by Dr. Dorner from London of adolescents with spina bifida from 63 families showed that they were gravely handicapped. The problems in social relationship which these adolescents had were proportional to their immobility and 20 per cent of the parents indicated that they were restricted by the child's problems, as would be expected.

With such findings it was not surprising that the Society once more addressed itself to the matter of selection in the management of patients with spina bifida lesions which are obvious at birth, and the President, Professor de Lange, gave a stimulating address on this subject. He pointed out that when we say that ethics are involved in making a selection as to whether a new-born child should be surgically treated or not, the ethics should not be solely those of the doctor, but those that are acceptable to

parents, society and the unformed ethical view-point of the new-born infant. In making these decisions, when it is common enough for the parents and doctors to agree with each other, it must be recognised that the responsibility of them all is to the helpless infant; they have to consider whether or not they can determine by examination and expert knowledge what degree of severity and incurability the child is born with, and exactly what this holds for the future in terms of function. The certainty of future serious mental disability might be generally acceptable as a factor towards the decision not to undertake surgical treatment, but in the final analysis it is the patient's view which is all important.

The Members of the Society listened to and discussed these things in detail, and came away from Gothenburg perhaps a little wiser, and with warm memories of the thoughtful hospitality of their Swedish hosts.

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## My holidays and My hobbies

On August 5 last year my mother and father and I set off on our Summer holidays at Plas-tan-Dinas, Dinas Dinlle, near Caernarvon. We have stayed at this hotel for the past three years. I enjoy myself there very much. Apart from having good food I have made a lot of friends there.

We went out every day we could but were not very lucky with the weather. In fact, I

think we only had a week of good weather during the fortnight we were there. But if the weather was bad we did not have to go out unless we wanted to.

I have a lot of hobbies and things I enjoy doing, such as playing cricket with my father and with my friends at school. I also play in goal in football at school. We normally win, thanks more to the attacking

football of my friends, than to my goalkeeping, which could be better than it is.

My ambition is to become a sports journalist and write about the World Cup final which I would like Wales to win. My favourite football team is Manchester United and my favourite player is Alex Stepney.

**Huw Griffith, Blaenau Ffestiniog**

# A MUM EYE VIEW

Mrs. Ursula Emmanuel lives in Jersey with her husband and three children — Lindsay, aged 10, Cheryl who is 7 and has spina bifida, and an adopted son of 5, Nicholas.

Recently Mrs. Emmanuel disciplined herself to sit down and write a personal account of her experiences in coping with a family which included a fairly handicapped spina bifida child.

The result — A Mum's Eye View is serialised in this and the next two issues of *Link*. We feel that Mrs. Emmanuel's experiences and views, although obviously personal to her family in many ways, nevertheless may be of value to others, particularly mothers who have recently had spina bifida babies.



Cheryl at eight months

*'My only qualification for writing this is as a mother of a handicapped child. I do not claim any professional knowledge either medically, educationally or otherwise, and all comments made are from my own experiences with my daughter. We have had a lot of fun, some scares and worries too, and have not always made the right decisions, and I hope that reading about them may help other mothers facing similar problems.'* Ursula Emmanuel



Mr. and Mrs. Emmanuel with their family (from left) Lindsey, Nicholas and Cheryl.

**I suppose the question that everyone wants to ask of a mother with a new baby who is not normal, is the one that they just can't ask - 'what does it feel like? How do you feel about it?'**

For me, it was as if I had been skating along on the surface of the world, in the sun, and suddenly a big hole had opened up in front of me and I had dropped in. And there I was floundering about in the dark, trying to struggle back up, whilst up there in the sun, life went on as usual. I remember thinking: this is *life*: this is what it's *really* like — I didn't know before.

We had never even heard the words spina bifida or hydrocephalus, and it had never occurred to us that our second child would be less perfect than our first.

I knew as soon as she was born that there was

something wrong with my baby, from the look in the eyes of the nurse over her mask. I asked in sudden panic — 'Is everything alright?' And the doctor told me that, no, it was not quite right, the baby had something wrong with her back and would have to go to England right away for an operation. They showed me her back and I remember it as a dark red patch covered with a membrane.

The first thing I wanted to know was if she *would* be alright, and I was told that she would never walk, and, when I pressed the point, that she would probably be very far

from normal mentally.

The baby was born in the early evening of Friday 14th April and on the Saturday she was baptised, Cheryl, and flown to London for the operation on her back.

## The unknown

I think our main feeling at the time was of bewilderment — we just didn't know anything about this thing that had happened to us, and I'm sure most parents are in the same position. Strangely this seems to be something that the doctors don't realise. It is the unknown which is so worrying. We found then and still do that unless one knows what questions to ask many doctors do not volunteer information. I feel that so



much help could be given to new parents facing this problem, including the important fact that children suffer different degrees of disability. Literature to take home would also help. I think more is done now but certainly for us it was difficult to find out anything.

The baby was in London for three weeks, during which time I phoned nearly every evening to see how she was progressing, and from talking to the nurses who were looking after her, I got my first feeling that I really had a baby, she was lovely, and getting on well.

So then we began to look forward to having her home. She had to stay in London while they were keeping check on her head to see if the hydrocephalus was developing. But we were very lucky, as the hydrocephalus arrested itself, so I went

across to London to fetch her.

During the first four to six months of her life we gradually realised that, apart from some physical problems, our daughter was developing in a normal way. She was bright and lively, a good and happy baby—but not so good that we wondered about her intelligence. She did her share of crying when she wanted something! Her legs were moving well at the hips and knees, although we knew from the total lack of feeling or movement in her ankles and toes that there was a degree of paralysis there.

And so we settled down a little, into a routine of normal babyhood, with clinics to attend and just a few more visits to the hospital than most people expect with a small baby.

### A good cry

I remember one day before Cheryl came home from hospital, sitting in our lounge and having a good cry because I hadn't got my baby and everything seemed so black. My husband was wonderfully understanding, and we decided then that if life had to have its black side, everything else was going to have to be extra good. We had our other little girl, and our home would be as bright and happy as we could make it. Our clothes and car would be as good as we could possibly afford, to compensate for the depressing side. And we have tried to keep to this. I know that if I let myself go and don't bother with my appearance, I very soon get depressed and then

everything goes from bad to worse. We always try to tackle the problems *together*. I think it's very important for *both* parents to be equally able to cope with the handicapped child, as with any ordinary child, so always try to go together to hospital appointments and clinics. If your husband can't go with you, make sure he really knows what is going on and can confidently handle the baby—this is even more important as the child gets bigger. It helps a great deal if dad can cope with the lifting and carrying.

So to any new mother reading this I would advise firstly, always take care of your appearance, hair, clothes, surroundings. . . . Secondly, if it is at all possible for you to have a car or the use of one, learn to drive. It makes such a difference to be able to get about, and enables you to keep more in touch with friends. It is even more useful as the child gets older and you have to cope with wheelchairs and perhaps other children too. Thirdly, when the baby is a few years old and can go to a nursery school, consider getting a part-time job. This does wonders for the morale, takes your mind away from the problems of spina bifida and keeps the finances going. It helps just to be with other adults, doing something useful and not connected with your children!

I think all the mothers I know with handicapped children have suffered some kind of depression during the first five years of the child's

*Continued on p. 10.*

# Attendance allowance

In future, Medical Officers attached to the Department of Health and Social Security are likely to be the doctors completing medical reports for Attendance Allowance claims, instead of family doctors as at present. This change should mean that a smaller number of people will be involved, and therefore more comparable decisions are more likely to be reached.

## £10 Petrol aid

Good news for users of a three-wheeler tricycle issued by the Department of Health and Social Security. As from January 1 this year the annual petrol allowance has been doubled to £10.

## Wanted — a home

Mary. Could you give a home to a pretty, lovable 7-year-old with spina bifida? She is paralysed from the waist down, and is backward. She is more like a 3½-year-old and is also physically petite. She was abandoned at birth and has spent her life in hospital. She would dearly love a family of her own. Enhanced fostering rates would be paid. Please contact: Mrs. H. Willson, Social Services Dept, Acol Crescent, South Ruislip, Middx. Tel: 01-841 6161.

## A MUM'S EYE VIEW—from p. 9

life. In some cases it is very mild and quickly overcome, and others take longer and have more problems, but the strain and anxiety seems to take its toll of everyone after a while. So if you find you are getting weepy, or terribly 'up-tight' with the other children or your husband do

see your doctor right away. So often treatment early on avoids more serious trouble. If you can afford it, get some help with the housework, even if it's just temporary to help you over a bad patch. If you can't afford paid help, try and enlist the help of a sympathetic friend or

neighbour. Either way, *get help before* you feel at the end of your tether.

I had my worst time when Cheryl was five, and fortunately after two or three months on a mild anti-depressant drug I was fine again, and since then I haven't looked back.

*(To be continued next issue)*

## Spring Conference 1975

11th—13th April

Owens Park, University of Manchester



ASBAH's 1975 Conference will have 'Leisure' as its theme. The Lady Jean Mackenzie has once more kindly agreed to be the Conference Hostess, and as in previous years, we shall have speakers of distinction and experience, films, and opportunities for the sharing of experience through discussion.

Owens Park offers an attractive venue, and accommodation will be available for both delegates to the Conference and, where desired, for their families.

Conference sessions will be open to those of 16 years and over, and play facilities for the children of delegates can be arranged.

Programmes and application forms can be obtained from National Office. We look forward to welcoming teachers, club leaders, members of the Association, and all others concerned... photo: Aerofilms Ltd.

*from previous page*

an old tortoise. At intervals tea and orange are served from the small kitchen area.

Outside the ground is rough, but the kids prefer it—they aren't cows just needing grass! There are two sandy hillocks that provide sliding areas, a sandpit, a paddling-pool, tyre swings, and piles of old wood which is delivered regularly and which is used in constructing all kinds of things by the kids. During our scheme we built a look-out tower, which was later surrounded by mattresses and used for jumping-off!

How were our children handicapped? Well, we had a group of deaf who kept to themselves for a long time, but finally started writing messages and joining in activities. Then we had some partially-sighted children, two mongols who demanded constant attention, and lastly we had a little girl in a wheelchair who, being extremely shy and introvert, needed a great amount of encouragement.

### **Circular Walk**

Most of our kids preferred outdoor play, but we organised activities if they wanted, such as puppet and mask-making, drawing, painting, papier mache with which we made a lovely dragon.

When any child tired of an activity, they would come to a volunteer in a wheelchair and ask enthusiastically, "Would you like a walk?" This meant three times round the concrete path outside the hut, as the ground was too bumpy

to go further, but pushing us about gave the kids such pleasure that it was hard to refuse.

As most of our children could walk normally, it was difficult to tell them apart from the others, and as they mixed well with everyone, too, integration was never forced—it just happened quite naturally. It was the same with the handicapped and able-bodied volunteers. After all, everyone is handicapped in some way, be it visible or not.

## **£120 — AND IT'S SO EASY**

The treasurer of the Essex branch of ASBAH remarked to his wife that funds were a bit low.

"Oh, I'll run a jumble sale then".

"Where?"

"In the garden".

"But our garden's too small".

"Oh it will only be a small sale. If we make £10 it helps, doesn't it?"

We decided to call it a "Good as New Sale"—it sounded better, and the date was fixed. But how do we go about it—never having done anything like this before? A friend who had been involved in many jumble sales was very helpful, and offered a duplicator to produce circulars. We decided to sell refreshments, charge 2p admission and have a raffle.

Some friends started to bring articles. Others donated raffle prizes. After a week one wardrobe was full of clothes and we decided that the next lot must go in the shed. About 300 circulars were put through letterboxes. Soon the

**On a Handicamp where everyone has to rough it, pull one's weight, and really join the team, it is super to forget one is disabled. . .**

*If you want to know more about Handicamps write to Mr. Alun Davies, Quaker Work Camps, Friends Service Council, Friends House, Euston Road, London NW1 2BJ (01-387 3601).*

*Quaker Work Camps' endeavour to take handicapped campers in any camps where conditions are suitable.*

shed was full!

We started to throw out anything which was slightly below par, but still the articles piled up. We borrowed a dress rail for displaying the better clothes and pasting tables from friends for the remainder.

Every spare moment was spent sorting, sewing, washing, ironing and pricing clothes.

The week of the sale arrived and a friend donated coffee, milk and sugar, for the refreshments. Another friend gave a tin of biscuits.

The day dawned sunny and fine—phew! Our helpers arrived and when all was ready I opened up. Six people walked in. Oh no! But after 20 minutes it was almost impossible to move.

Two hours of chaos—but fun as well—and it was all over. The result of my wife's 'little jumble sale to raise about £10—£120! And really it was so easy!

**Martin Wales,  
Treasurer, Essex Association**



## Appeals and publicity

ASBAH'S Patron, HRH The Duchess of Gloucester will be attending the *Midwinter Ball* on January 22 at the Dorchester Hotel. As this will be her first public engagement since the birth of her baby we are very much honoured.

# New ideas for the New Year

I do hope you've all had a good Christmas—and are not too exhausted by the effort involved. Somehow, when the jollifications get under way the tiredness gets forgotten, doesn't it?

Of one thing I'm sure: as the times get harder we shall have to think up new ways of raising money for our projects and not rely entirely on our faithful supporters and on the old, well-tried methods. As inflation makes the £1 in people's pockets grow smaller, charitable contributions are bound to shrink, too.

The clever thing to do if we can is to slot into current trends. Take re-cycling for example. This is in fashion now—newspaper, old iron, used postage stamps, silver paper, etc, etc. Though the yield may not be great intrinsically, and collecting may need quite a bit of organisation, it widens our sphere of influence, brings in a greater number of people to support the work Local Associations are doing and creates goodwill and public interest.

The market in what was once near junk has increased enormously—perhaps an auction sale could be organised on the basis of a 10

or 15 per cent levy on what the items fetch being paid into the funds of your Local Association. Sometimes people are so astonished at the price Aunt Aggie's old vase has fetched that they'll share the proceeds half and half.

Such schemes, whereby the donor as well as the recipient gets something out of the transaction, are becoming increasingly popular.

It might be useful to remind you here that in Devonshire Street we carry a small stock of fundraising items for sale at bazaars, agricultural shows, etc, and are always willing to make enquiries about items not in stock which Local Associations are interested in promoting.

We're also very interested in any new ideas which you may have—do please share them with us.

\* \* \* \* \*

At the moment we're in the throes of two traditional-type events: the annual *Homing Pigeon Show* at Doncaster on Friday and Saturday 17th and 18th January, where any budding pigeon fanciers can have a most enjoyable visit; and our *Midwinter Ball* at the Dorchester in aid of the Short Term Care Appeal. We hope a good time will be had by all and big profit.

## SHORT TERM CARE APPEAL

With donations and promises we have nearly reached half way to our target of £100,000, thanks to very many kind and generous gifts from individuals, trusts, Local Associations, Groups and Societies. And another bed has been 'bought' by *Writtle Agricultural College* whose Rag Week Chairman spent three nights peeling potatoes at the local Hospital to swell Rag Week funds!

To all who have helped us we are most grateful and pray their example will be followed by many more, for the longer we delay the scheme the more it will cost us, and that's for sure.

Again, our best wishes to you all for all you wish yourself in 1975.

KATE WHITE

## ASBAH publications and publicity

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

### Scottish Spina Bifida Association booklets

<i>The Spina Bifida Baby</i> by O. R. Nettles, MCSP, ONC	10p
<i>Growing Up with Spina Bifida</i> by O. R. Nettles, MCSP, ONC.	20p

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

## Films

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

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

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

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

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

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

**Posters.** Double Crown, 5p each, "Future Bright", 10 for 20p.

**Flag Day emblems.** 1,000 for 50p.

**Cards** for notice boards. 10 for 10p.

**Car stickers.** 5p each. Postage extra.

**Fund-raising** items. Price list/details on request.

## Local Association offers

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

**Badges for children.** Good quality 1 1/4 in diam. SB symbol and the words, "Spina Bifida Children" in black on green background. Price: 25 badges for 75p; 50 for £1.40; 100 for £2.65, including postage. Cheques and postal orders crossed and payable to "SASBAH". Send with order to: Mrs. I. Olditch, High Lea, Turners Green Lane, Wadhurst, Sx.

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

## Inter-association holiday opportunities

**Camber Sands, nr. Rye, Sussex.** New, well-equipped chalet, on 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.

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

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

**Looe.** Holiday bungalow at Millendreath Holiday Village.

Lincolnshire Association is interested in exchanging its holiday bungalow at Humberston Fitties, near Cleethorpes for one further afield. It is a three bedroom bungalow to accommodate 6-8 people. Further details from Mrs. W. Steele, 59 Louth-le-Clay, Grimsby.

Sleeps six. Fully furnished. Further details Mrs. Cook, 19 Winslade Road, Harestock, Winchester.

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

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

**Prestatyn.** 6-berth luxury San Capelle caravan situated at the Bourne Leisure Centre, Bastion Road, Prestatyn, North Wales. Bookings to Liverpool Association, 46 Manchester St., Liverpool, L1 6ER. Tel. 051-236 4732.

**Selsey.** New well-appointed, self-contained 16ft. x 30ft. 6-berth mobile for families with spina bifida members. Sited at Selsey, Sussex. For full details please send s.a.e. to Mr. R. V. Taylor, 20 Orchard Road, Horsham, Sussex.

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