

# Link

See pp 8/9  
48

JAN/FEB 1977 5p

Association for Spina Bifida and Hydrocephalus (ASBAH)



The Hulme Family—on page 10 Mrs. Hulme writes about her experience of having another baby after having had a spina bifida child.

# the go-between



Sore skin around the stoma can be prevented by using Stomahesive, the Go-Between, from the beginning.

Protective Stomahesive goes between the tender peristomal skin and the appliance reducing risk of leakage and frequency of appliance changes. It fits like a second skin.

Companion products Orabase and Orahesive Powder help to increase security by filling up even those minute spaces through which irritant fluids can attack the skin.

## **Stomahesive™ -right from the start.**

Stomahesive – boxes of 5 10 cm × 10 cm squares  
Orabase – 30 g and 100 g tubes    Orahesive – 15 g puffer pack

Stomahesive, Orabase, Orahesive and Plastibase are Squibb registered trademarks.

Full information available on request:

E.R. Squibb and Sons Limited, Regal House, Twickenham TW1 3QT.





Link No. 48

Association for Spina Bifida  
& Hydrocephalus (ASBAH)

Patron:  
HRH The

Duchess of Gloucester

Chairman:

**Prof. R. B. Zachary, FRCS**

Hon. Treasurer:

**Mr. E. S. Gower, FCIS, FHA**

Correspondence to ASBAH  
at the National Office:

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

Chief Executive Officer:

**Miss M. P. Gilbertson, MCSP**

Appeals Secretary:

**Mrs. Kate White**

Liaison Officer:

**Mr. H. D. Macfarlane**

Link Editor:

**Mrs. Susan Gearing**

#### Contents

pages

- 5 **New Chief Officer**
- 5/6 **News from all around**
- 7 **The role of the social workers**
- 8/9 **Home linking holidays**
- 10-12 **Genetic counselling**
- 13 **Aids and Equipment**
- 14 **Appeals and publicity**

## ● STOP PRESS

We were delighted to learn as we went to press that Miss Oughtred has been awarded the MBE in the New Year's Honours List.

# A tribute to Mary Oughtred

'I care about people and wish to serve them'. These were the first words written by Miss Mary Oughtred in *Link* when the Spring 1970 issue introduced her to readers, following her appointment as General Secretary of ASBAH in December 1969.

Now seven years later, Miss Oughtred has reached retirement. Anyone who has known her tireless energy and dedication during the intervening years will surely agree that rarely can caring and service have been demonstrated in so practical and vigorous a manner.

The challenge accepted by Miss Oughtred was to take responsibility for all aspects of the Association's work and then to get on and do it herself, for at that time she had only a very small staff.

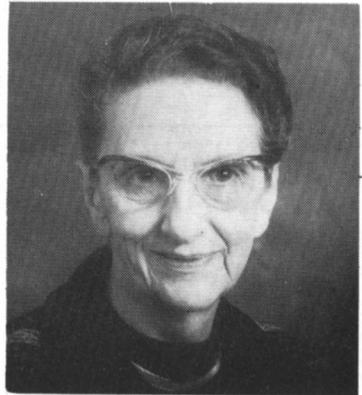
Within a short time solid foundations were laid, welfare problems began to receive sympathetic and skilled attention and our local associations began to seek advice from national office and to receive it. Effective committees were set up to push forward various aspects of the work, and the necessary senior staff were sought as the work and influence of the Association expanded.

There was no aspect of the work which did not receive her careful attention; no calls went unheeded; no demand on her time was too great.

Under her guidance the Annual Conferences were started in 1971, and the Association began producing publications and films which are used universally and have been of great benefit to members and professionals.

Every day Miss Oughtred received telephone calls and letters from individuals, from parents, and from professional workers not only from this country but increasingly from abroad. Inspired by the growing strength of ASBAH, spina bifida associations have been set up in other countries.

No-one knows precisely how many seven day weeks or sixteen



**MARY OUGHTRED**

**Continued on page 4**

## Miss Oughtred Continued from page 3

hour days Miss Oughtred has put in during recent years. Few realise the steady leadership and guidance given by her daily. Yet the effects are obvious in the strength of the Association today—an Association which is widely known and respected for its achievements, notably in the fields of welfare, appliances, research and short-term care.

We wish her many years of happy reward and well-earned leisure.

---

## ASBAH Spring Conference

1st-3rd APRIL, 1977

CLIFTON COLLEGE OF EDUCATION  
WEST BRIDGFORD, NOTTINGHAM

### "A Partnership Approach to the Years Ahead"

*Making the most of Statutory and Voluntary Provision*

Programmes will be ready by mid-January from:

**ASBAH, 30 Devonshire Street, London, W.1**

---

## MOBILITY ALLOWANCE for 5-10 year olds

Alfred Morris, Minister for the Disabled, has announced the date when 5-10 year-olds will receive their slice of the cake—the Mobility Allowance. *April 13, 1977* is the day when payment will begin, but applications will be accepted by the DHSS from *January 12*.

As before, the Allowance is payable to disabled children in their own right, whether living at home or in residential care. Parents of children who are in residential care may claim the allowance on their behalf provided that they give an assurance that their child will benefit from it. Parents of children who are living at home may also claim, even if they are already in receipt of the Attendance Allowance.

## Water sports for all

A water sports course for the disabled is being organised at Stevenage, Herts on 12-15 June by the Central Bureau for Educational Visits and Exchanges. It is hoped that there will be participants and instructors from this country and overseas. The course will include sailing, canoeing, fishing, water skiing and swimming and will cater for all, from novice to expert. The aim is two-fold—to introduce qualified water sports instructors to the problems of teaching the disabled, and actively to encourage young disabled to participate. For more details contact Mr. Bob Price at the CBEVE, 44 Baker Street, London W1M 2HJ.

## Fishing film planned

The Disabled Living Foundation, with the active support of the National Anglers' Council is to make a technical film for disabled people already enjoying angling and for those who wish to do so. The film will cover sea, coarse and game angling. It will show how disabled people can enjoy this sport; how special tackle has been designed for them; where they may fish in safety and comfort and how they may learn the basic techniques of angling.

The DLF is anxious to obtain as much information as possible from disabled anglers, fishery owners willing to cater for handicapped people, equipment designers and would-be anglers who have met snags in trying to take up the sport. Clubs may also be able to help. Please contact: Miss Kay Evans MBE, DLF, 346 Kensington High Street, London W14 8NS. Tel: 01-602 2491.

### New 'loo' guide

The new edition of 'Access to Public Conveniences', published by the Central Council for the Disabled is now out—more than double the size of the former guide. It gives details of facilities at public conveniences all over England and Wales (and now includes those at some National Parks, Royal Parks and Picnic Areas). Price 50p from CCD, Publications Dept, 34 Eccleston Square, London SW1V 1PE.



# News from all around

## Growing up: teenagers' plea

Mr. Tim Robinson, Secretary of Sheffield Local Association writes about a recent day conference for teenagers organised by the Yorkshire Associations and held in Leeds.

'There were over twenty teenagers there from all over Yorkshire. We had three speakers talking about getting on with other people, including sex and marriage. Afterwards we had discussion groups and ended up with a disco.

'Perhaps the main thing that came out was that, like any other teenagers, they want to be allowed to grow up. The trouble is we often wrap them up in cotton wool and do things for them they could do for themselves, or stop them taking risks and doing things they want to do. We obviously do this a lot more than we think.

'One little thing — if you've got a teenager, have they ever seen their Consultant on their own, or do you always go with them? Many of the teenagers said they wanted to see the Consultant on their own but they'd never had the chance. Are you letting your youngster grow up enough? . . .



## Stepping out for £200

Four energetic young men from Cardiff who raised £200 through a sponsored walk from Cardiff to Porthcawl (35 miles) to pay for the children of the Cardiff group of South Wales Association to go to the pantomime. With them (left) is comedian Stan Stennett, the star of the pantomime, and Mrs. Janet McNulty, Secretary of the Cardiff group. Stan Stennett is pictured presenting the walkers with a small shield each and he has suggested that the mums of Cardiff group organise a sponsored walk which he will lead. Photo: *Western Mail*.

## ASBAH's Chief Officer

Link extends a warm welcome to Miss Moyna Gilbertson who became ASBAH's Chief Executive Officer at the beginning of the year. She takes over from Miss Mary Oughtred.

Miss Gilbertson has been Group Superintendent Physiotherapist at the Hospital for Sick Children, Great Ormond Street. Outside her professional work she has been actively concerned with the welfare of disabled young people in the community.

Link will introduce Miss Gilbertson more fully in a future issue.

## Glyn lends a hand

A letter from Glyn Castrey of Biddulph, Stoke-on-Trent: 'I am twelve years of age. I was born with severe spina bifida and hydrocephalus, and I have had a total of 16 operations. I realise what a lucky boy I am

to be alive. And I realise there are hundreds more children like me. So out of my pocket money I bought a small gift and had a raffle which fetched a total of £6.50. I would like the Spina Bifida Association to have this money.'

Thank you Glyn.



# News from all around

The Association in Preston and District started in 1967 through the efforts of a small group of determined parents. Enthusiasm ran high with activities such as coffee mornings, jumble sales, garden fetes and Christmas card sales in addition to the monthly meeting.

A seaside holiday home was an early priority and within three years the ambition was realised with the purchase of a bungalow in Fleetburgh near Grange. A few years ago camping equipment was also bought and is available for the use of members.

Over the years the Association has grown and developed

## Preston's progress

and now serves a much wider area.

The aims of the group have remained broadly the same but it has been necessary to split the Committee into three to meet present day needs. The Social Committee was extremely pleased with a day trip to London in June last year for 12 children. A recent parents' evening proved popular and the Christmas party was also a great success. The Fund Raising Committee, despite the difficulties of

inflation, continues to raise considerable sums of money. The generosity of many local organisations and individuals is tremendous. The Welfare Committee seeks to resolve family difficulties and is particularly concerned with schooling and medical treatment.

The problems of secondary education and employment prospects have been recognised and discussions have been held with the Department of Employment and local Council officials on sheltered workshops and occupation centres.

● **Link hopes to take regular looks at the activities of the Local Associations.**

# Mobility for the disabled



- Get out and about.
- Range - up to 12 miles.
- Just plug in for overnight battery charging.
- No licence required.
- Climbs kerbs and steep gradients.
- Weather equipment and road lighting available.

Send for free folder and demonstration details

Braune of Stroud, Griffin Mill, Thrupp, Stroud, Gloucestershire GL52AZ. Telephone 045-3882243.

Name \_\_\_\_\_

Address \_\_\_\_\_

LINK

Mr. Peter Poole, ASBAH's Social Work Adviser writes the second of his articles on the vital role of the social worker.

## Social workers provide some of the answers

### Princess Anne presents Jackie with trophy

Congratulations to 16-year-old spina bifida rider, Jackie Doughton of Wolverhampton who was recently presented with a riding trophy by Princess Anne. Her Royal Highness presented the Giltspur Senior Cup to Jackie, and trophies to other riders when she visited the National Equestrian Centre at Stoneleigh in Warwickshire. Jackie has been riding with the Wolverhampton Riding for the Disabled group for more than two years, and in fact this was the second time that she had won the Giltspur Cup.

Most mothers hearing the first few devastating words describing their child's condition find it incredibly hard to accept. "Why me? What did we do wrong? Whose fault is it? Will there always be a risk to future children?"

As if this were not enough parents also have to face the often complicated and sometimes confusing information about the nature of the condition and how this may affect the baby's future. Inevitably they ask—"Will our baby die? How handicapped will he be? Will this affect the intellect?" The doctors, no matter how skilled, do not always have an absolute answer.

It is not surprising then, that the seemingly secure world becomes a much more frightening place, especially when many of the questions appear to have no immediate answer. It is also very hard, at a time like this, to sit down and read a book even though it may be comprehensive. Parents are, naturally enough, anxious about the future of the child and the whole family.

Most parents will not have considered the question of handicap prior to the birth of their spina bifida child and to bear this kind of shock on top of the experience of actually giving birth is the greatest trial any mother could be expected to endure.

It is at this point that many mothers feel they are most vulnerable and would be greatly reassured if they were able to discuss these fears and anxieties with someone who has special experience with this particular problem—someone who understands not only the medical and physical aspects of the condition but also realises just what this will mean to parents and the family not only just now but in the future. It was for this reason that the Association's social work service was begun.

How then does our worker know about the spina bifida child? In most cases the information comes either from the hospital or from the local health visitor—sometimes via the local authority social services dept. (medical social workers now form part of the local authority team). Occasionally we hear direct from a parent asking to join the Association and, of course, our social workers visit any members in their area who wish to see them.

All ASBAH social workers co-operate very closely with hospital and local authority staffs. We see ourselves as complementary rather than replacing the statutory services because this enables us to make the most of all available help and to take advantage of many extra resources.

Absolute confidentiality is maintained at all times so that all our members can be assured that nothing will be passed on to any other person without the authority of the person concerned. This is the only way in which we can ensure absolute trust between ourselves and those we seek to help.

It is a source of great comfort to hear how much the service is appreciated both by members and by other workers. Social workers meeting together share the information gained from the members themselves as well as from other sources. The amazing courage and perseverance of those with spina bifida and their families gives us all tremendous encouragement in the work we do.

# Travelling abroad

## Home Linking opens up opportunities for the disabled

**For many years thousands of able-bodied young people in this country have been able to enjoy holidays with families on the continent. Now this is becoming a possibility for more and more disabled.**

In the last two years a number of young disabled — some severely disabled — have enjoyed exchange holidays or paying guest visits, arranged through the Home Linking Scheme. The scheme is organised by Mrs. Kay Duncalfe, a member of the Disabled International Visits and Exchanges (Dive) Committee.

The holidays are flexible, lasting one or two weeks, a month or longer, and arranged to suit the wishes and needs of the young people concerned. In some cases the disabled visitor has been able to attend classes at language course centres and to take a full part in the centre activities.

Here are a few young people who have taken advantage of the scheme so far:

● *Barbara Schnitger*, a 16-year-old German girl with spina bifida — needing a wheelchair most of the time —

stayed for a fortnight with an English family with two severely handicapped daughters of 17 and 21. She returned home to Germany with the elder English girl who stayed with her for eight days.

● *Lucy Savage*, 20, a University student who has spina bifida was able to spend a year in a French school, staying with a family nearby. Lucy is more-or-less confined to a wheelchair.

● *Eva Rundstrom*, a very severely handicapped spina bifida girl from Sweden stayed for three weeks with an English family where the wife is a nurse and where there were two able-bodied boys. She met an English spina bifida girl and they became penfriends which may hopefully lead to an exchange.

If you would like to know more about the Home Linking Scheme, or if you would like Mrs. Duncalfe to come and talk to your Association contact her at: The New Forest Continental Youth Centre, Corner Cotage, Hangersley, Ringwood, Hants. (Tel: Ringwood 2017).

**Don't forget that ASBAH National Office is always very willing to help anyone with their holiday arrangements whether for a holiday in this country or abroad and has a lot of useful information, contacts and addresses. The person to contact is Mr. Macfarlane.**



**Annette Brayley who visited Sweden in the Summer (see her story below).**

## Annette in Sweden

**Annette Brayley from Southampton writes about her two week visit to stay with a Swedish girl in Gothenburg, arranged by Mrs Duncalfe and an organisation in Sweden called 'People to People—Sweden'.**

"After a very pleasant flight from London Airport I arrived in Gothenburg to be met by two very friendly people who after taking me to tea took me to the house of my host.

"I had a very happy time in Sweden, but found everything rather expensive, especially

taxi fares. I had to use taxis quite often when my host was working or unable to accompany me on tours.

"I did find out near the end of my stay, too late for myself, unfortunately, that there is a pass available for disabled visitors to Sweden.

"I visited a place called Dulhamous Hus. This is almost like a motel especially adapted for the disabled with its own swimming pool. It

accommodates parties of disabled people from all over the world. I found the staff and visitors there very helpful and I spent two days in their company. I visited many other interesting places whilst in Sweden and returned to England with many happy memories".

## Ulrich in England

**An exchange holiday was arranged for nine-year-old Nina Bugden of Southampton who has spina bifida and Ulrich Bauer, a 15-year-old German boy. Ulrich stayed with Nina's family in the Summer and here Mrs. Bugden writes about his visit. (Nina was due to go to Ulrich's home for Christmas and the New Year.)**

"We met Ulrich at Heathrow. He had travelled from Stuttgart in the care of a hostess and had enjoyed the flight.

"He was very small for his age and was not able to go up and down steps unaided as he could not judge their depth. He had hydrocephalus controlled by a shunt. His

arms and legs were weak and he had to wear built-up shoes. Although he spoke very good English he was forgetful. If we told him to get ready for bed, he had quite often forgotten before he reached the bedroom! This meant that although he was physically capable of doing things for himself we still had to continually check on him.

"We all went to Looe in Cornwall for a week. We travelled to Land's End and other places of interest and we helped Ulrich to keep a diary so that his family could read of his holiday . . .

"His mother has said that Ulrich enjoyed his holiday and we are hoping that Nina will enjoy her stay in Germany".

## AIDS FOR THE INCONTINENT

### the 'INCO' range

AS SUPPLIED TO HOSPITALS & NURSING HOMES

#### PULL ON PANTS

Soft, washable, waterproof PVC - low cost re-usable protection for men, women and children. Elasticated at waist and leg for extra confidence. Ideal for handicapped or arthritic people. Retaining bands ensure the absorbent, disposable liner is held securely in place.



Quantity	1	2	3	4
28"-32"hip	£1.30	£2.50	£3.70	£4.80
34"-38"hip	£1.40	£2.70	£3.90	£5.20
40"-46"hip	£1.60	£3.10	£4.50	£6.00
48"-54"hip	£1.80	£3.50	£5.10	£6.80
56"-60"hip	£2.00	£3.90	£5.70	£7.60

#### DROP FRONT GARMENTS

Light weight, washable, waterproof garment. Sealed elasticated back and a tie tape adjustment at the legs for a snug, confident and comfortable fit. Waist tapes at the front enable the front to be dropped to replace the absorbent pad without the garment falling down. Press studs allows additional adjustment round the hips.



Quantity	1	2	3	4
24"-32"hip	£1.90	£3.70	£5.40	£7.20
34"-46"hip	£2.10	£4.10	£6.00	£7.90
48"-58"hip	£2.40	£4.70	£6.90	£9.20

#### INCONTINENCE ROLLS

Quantity	1	2	3	4
6" x 10ft. 65p	£1.15	£1.70	£2.30	

Special discount terms available for group orders. Please ask for details



Replies in complete confidence together with cheque/P.O. IMPORTANT - Please state your hip size when ordering. Please add 25p P & P to each order.

**HAZELOAK SUPPLIES**

Dept. L1 39 Otley Road, Leeds LS6 3AP

---

# GENETIC COUNSELLING...

The main aim of genetic counselling is to help parents to have normal children and the commonest question which genetic counsellors have to answer is "Will it happen again" following the birth of an infant with birth defects.

This question can be answered in some cases by a definite "no". For example a baby born with defects due to German measles during pregnancy will rarely have a brother or sister with the same problems. However, in the majority of cases there is a small risk of recurrence although only in a few is the risk very high. For example, in spina bifida which probably is caused, at least in part, by an environmental agent a subsequent brother or sister generally has a 1 in 20 chance of being affected by spina bifida or a related condition. In other situations in which the defect is

definitely inherited, the risks may be rather greater. For example some forms of dwarfism would have a 50% risk with each subsequent pregnancy while in haemophilia and Duchenne muscular dystrophy half of all sons are likely to be affected. In some biochemical disorders like cystic fibrosis and phenylketonuria the recurrence risk is 25% for each successive child.

Thus, it can be seen that recurrence risks vary from effectively nil to as high as 50% for successive children. However, in most cases the recurrence risk turns out to be relatively low and much less than the parents expected while in moderate or high risk situations it is increasingly possible to offer the parents pre-natal diagnosis so that a defective fetus can be aborted.

Pre-natal diagnosis of birth defects can be best illustrated by two of the commonest handicapping conditions, spina bifida and the Down's Syndrome (mongolism). Mongolism occurs in about 1/600 live born children. Spina bifida and related disorders occur in about 1/200 births. In both cases a sample of



---

**We are a family which includes Richard, a six-year old spina bifida sufferer, who was the youngest until last year when we had our fourth child. It was the first time I had really been afraid that my baby would not be normal.**

Every mother fears her baby could have something wrong with it but this can normally be pushed into the back of one's mind. This is not so easily done when you have already had one child with spina bifida as you have a 1 in 20 chance of it happening again. Luckily in the last few years doctors have devised a test which can, in most cases, show whether the baby has severe spina bifida or not.

The test is done by drawing off some of the amniotic fluid from around the baby, quite

*"Now all the worry has been worth it"*

painlessly, and analysing it. Too much of a special protein means that the baby has an open spina bifida through which the spinal cord fluid is escaping. If this proves to be the case then an abortion can be arranged.

I had this test done when I was 13 weeks pregnant and after a terrible wait of a week, we were told that everything appeared to be normal. Even so it was still possible the baby could have a closed spina bifida, which normally means

little or no paralysis.

So even after the test the worry was still with us. For the rest of the pregnancy I was fine except for the heat of last summer which more or less disappeared whilst I was in hospital having the baby. Matthew was born by Caesarian section after I had to go into hospital because my blood pressure shot up at the end of my pregnancy, due I'm sure to all my fears about my baby.

Now all the worry has been well worth it. You can have no idea how marvellous it was to watch him kick his legs about.

We also feel that having this baby has done Richard a lot of good; he has had to become more independent as there has not been as much time to see to his needs.

SANDRA HULME

---

---

# ... the aim is to answer the vital question—Will it happen again?

amniotic fluid ("the waters") obtained at 16 weeks of gestation can be examined and if found to be normal the mother can be reassured that her fetus probably does not have spina bifida or mongolism.

Sadly, we cannot always check the amniotic fluid for mongolism when the test is done for spina bifida (because we do not have enough trained laboratory staff) although we do so when the mother is over 35 or has a family history of mongolism.

The test for spina bifida depends upon the leakage of blood products from the fetus into the amniotic fluid when there is an open spina bifida present. The test is carried out following an ultrasonic scan which allows the baby's head to be measured and the placenta (after birth) to be located. A sample of fluid is taken through a fine needle carefully avoiding the placenta. This test is now routine and should be offered to the majority of women who have had a child with spina bifida or related neural tube defect.

Mongolism can be diagnosed by looking at baby's cells which are floating in the amniotic fluid in which the baby swims. These cells have to be cultured for a period of 3 or 4 weeks before it is possible to examine the chromosomes. Since mongols have an extra chromosome a fetus with a normal number of chromosomes is almost certainly not going to be a mongol.

Although the amniotic fluid is obtained as before, this test is not so easy to perform in the laboratory and the number of women who can be offered this investigation is still restricted. However, the chance of having another mongol child is quite small in most cases being of the order of only 1%. Women over 40, however, have a relatively high risk of bearing a mongol child even if they have not had one in the past. Consequently, it is now usual for pregnant women over the age of 40 to be offered this test.

I pointed out earlier in this article that the majority of birth defects came without warning

so that genetic counselling today is still largely concerned with helping women to avoid a second tragedy. However, much research is going on into ways in which a **first** child with birth defects might be detected during the early stages of pregnancy, thus, allowing a termination to be carried out. One of these is to examine the blood of pregnant women to see whether any of the blood products of the spina bifida fetus spill over into the mother's circulation as they do into the amniotic fluid. So far this has not proved to be completely reliable but it does at least show the way in which these tests may develop.

Genetic counselling is becoming more widely available in Britain and its success depends on parents themselves asking for advice. No attempt is made to tell people what they should do and no attempt is made to force parents not to have children. Experience has shown that when most parents are given clear information about risks they generally behave extremely sensibly.

Genetic counselling is a very important development in the Health Service and involves geneticists, hospitals, family doctors, health visitors and the community generally. Good genetic counselling takes into account the need for access to family planning and sterilisation. Abortion of fetuses with defects is accepted by a majority of people in this country. Women who come early enough to the genetic clinic have access to selective termination of pregnancy if the fetus is shown by tests to be defective.

Fortunately, the pre-natal diagnostic tests usually show that the baby does not have the defect for which tests are being done and thus is a great source of comfort to parents. In the rare event that the child is a mongol or does have spina bifida then an abortion can be followed by further pregnancy which has a good chance of bearing a normal child. In this way one is exchanging a defective fetus for a healthy normal child.

DR. R. HARRIS

# GENETIC counselling...

I am writing to *Link* in the hope that our experiences may give reassurance to other parents of children handicapped by hydrocephalus but who long to expand their families.

After losing two babies at birth, I gave birth to a daughter in 1967. You can imagine our bewilderment and fear when Annwen was diagnosed as suffering from a severe degree of hydrocephalus; we were told that there was little chance of her survival and even should operations prove successful that she would always be a vegetable, unable to walk, talk or communicate with us. So severe was her disability that we were urged to have her admitted to an establishment where she could receive specialised help.

Annwen came home to us after her valve was fitted. There had been numerous problems during her stay in hospital and there were to be more during the following years, but by the time she reached six she could walk for a short distance without aid and had a vocabulary which was wide and varied. My husband and I had spent seemingly endless hours trying to help and encourage her development but we could take no credit at all for her most startling characteristic—a disposition so sunny, so loving that she was known and loved by everyone who met her.

Unfortunately Annwen died suddenly at the age of six; our sense of loss was so great we



The Llewellyns with Cerian

“Having taken  
... help and  
advice  
go ahead,  
good luck”

felt that it could never be filled and the thought of another child taking her place was out of the question. But gradually our ideas changed, for Annwen had wanted a brother or sister and we both love children.

Of course, we were now aware of the dangers of another pregnancy. We received genetic counselling and when I became pregnant again I was able to have amniocentesis and constant care.

Following a prolonged stay in hospital where I received excellent and compassionate care and nursing, our daughter

Cerian was born in February last year, a perfect baby, small but already full of vitality.

Now at eleven months she continues to make excellent progress. She does not replace Annwen for after all they are different children. Annwen is remembered daily with love and with gratitude. The little we gave her was repaid tenfold by that which she gave us.

To other parents, afraid as we were to consider another child, I would say, having taken advantage of all the available help and advice, go ahead and good luck.

**CHRISTINE LLEWELLYN**  
Penarth  
South Glamorgan

---

## Chalet swap

South London Association would like to exchange their six berth chalet at Highlands Park, Clacton for a similar one elsewhere. Would any other Association be interested in a swap? Please contact Mrs. C. Byrne, 10 Wexford Road, London SW12.



## Aids and equipment

The National Aids for the Disabled Exhibition, in its 4th year returned to the original site in Brighton after two years in Harrogate. It was linked with a Conference run by the Central Council for the Disabled featuring **Holidays and Employment.**

The Exhibition and Conference attracted a record number of people—about 5,600, and over 300 respectively.

There were over 80 exhibitors mainly concerned with products to help the disabled with daily living. The Open University, the Department of Health and Social Security, and some voluntary organisations were also there to make their work known among professionals and other people visiting the Exhibition.

Exhibitors included a wide range of firms concerned with the manufacture of wheel-chairs, both hand-operated and

## 80 Exhibitors with disabled in mind

powered; a number of firms concerned with bathroom aids and shower units, lifts and stairlifts.

**ASBAH's representatives at the Exhibition had several talks with Mr. Braune, maker of the Batric Chair. This has now been redesigned and looks very much more "with it" and less like a "grass cutter". The firm is developing a waterproof cover which will make the chair more practical. The Batric Chair is more within the grasp of the average family as a result of the Mobility Allowance as some people may decide to save up the weekly allowance to obtain one.**



Another piece of mobility equipment for which a waterproof cover has been newly designed is the Baby Buggy (see picture). The cover—called the hood and apron—can be obtained at the special price of £4.60 plus VAT if ordered through ASBAH.

## New "Aids and equipment" booklet

**Many Association members will know of the booklet written by Mrs. Olwen Nettles. This became out of date, and just before she left the Association, Miss Felicity Birkett the Appliance Officer, revised the original sections and included a new section on manufactured equipment.**

This new 88-page booklet is extremely well illustrated in order to help both families and professionals study the range of what is available and so find what is best for the individual concerned.

It is important to remember that the booklet cannot possibly cover all available products and inclusion of items does not indicate any special approval of them. The role of the Association is to make known the type and range of products available. Recommendations can only be made in the light of individual circumstances.

"Aids and Equipment" costs 60p plus 14p postage. The special price for Local Associations ordering 10 or more copies is 55p plus postage. A sample copy has been sent to each local association secretary.

The baby buggy manufacturers, Andrews Maclaren Ltd., have now produced a de luxe version of the buggy, offering extra support and comfortable padding, which could prove very suitable for many handicapped youngsters. If you would like more information contact ASBAH at National Office, who will be able to arrange a special price.

For the national staff responsible for the ASBAH stand it was a great pleasure to have the help and support of the Sussex Association, and to welcome visitors from the Sussex and other Associations.



## Appeals and publicity

### "A DAY WE SHALL NOT FORGET"

Following the opening of Five Oaks I had many letters but would like to pass on part of one as the sentiments apply to all the work that is done by our members up and down the country.

"I must write to say how much we enjoyed attending the opening of the Home at Five Oaks. When we realised to the full what the home meant to the children, we were indeed extremely moved and very gratified that we had been allowed to take part in helping you and your team to achieve such a marvellous dream. It was certainly a day we shall not forget and one which will be recounted on many occasions. The devotion, love and compassion shown by many for those less fortunate than themselves never ceases to impress us and at Five Oaks it was there in abundance for all to see."

### Albert Hall Concert

ASBAH is planning a wonderful concert with the Royal Philharmonic Orchestra at the Albert Hall, London, on Thursday, 29th September, 1977. Music lovers please book the date.

Kate White

### 'SPECIAL FOR LIFE'

The National Council for Special Education is holding its 1977 National Conference at Padgate College of Education near Warrington, Cheshire on July 25-28. The theme will be 'Special for Life?', and the Conference will review the different provisions within the community before, during and after school-life for all kinds of handicaps. The speakers will include Dr. R. Harris, Prof. P. Mittler, Prof. N. Butler, Dr. L. Rosenbloom, Dr. A. I. Rabinowitz and Dr. E. E. Simpson. More details from: Mr. J. D. Waler, Greenbank Residential School, Greenbank Lane, Hartford, Northwich, Cheshire. (Please enclose foolscap s.a.e.)

### THE SILVER JUBILEE

As ASBAH's tribute to Her Majesty's Silver Jubilee, we are organising in London and the Home Counties THE GREAT JUBILEE BOAT RACE:

Companies and individuals will be invited to sponsor a toy boat or boats, which will each carry the name of the sponsor and the address to which the finder should return it. The fleet of boats will be launched in the English Channel on a date early in May and the finder and sponsor of the boat that travels the furthest will be rewarded with a small prize. We shall probably launch the boats from a helicopter in mid-Channel. If any Local Associations would like to join in would they contact me for more details.



#### THE SHASBAH TROLLEY FOR HANDICAPPED CHILDREN

(Now fitted with rubber caster on the front)  
Patent applied for in

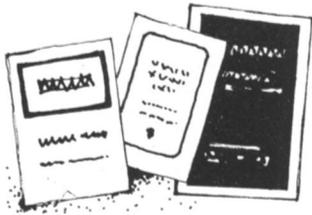
UK, Commonwealth Countries, USA, Canada

**Standard model** for children one to five years old costs £13.00 plus carriage.

**Large model** for children five to ten years old costs £16.50 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.



**READ  
ALL  
ABOUT  
IT**



## ASBAH booklets . . . leaflets . . . posters

<i>Your Child with Spina Bifida</i> , by J. Lorber, MD, FRCP	20p
<i>Your Child with Hydrocephalus</i> by J. Lorber, MD, FRCP	15p
<i>The Nursery Years</i> , by S. Haskell, M.A., Ph.D., and M. E. Paull, Dip. Ph.H.	15p
<i>Children with Spina Bifida at School</i> . Ed. P. Henderson CB, MD, DPH	30p
<i>The Care of an Ileal Conduit and Urinary Appliances</i> by E. Durham Smith, MD, MS, FRACS, FACS and others	15p
<i>Clothing for the Spina Bifida Child</i> by Barbara Webster, SRN, RSCN	15p
<i>Aids and Equipment (1976 Edition)</i>	60p
Information leaflets	100 for £1.30

All available from ASBAH, 30 Devonshire Street, London W1N 2EB. (Special rates available to Local Associations.) Please note that postage is extra. Allow a minimum of 9p per booklet.

### Scottish Spina Bifida Association booklets.

*The Spina Bifida Baby* . . . being revised.  
*Growing Up with Spina Bifida* . . . 20p. both by O. R. Nettles, MCSP, ONC.  
Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh, EH4 2BW (at special rates for bulk orders).

### Fund raising and publicity material

#### Posters

Best Foot Forward 20 x 30in. — 10p each.  
Best Foot Forward 15 x 10in. — 10 for 40p.  
For local publicity 15 x 10in. — 10 for 40p.

#### Car Stickers 5p each.

**Cards for Notice Boards** 10 for 10p.  
**Flag Day Emblems** 1,000 for 70p.  
**Plastic Lapel Badges** £2.10 for 100.

All available from Appeals Dept. — postage extra. Full list on request.

**Spina bifida badges.** 25p each, postage extra. (for one badge enclose s.a.e.). Bulk orders particularly welcome. Available from: Mr K. McKenzie, Salisbury & District ASBAH, 111 East Gomeldon Rd, Gomeldon, Salisbury SP4 6LZ.

## Holiday accommodation for spina bifida families

**Camber Sands, nr. Rye, Sussex.** New well-equipped 6-berth chalet near the sea. Details: Mrs Evans, 1 Coniston Gardens, Wembley, Middx. 01-904 7840.

**Christchurch, Dorset, Hoburn Farm.** 6/8-berth caravan, 1 mile from sea, near New Forest. Details: G. R. Large, 89 Duchess Way, Queensfield, Swindon.

**Easington, Withernsea.** 7-berth caravan on well-equipped site by sandy beach. Details: Mr A. Clark, 3 Leys Close, Carleton, Skipton, N. Yorks, BD23 3EW.

**Golden Sands, Voryd, Rhyl, N. Wales.** 8-berth caravan, mains water, electricity, gas, shower and T.V. Every facility on site, right by the sea. Details: Mr Adams, 58 Strathedan Road, Bradeley, Stoke-on-Trent.

**Great Yarmouth.** Caister Beach Caravan Camp — 6-berth caravan. Details: Mrs E. N. Barefoot, 23 Marlborough Road, Southall, Middx. Tel. 01-574 5067.

**Haggerston Castle** (5 miles south of Berwick-on-Tweed). 8-berth caravan. Details: Mrs Connolly, 103 Raby Rd, Oxclose, Washington, Tyne and Wear.

**Isle of Wight.** Brambles Chine, Yarmouth. 6-berth luxury chalet-bungalow, adjoining beach. Available all year. Car an advantage. Details: Mrs S. Gully, Little Orchard, Eddington Road, St. Helens, I.W. Tel. Bembridge 2141.

**Looe.** Millendreath Holiday Village. Three bungalows. Details: Mr Keith Jackson, 202 Exeter Street, Plymouth. Mrs Cook, 19 Winslade Road, Harestock, Winchester, and Mr C. Matthews, 11 Kingsbere Ave., Wallisdown, Bournemouth. Tel. Bournemouth 53850.

**Mablethorpe.** Two well-equipped self-contained chalets, 6-berth, at Golden Sands Estates. Details: Mr B. Guest, 57 Bloxwich Lane, Leamore, Walsall, Staffs.

**New Forest.** Well-equipped 6-berth chalet. Easy reach of Bournemouth, Beaulieu etc. Swimming pool, paddling pool, restaurant, playground on site. Details: Mrs A. Rae, 16 Clifton Rd, Lee-on-Solent, Hants. Tel. Lee-on-Solent 550242.

**Prestatyn.** 2 luxury 6-berth caravans at Bourne Leisure Site. £22 per week. Due to demand one week bookings only are possible. Bookings from March 1 to: Mrs E. Taplin, Colonial House, 63 Corporation St, Manchester M4 3DT.

**Selsey.** New well-appointed, self-contained 16ft x 30ft 6-berth mobile home. For details send s.a.e. to: Mr R. V. Taylor, 3 Dickins Way, Horsham, Sx RH13 6BQ.

**Skegness.** Specially designed, well-equipped bungalow, sleeping 8, at Chapel St Leonard's, nr. Skegness. Pleasant site near safe beach. Details: Mrs J. Brook, 11 Standforth Rd, Dalton, Huddersfield HD5 9HD. Tel. Hudd. 21776.

**Winterton-on-Sea, nr. Great Yarmouth.** New well-equipped 6-berth chalet. Indoor swimming pool, shop, and play areas. Details: Mr R. Morris, 127 The Pastures, Downley, High Wycombe, Bucks. Tel. H. Wycombe 32184.

**Withernsea.** Well-equipped 6-berth chalet at Golden Sands Chalet Park. Shop, licensed club, play areas, amusements on site. Details: Mrs F. D. O'Callaghan, 14 Dyer Lane, Wheatley, Halifax. Tel. 0422 56402.

## AFFILIATED ASSOCIATIONS – Hon Secretaries

### **BEDFORD AND DISTRICT**

Mr. S. Odell,  
9 Beauchamp Rd, Wootton,  
Beds MK43 9EZ.

### **BOLTON AND BURY**

Mrs. B. Grosvenor, 12 St. Peter's Rd,  
Bury, Lancs, BL9 9RB.

### **BOURNEMOUTH CHRISTCHURCH & DISTRICT**

Mr. R. A. Frake, 11 Scott Close,  
Wallisdown.

### **BRISTOL**

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

### **BROMLEY & DISTRICT**

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

### **BUCKINGHAMSHIRE**

Mrs. L. E. Tilly, 2 St. John's Drive,  
Windsor, Berks.

### **BURNLEY**

Mr. M. Lane,  
5 Creswick Ave, Burnley, Lancs.

### **CALDERDALE**

Mr. A. L. Crowther,  
42 Marldon Rd, Northowram, Halifax.

### **CHESTER & DISTRICT**

Mrs. K. Jones,  
58 Park Avenue, Howarden, Clwyd.

### **DARLINGTON AND DISTRICT**

Mrs. M. Crawford,  
53 Linden Terrace, Copley,  
Bishop Auckland, Co. Durham.

### **DERBY**

Mr. O. Baker,  
16 Marston Close, Littleover.

### **DEVON AND CORNWALL**

Mr. J. Carter,  
5 Dunle Rd, Mannamead, Plymouth.

### **DOL AND DEARNE**

Mr. T. J. Murphy,  
43 Cutts-Ave, Wath-on-Dearne, Yorks.

### **DUDLEY & WOLVERHAMPTON**

Mrs. G. M. Norman,  
231 Coalway Rd, Merry Hill,  
Wolverhampton.

### **EAST ANGLIAN**

Mrs. M. Drewry,  
1 Fieldsteads, New Rd, Impington,  
Cambridge.

### **ESSEX**

Mr. V. Williams,  
122 Rothbury Ave, Rainham.

### **GLOUCESTERSHIRE NORTH**

Mrs. J. Hall,  
Old School House, Church Rd,  
Caincross, Stroud.

### **GREENWICH**

Mrs. A. Pearson,  
80 Brinklow Crescent, Woolwich, SE18.

### **HAMPSHIRE NORTH, W. SURREY & S. BERKS.**

Mrs. Selby,  
The Old Police Station, Leapale Road,  
Guildford.

### **HAMPSHIRE SOUTH**

Mrs. P. J. Jewell,  
19 Stockheath Lane, Havant, Hants PO9 3BU

### **HERTS AND SOUTH BEDS.**

Mrs. E. M. Thomas,  
19 Florence Ave, Sundon Park, Luton.

### **HUDDERSFIELD**

Mrs. J. Brook,  
11 Standiforth Rd, Dalton, Huddersfield,  
W. Yorks.

### **HULL & DISTRICT**

Mrs. G. D. Brown,  
233 Cranbrook Ave. Hull HU6 7TX.

### **JERSEY (Channel Islands)**

Mrs. U. Emmanuel, Le Lavandou,  
Gorey Village, Jersey, C.I.

### **KENT**

Mr. M. J. Apps  
33 Beresford Rd, Gillingham.

### **LEEDS AND BRADFORD**

Mr. G. Baxter,  
38 Hoyle Court Rd, Baildon, Yorks.

### **LEICESTERSHIRE**

Mr. P. Cusack,  
31 Lime Grove, Kirby Muxloe.

### **LEIGH & DISTRICT**

Mr. T. Power,  
3 Taunton Drive, West Leigh, Lancs.

### **LINCOLN, GAINSBOROUGH & MID Lincs.**

Mrs. P. Keyse,  
Pinfold, Chapel Lane, North Scarle,  
Lincoln.

### **LINCOLNSHIRE N.E. & S. HUMBERSIDE**

Mr. T. Chapman,  
32 Glenfield Rd,  
Grimsby, S. Humberside.

### **LINCOLNSHIRE SOUTH**

Mrs. P. Mason,  
2 Mayfair Gardens, Boston.

### **LIVERPOOL**

Mr. P. A. Glennon,  
Tudor House, Wood Lane, Netherley,  
Liverpool L27 4YA.

### **LONDON, CENTRAL & NORTH**

Mrs. J. Mason,  
65 Belmont Lane, Stanmore,  
Middx.

### **LONDON N. EAST**

Miss D. Baxter,  
8 Keith Ave, Wickford, Essex.

### **LONDON N. WEST**

Mr. L. R. Mower,  
59 Betham Rd, Greenford,  
Middx.

### **LONDON SOUTH**

Mrs. C. Byrne,  
Flat 1, 10 Wexford Rd, London SW12.

### **MANCHESTER AND DISTRICT**

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

### **MANCHESTER CENTRAL**

Mrs. J. Whiting,  
33 Weston Ave, Manchester, M10 0QP.

### **MANSFIELD, WORKSOP AND DISTRICTS**

Mrs. E. Freeman,  
23 Melbourne Street,  
Mansfield Woodhouse, Notts.

### **NORTH EAST**

(Northumberland)  
Mrs. E. Grant,  
27 Redwell Rd, Prudhoe, Northumberland.

### **NORTHAMPTONSHIRE**

Mrs. A. Hardy,  
28 Eastbourne Ave, Corby, Northants.

### **NOTTINGHAM & DISTRICT**

Mrs. S. E. Plant,  
305 Foxhill Rd, Carlton, Nottingham.

### **OXFORDSHIRE**

Mrs. M. Staddon,  
11 Stansfield Close,  
Headington, Oxford OX3 8TH.

### **PONTEFRACCT CASTLEFORD & DISTRICT**

Mrs. N. Robinson,  
4 Sandal Rise, Thorpe, Audlin,  
Pontefract WF8 3EX.

### **PRESTON**

Mrs. B. H. Waring,  
6 Demming Close, Lea, Preston, Lancs.

### **ST. HELEN'S & DISTRICT**

Mrs. N. Maddocks,  
324 Warrington Rd, Rainhill,  
Prescot L35 9JA.

### **SALISBURY AND DISTRICT**

Mrs. J. Renshaw,  
195 Gainsborough Close,  
Salisbury SP2 4HB.

### **SHEFFIELD**

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

### **SOUTHAMPTON & DISTRICT**

Mrs. P. M. Trim,  
Abetta, The Drove,  
Southampton SO4 1XB.

### **STAFFORDSHIRE**

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

### **STAINES, HOUNSLOW AND DISTRICT**

Miss S. Karmios,  
36 Melbourn Avenue,  
West Ealing W13 9BT.

### **STOCKPORT**

Mrs. S. Silver,  
1 Brookside Ave, Offerton, Stockport.

### **SUNDERLAND**

Mr. W. D. Easton,  
4 Irene Ave, Grangetown, Sunderland.

### **SURREY (NASBAH)**

Mrs. D. M. Driscoll,  
26 Limes Ave, Waddon, Croydon, Surrey.

### **SUSSEX**

Mrs. M. White,  
Averys, Rusper, Horsham, Sussex.

### **SWINDON AND DISTRICT**

Mrs. J. Trembling,  
3 Church Place, Swindon, Wilts.

### **TRAFFORD AND SALFORD**

Mrs. J. Gray,  
9 Whitegates Close,  
Timperley WA15 7PG.

### **WARRINGTON & DISTRICT**

Mr. S. J. Charlton,  
36 Park Ave, Latchford, Warrington.

### **WARWICKSHIRE**

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

### **WESSEX**

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

### **WIGAN AND CHORLEY**

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

### **WIRRAL**

Mrs. S. Keeler,  
7 Church Road, Upton, Wirral L49 6JX.

### **WORCESTERSHIRE**

Mrs. M. Davis,  
Lower Field, Wynniatts Way, Abberley.

### **YORKSHIRE NORTH**

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

### **NORTHERN IRELAND BELFAST & DISTRICT**

Mr. E. B. C. Green,  
169 Warren Gardens, Lisburn, Co. Antrim.

### **SCOTTISH ASSOCIATION**

Mrs. G. McIntyre,  
General Secretary,  
190 Queensferry Rd, Edinburgh EH4 2BW.

### **MID WALES & BORDER COUNTIES**

Mrs. D. Brayne,  
5 Woodcote Way, Monkmore,  
Shrewsbury, Salop.

### **NORTH WALES**

Mrs. M. Messham,  
47 Cherry Tree Rd, Bradley, Wrexham.

### **SOUTH WALES**

Mrs. D. Cox,  
28 Cromwell Rd, Bulwark,  
Chepstow NP6 5AD.

### OTHER LOCAL ASSOCIATIONS

#### **Blackpool & Fylde**

Mr. L. F. Sharpe,  
1 Broadfield Ave, Poulton-Le-Fylde.

#### **Cannock and Walsall**

Mr. C. Bird,  
2 Lime Grove, Rushall, Walsall, WS4 1JS.

#### **Cheshire South**

Mr. J. Bill,  
4 Taxmere Close, Sandbach, Cheshire.

#### **Chesterfield**

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

#### **Consett & District**

Mrs. M. Holmes,  
30 Watling Street, Leadgate, Co. Durham.

#### **Isle of Wight**

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

#### **Lunesdale (Lancaster)**

Miss P. Crook,  
Brananlor, Ball Lane, Caton, Lancaster.

#### **Rochdale**

Mrs. Ann Lawton,  
55 Wimpole Street, Shaw Rd, Estate,  
Oldham.

#### **Somerset**

Mr. N. H. Smith,  
Zermatt, Church Hill, High Littleton, Avon

#### **Spennorth (Yorks.)**

Mrs. H. Lodge,  
38 George Street, Cleckheaton, Yorks.

#### **Teesside**

Mr. J. Gray,  
Marchesi Centre, Tollesby Rd,  
Middlesbrough.

#### **NORTHERN IRELAND**

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