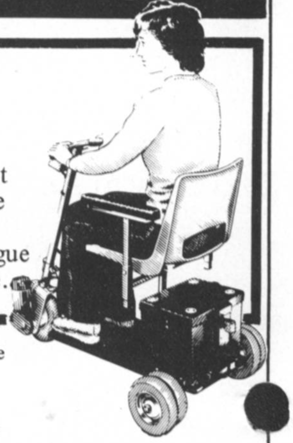
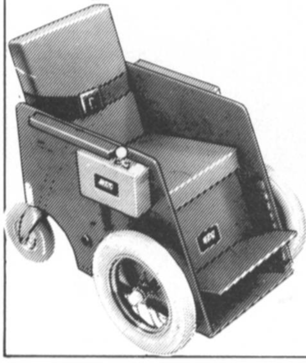
# Link

Association for Spina Bifida and Hydrocephalus/ASBAH 20p Nov/Dec 82

Happy Christmas

New feature—Answering Service: Workshop opens in Birmingham: CB Radio: Letters from LIFT members: Spina Bifida Prevention: ASBAH's Annual Meeting: Monopoly brings in real money



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**Link** 83

Association for Spina Bifida and Hydrocephalus/ASBAH

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London WC1H 9HJ.
Registered Charity No. 249338
Tel: 01-388 1382/5

**Patron:**
HRH The Duchess of Gloucester

**Chairman:** Mr D M Bryant

**Hon Treasurer:** Mr R H Smith

ASBAH has an experienced staff ready to help with any problems relating to those with spina bifida and hydrocephalus.

**Chief Executive Officer:**
Miss M P Gilbertson, MCSP

**Finance Officer**
Mr F G Armour, FCA

**Director of Appeals:**
Miss Judy Kay, MIPR

**Education, Training & Employment Officer:**
Mrs B Newman

**Disabled Living Adviser:**
Miss J Vernon, BSc

**Information Officer:**
Miss B Holland

**Link Editor:**
Mrs S I Gearing

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# Education Act delayed

**THE FINAL provisions of the Education Act will not come into force on January 1, after all. The local authorities say they need more time, and therefore the date has been postponed, hopefully until no later than the Spring.**

If you are hazy about the Education Act (even after reading LINK March/April 1982 issue) get in touch with Barbara Newman, Education, Training and Employment Officer at National Office and she will do her best to help.

At the recent meeting of Local Association Secretaries in London, Barbara Newman pointed out the importance of monitoring the attitudes and actions (or inactions) of your local authority with regard to the Education Act. Let Barbara know if you feel they are falling down on their responsibilities. Only by letting National Office know what is happening in your area can we build up a complete picture, and press for improvements.

Although the Education Act is mainly concerned with young people to the age of 16, it shouldn't be forgotten that everyone has a right to some form of education to the age of 19.

You should be finding it easier to get information about education in your area. Local authorities must produce a broad policy document about what provisions they are making, and each school has to issue a leaflet giving details of the curriculum and facilities they provide.

# A Working Relationship

THE RELATIONSHIP between the disabled and their families, and the local authority is an important one. Through the Secretaries of Local Associations it is hoped that each Association will be able to establish a friendly working relationship, so each side learns about the other. This should be useful if the Local Association has to make a complaint about something.

# Answering Service

MANY LETTERS sent to ASBAH officers contain queries which affect a great many families, and LINK has decided therefore to start a new feature 'Answering Service' (see page 7) in which your queries about anything to do with spina bifida and hydrocephalus can be carried, together with the answers from the staff. Correspondents' names will not be disclosed. We look forward to getting some interesting letters and queries from you.

# ASBAH at NAIDEX

THE EXHIBITION, held at the Cunard International Hotel in London, was very busy this year, and ASBAH had a great many visitors and distributed a mountain of material and information. It was good to meet supporters and members from all over the country who called at the stand to introduce themselves, and to ask for advice. LINK hopes to carry details of some of the products on display, in the next issue.

# Happy Christmas

FINALLY, LINK is very pleased to send all its readers very best wishes for Christmas and for a happy New Year. So that LINK lives up to its name, perhaps you can make a New Year's resolution to make some contact with us next year, by sending in your views, news, letters, queries, suggestions, photographs.

**COVER PHOTO:** It's a happy new year in prospect for 16-year-old Elizabeth Livesey who tore up her L plates this year. Elizabeth, of Queensgate, Bridlington, read in LINK about the new scheme whereby disabled young people of 16 can learn to drive, and immediately decided to apply.

'It is surprising how many people still don't now about this scheme' said her mother. 'It's really marvellous for Elizabeth being able to drive herself'.

It took a good deal of perseverance on Elizabeth's part to pass the test, as well as support from her parents. Dad took her out every night for an hour for about two months before the test, and she had proper lessons, too.

She drives a Vauxhall Chevette Automatic to school every day—to Headlands School, Bridlington, where she is in the sixth form. Photo: Bridlington Free Press.

News of the 'vitamin trial'—page 20

**ASBAH's Patron, HRH The Duchess of Gloucester talking with Beverley Holland, Information Officer and Rosie Horsfall (right) Disabled Living Adviser, at the Nursing Times International Congress and Exhibition held in September in London.**

**ASBAH's stand at the Exhibition attracted a pleasing number of visitors connected with the nursing world..** Photo: Nursing Times

IN AN AREA of outstanding natural beauty, at Stackpole in South Pembrokeshire, a holiday and study centre is being developed for the use of disabled people of any age, their families and friends.

The Stackpole Trust is a registered charity whose trustees include Miss Moyna Gilbertson of ASBAH and five other people involved with major UK charities. The Trust has leased from the National Trust the disused Home Farm on what was formerly the Earl of Cawdor's Estate.

Already five cottages have been beautifully restored and are ready for letting (see photo). The cottages have all amenities and have been specifically designed for use by visitors in wheelchairs. They are self-catering and visitors need only bring personal requisites.

The weekly charges range from about £30 to £75 depending on the size of cottage and time of year. The rest of the project will be developed in the next few years.

For more details contact: Project Director Alun Jones, Reaches Riant, Lawrenny, Kilgetty, Dyfed.

## TV looks at social work

YOUR views on the social work service—the kind of service you now get from your social worker, and what you expect—would be welcomed by the Central TV's 'Link' programme.

The programme is planning a detailed look at the subject of social work and physical handicap. Your letters will be dealt with in confidence. Write to: 'The Link Programme', Central, Birmingham, B1 2JP.

They'd like to hear the views of social workers too!

## Neroli is a Golden shot

NEWS of the Gold Medal for archery won by Neroli Fairhall in the recent Commonwealth Games must surely be a great encouragement to all disabled young people interested in sport.

Neroli, a New Zealander, is paralysed from the waist down after a motor bike crash 13 years ago. After four long often tedious days in a competition spoiled by the wind, she finished level with a competitor from N. Ireland, and it was a very closely fought contest between the two.

The big encouragement, of course, is that she was competing on equal terms with able-bodied women archers and no allowances at all were made for her handicap.

## Care with a Chair

LARGE department stores, chain stores, supermarkets and smaller shops are cooperating enthusiastically with the 'We Care with a Chair' scheme. All they are asked to do is to make sure that a chair is provided in their shop for disabled or elderly people who need a sit down. The campaign was started in Cheam in January 1981 by Margot Knowles. She would like help in spreading her one-woman campaign, so try and encourage your local shop to provide a chair.

## Access at the hostel

YOUTH hostelling is made possible for disabled people at Pen-y-Pass hostel in Snowdonia National Park. This year nearly 200 hostellers with various kinds of disability have taken part in rock climbing, pony trekking, mountain walking and canoeing. Some of the hostellers were in chairs.

The idea came from Friends Together, a Merseyside group keen to encourage disabled people to go hostelling. The wardens of Pen-y-Pass hostel, made it accessible by designing and constructing ramps, altering doorways etc.

Individuals and groups are welcomed. Contact: Helen Cameron, YHA, Trevelyan House, 8 St Stephen's Hill, St Albans, Herts, AL1 2DY. Tel: St A. 55215.

Focus on Wessex Association

# More freedom for members

'THE PAST year has brought new freedom for our young handicapped members' reports Mrs Valerie Poole, Welfare Officer for the Wessex Association.

After seeing the BEC battery driven Scoota at NAIDEX, the committee decided to switch its fund-raising efforts from buying a holiday caravan to buying Scootas.

'We ordered the first in April 1982 for assessment purposes, and took it round to the members' homes for them to try out' said Mrs Poole. This proved that the need was greater than the £1,500 in the kitty would allow, so the association contacted the Lions Club and Round Table and they came to the rescue. Blandford Lions and Blackmore Vale Lions each bought a Scoota for a child in the association, and Weymouth Round Table bought a Scoota and a Speedwell Superkart (as advertised in LINK).

Wessex's money went into buying two Scootas for two young members, Paul and Mandy, and a re-conditioned BEC electric wheelchair for Rosemary.

'Then the BEC company asked if we had a child who would benefit from the use of a BEC Fireball electric wheelchair as Golf Fanatics International wished to present one to an organisation in the area' said Mrs Poole. 'We realised that Jamie one of our youngest members would find it most useful. So on August 15 we set off with him for Parkstone Golf Club where we met Val Doonican, Roy Castle and Anne Aston. Jamie was presented with his chair and has found new independence.'

Mrs Poole said there had been many other ventures. 'We have also still found time to carry on helping families with the cost of long distance hospital visiting. Most of the children have their own portable televisions. Some have received CB radios to help them if they should break down if out in the car on their own. We are now helping some of the mums and teenagers with the cost of driving lessons. Two mums have received tumble dryers to help with the never-ending laundry, and we have helped by giving holiday grants.'

Other activities have included outings, and the running of a holiday club for children and mothers of the association. In order to encourage more families to go camping, the association hopes to be able to equip a large tent that it has by next year.

'It has been one of the busiest years since we formed 15-17 years ago' said Mrs Poole.

**A Scoota for Tina, 12, a member of Wessex Association. She is pictured with Weymouth Round Tablers who bought the scooter for her.**

## Editor's Note

● *Mrs Leonie Holgate, ASBAH's Mobility Adviser points out that although the Scootas may prove very useful for some young people who can walk, and for use on fairly flat pavements, there is such a wide range of vehicles to choose from that it is worth checking carefully before making a purchase. Leonie is available to give advice. Contact her on Thursdays at Banstead Place (tel: Burgh Heath 56222) 9 a.m.-3.30 p.m. She is also happy to visit local associations and talk about the many aids to mobility now available. (See page 20)*

# Fired with enthusiasm

**A visit to Guildford Fire Station for youngsters from Surrey Association and helpers from PHAB. They were on holiday nearby at Felbury House, and enjoyed a host of events from horse riding to pottery, to river trips and a cinema visit.**

# Big push for £100

**Members and friends of Cannock, Walsall and District local association at the start of their wheelchair push which raised £100 towards two holiday chalets. Nine disabled members turned up—the committee had hoped for a bigger response—and were pushed round the five mile course.**

Photo: Walsall Observer.

Any of you who have read the ASBAH publication 'Little Joe'—a moving story of a baby born with spina bifida, written by his grandmother, will be pleased to learn that 'Joe' is continuing to make good progress. He is now a happy, active little boy of 5½ and this picture taken in the Summer shows him (left) on holiday with his cousin.

His grandmother, Mrs Winifred Foster was able to be at ASBAH's Annual Meeting this year, and brought this good news of her grandson.

# Funding the Zachary Fund

STAFFORDSHIRE local association presented its annual cheque to help ASBAH's work at the Annual Meeting in London in September.

Mrs J. Davies, Secretary, who made the presentation said that it was to be divided between ASBAH's fieldwork and research, and the Prof. Zachary Fund.

Donations are always welcome for the Fund, which was set up to provide help for young people with spina bifida who need special equipment, or financial help of some kind for travel, music, or a hobby.

When setting up the Fund, Prof. Zachary asked that the young people themselves should write in, setting out the reasons why they were applying.

The Fund is quite separate from the normal welfare activities of ASBAH.

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# ASBAH's 1983 SPRING CONFERENCE

## 8- 10 April, Goldsmith's College, South London

**At the time of going to press, plans were still being worked out, but a full and interesting programme is promised. Subjects that will be on the agenda include accommodation, independent living, Sheltered Industrial Groups, mobility (particularly driving), LIFT's volunteer scheme.**

**The venue is the same as in 1981 because Goldsmith's proved popular and suitable for most people.**

**Booking Forms and full details will be available from National Office by the end of November.**

# answering service

your questions answered by experts

**MY DAUGHTER has a urinary diversion and unfortunately often gets infections. She also has to have her bowels emptied manually. This all tends to get rather smelly. We have tried all the ordinary air fresheners, but they really don't do a very good job in covering up the smell. Have you any ideas?**

FIRST of all, obviously your daughter is getting urinary infections and you will need to ask your doctor about possible drugs that could control this. Turning to the problem of odour, it is possible to get effective liquid deodorants, and if you put a drop of one of these in the bag this might help. There are various kinds such as Nilodor or Chironair Odour Control Liquid and these are available under the National Health Service and can be prescribed by your doctor. It is also possible through the NHS to get aerosol sprays on prescription.

You don't say whether you are dealing with your daughter's bowels in the bathroom or in the bedroom. The best idea is to get her to sit forward on the toilet, and then if she tries this position she might in time be able to learn to reach behind and cope on her own.

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**WE HAVE had great difficulty in getting shoes to fit our daughter, Deborah. We bought a new pair of shoes for over £11 recently—two sizes too big so that we could get the correct width. We gave them to the fitter who comes to the hospital so that he could put caliper sockets in them and at the same time raise one heel.**

**When they came back, the shoes had been built up inside and Deborah wasn't able to get her feet inside. Also we were upset to find that the uppers were coming apart from the soles. Can you possibly assist in trying to get the shoes replaced or advise about the next step we could take.?**

AS YOU probably know children or adults with spina bifida can get special shoes supplied or made to measure through their local hospital department if their feet are a very awkward shape. Your consultant will be able to advise about this.

Unfortunately, if you have fairly 'normal' feet then you are expected to buy your own shoes, but the hospital will carry out the necessary adaptations such as fitting caliper sockets or raising heels.

I have been in touch with the fitter that you saw, and if you send back the shoes, he has agreed to see what he can do, or if necessary replace them.

However, in future it would be a good idea to buy shoes on approval, and then check with the fitter about whether they are suitable for adaptation. It's virtually impossible to adapt some types of shoes, particularly those with moulded heels where it isn't possible to remove the heel for adaptation.

If you are on Supplementary Benefit and your child goes through footwear (or clothing for that matter) unusually quickly because of their handicap, you can claim the estimated cost of repairing or replacing them. Ask your DHSS office how to set about this. And don't forget your local ASBAH branch might be able to help out with the high costs of footwear. It's worth a try.

*Jill Vernon, Disabled Living Adviser*

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## Independence course in N. Ireland

THE NORTHERN IRELAND Association recently held its first Independence Training Course for 9-13 year olds. This took the form of a residential weekend at Ballinran, near Newcastle, Co. Down.

'The weekend proved most successful' reports Mrs E. McDowell the Honorary Secretary. 'This was thanks mainly to our excellent team of helpers who gave their help not only willingly but enthusiastically. Many thanks go to Jill Vernon of National ASBAH whose advice on the organising of this course proved most beneficial. This was our first venture of this kind, and we hope it will be the foundation for many more independence weekends.'

## First on the road

THE DISABLED DRIVERS' SCHOOL OF MOTORING in Northern Ireland has had its first success. Anna McAleer, the first pupil when the school started in May 1982 in Holywood, Belfast—has passed her test with flying colours. The School was formed by Belfast Disabled Drivers' Association with the help of the Northern Ireland Council for the Handicapped.

.......... engraving .......... Shasbah trolleys .......... packing ..........

# ASBAH Workshop opens for business

THE MIDLANDS Association saw the result of five years hard planning and fund-raising put into action on September 25. This was the date on which their new sheltered workshop opened, known as Court Enterprises.

The new venture, which owes so much of its existence to the Association's Chairman, Mrs Dorothy Artingstall, is situated in the Sparkhill area of Birmingham, in Court Road, hence the name. It aims to give employment to teenagers and young adults with spina bifida and hydrocephalus.

'Five years ago we became very worried about what our young people were going to do in a few years time' said Mrs Artingstall. 'We carried out a survey and estimated that ten years on (five years from now) there would be 90 young spina bifida members in our area needing some kind of occupation.'

As a result the Association decided to try for a workshop, and a fund-raising committee was formed especially for the project. It has done a magnificent job and raised £82,000 from a host of different events, and a lot of it from trust funds. There was a big boost to the kitty last year as a result of the local radio BRMB's appeal 'Susan and Friends which was co-ordinated by a National ASBAH fund-raiser and which raised over £82,000. One third of this went to the workshop, (and the remainder towards research into spina bifida, and to further the social work services for spina bifida families).

**Steve Mason tackling a job with the engraving machine.**

**Rosemary and Geraldine getting down to some office work.**

**The workshop when fully operational will be able to provide employment for 25 people. At present seven young members of the Midlands Association are employed there—Paul Jinks, Steve Mason, Rosemary Easthope, Geraldine Coakley, Catherine Turner, Peter Cusack and Andrew Hinchliffe. Already there are several others wanting to work there, and there have been numerous enquiries.**

The young workers undertake engraving for local industry—making engraved signs, plaques, name plates, instruction plates. 'There are few engravers in Birmingham and there seems to be a need for this kind of work, so we hope to build up our orders steadily' said Mrs Artingstall.

The pentograph engraving machine requires a certain amount of hand coordination but can be managed by most of the young people. And there are plenty of other jobs available there, too.

## Trolley take-over

**The other main work at present is the production of the tried, tested and very popular SHASBAH trolleys. These were previously designed and made by Mr Stan Fitzgerald down in Southampton. He decided to retire, and offered to hand over to Court Enterprises.**

The trolleys are made for the DHSS—Court Enterprises took over the DHSS contract from Mr Fitzgerald—and will be marketed privately too, both for this country and overseas. One order from Belgium has already been received.

'We are looking at the possibilities of adapting and modifying the trolleys slightly' said Mrs Artingstall 'and will be happy to help customers with individual requirements'.

The trolleys are an ideal product for the workshop being relatively simple to make, but requiring a number of specific assembly and production tasks.

### . . . . . . . . . . . . . office accounts . . . . . . . . . . . . . light assembly jobs . . . . . . . . . . . . .

Court Enterprises also has a small business computer to help local firms with accounts work. Already the workshop have made a small income from packing and selling Christmas cards, and is willing to take on a variety of different packing, collating and assembly jobs.

The workers are under the supervision of a manager, and also have the help of a care assistant, Eileen Jinks, whose son Paul works there.

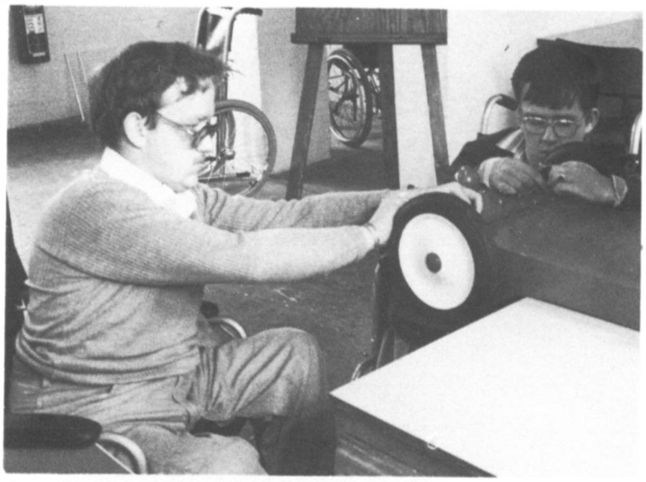
## Room to grow

The workshop buildings are of sturdy Victorian red brick, and will allow for expansion. About £10,000 has been spent on putting in toilet facilities and generally modernising them. The Midlands Association has its office there, in the capable hands of Secretary, Mrs Diane Britt.

**Although the workshop is now underway, the fund-raising will have to continue, as in common with other workshops in the country, it is unlikely to become self-sufficient, at least not for a good while. At present about £20,000 a year is needed to run it, but hopefully the figure will be reduced in time.**

The young workers used to come in by taxi, but the Social Services Department has now given one of their old ambulances thanks to the staying power of Mrs Artinsall who wouldn't take 'No' for an answer.

At the grand opening in September there were over 200 guests. Miss Moyna Gilbertson and Barbara Newman from National ASBAH were there, and so too were representatives from the local authority, local industry, etc. It was a memorable occasion largely due to Cllr Bailey who stepped in at the last minute and performed the opening in place of the Lord Mayor who unfortunately was ill.



**A trolley gets the finishing touches from Steve and Paul.**

**If anyone would like details of the SHASBAH trolleys—which will probably soon be renamed—they should contact Court Enterprises, 14 Court Road, Sparkhill, Birmingham, B11 4LX. Tel: 021-771 0380.**

# "Cohesive"

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L/7/C

# Making friends at the flick of a switch

## CB RADIO

**CITIZENS BAND RADIO is legally a year old this month (November) and is proving its worth as a great means of communication for people who through disability or other reasons are more housebound than others.**

At the flick of a switch, new friends can be called up, contacts renewed, and strange conversations embarked upon. Help can be enlisted if your car breaks down and you can't go for assistance yourself.

More and more young people with spina bifida are becoming 'breakers' and joining CB clubs as a recent article in the magazine of LIFT (young ASBAH) showed. There's 'Eight Ball' from Norwich, 'Ironside' from Walsall, 'Elvis' in Hackbridge, and 'Space Invader' who calls up from Brighton...to name just a few.

It was the Americans who developed this cheap means of communication without having to resort to a phone. It came over here from the States ten years ago, with the first club starting in North London. There, the Lima Charlie group used CB radio handsets from their cars.

Unfortunately, it didn't take long for CB to become illegal—in 1970, in fact—when the Home Office decided that CB was interfering too much with messages sent by low flying aircraft, certain TV sets and other channels.

CB went underground and those who were caught received heavy fines. Nevertheless the craze grew, and the boom came about the time of a film 'Convoy' starring Kris Kristofferson, which used humour to show the many uses that CB could be put to—in assisting the motorist for instance.

With more and more people getting hooked on CB and able to get hold of sets for as little as £25, the Government realised that it had no alternative but to legalise the whole thing.

However, legalisation—on November 4, 1981—wasn't greeted with the joy one might have expected. This was largely because the government decided that the 11 meter FM band should be used. This can prove very noisy and has a shorter range than the AM frequency previously used.

Nevertheless despite the problems CB is here to stay without doubt.

**Lift member, Helen Collingbourne from Essex writes:** *"I go out Monday evening to a CB club and am hoping to get a CB set soon. My friend has already got one and I go round her house sometimes. We love listening in and talking, too"* **Another Essex Lift member, known as 'Little Lil' writes:** *"I am a CB breaker from the Wickford 20 and have been on channel for just over a month. I find CB a great help not only for company but when I have an emergency I can just flick to Channel 9, the emergency, and someone will come to my aid.*

*"Also we have a Channel 10 network that I can contact if ever I want someone to talk to at any time of the day or night. We have a mass eyeball every Sunday so we can meet everyone we have been talking to in the week.*

*"I find CB very enjoyable and sometimes I forget the time and find I have been talking all night just to one person. Anyway I shall give you all the high numbers and bye-se-bye and 10-10 from Little Lil."*

## "CB RADIO AND THE HANDICAPPED"

*THIS is the title of a one day course for CB users, and professionals working with the disabled.*

*It will be held at Castle Priory College in Oxfordshire on February 5. The cost of £9.50 includes lunch and refreshments.*

*Apply: Castle Priory College, Thames Street, Wallingford, Oxon. OX10 0HE. Tel: (0491) 37551.*

**'PLASTIC BAG' from Lincoln—alias Steven Robinson—on the air using his own CB set.**

**Steven, 12, who has spina bifida and comes from Birchwood, Lincoln, has reaped so many benefits since he became a CB enthusiast.**

**He first saw a CB set at a friend's house. At the time he had a fairly bad speech impediment. The neighbour let Steven listen to him contacting friends for quite a few weeks before he let Steven have a short chat. After a few more weeks under strict supervision Steven was allowed to get 'copies' by himself.**

**After some time Steven was known by his own handle as 'Plastic Bag' a name to be heard over the airways many hundreds of times in the next year. Steven became very popular, but he hadn't a rig of his own. However, the local CB club, known as the Cathedral City Breakers came to his rescue. They had a whip round and presented 'Plastic Bag' with his own complete home base equipment.**

**Steven was on the air in his own right. He is now a very confident and well-known young breaker, and his friends and family maintain that it's due to CB that he now has hardly a trace of a speech impediment.**

**Steven's advice to other young people in the same position as him is: 'Try to get yourself on the air and become a good buddy. You'll never regret it, and it will give you a new lease of life.'**

*PROOF that LIFT (young ASBAH) is thriving, comes in the increased number of letters that arrive 'on the doorstep' of the LIFT office in London. They tell of LIFT members getting up to all kinds of things, from organising a wheelchair push, to moving house, or watching a parachute jump, or just being the friend of someone who is in a wheelchair.*

*See for yourselves from these recent letters...*

# LIFT is on the up and up!

## Teenagers back South Atlantic Fund

**MY NAME is Peter Miller. I am 17 years old and I am a pupil at Hatchford Park School, Cobham, Surrey. My friends, Steven Sharman who is 17 and Andrew Gunstone, 15, are like me in wheelchairs because we have spina bifida.**

We decided to organise a 12-mile push in our chairs to raise money for the South Atlantic Fund. We thought this was a worthy cause because so many of our soldiers had been wounded at the Falklands and would now be disabled, like us.

We had no trouble finding people to sponsor us. We duplicated lots of forms on our classroom duplicator and passed them to our friends, our families, and to staff at school and to our local church.

Then we had to find a suitable place to do our hike. One of our teachers suggested his last school, so the headmaster of St George's College, Weybridge was approached and he very kindly gave us his permission to use his athletics track. This turned out to be super—flat and with a hard surface.

We spent a couple of weeks training and preparing for our hike. We bought leather gardening gloves to stop us getting blisters, and juice and Mars bars to drink and eat on our way round the track to keep us going.

At last the great day came. It was a hot sunny afternoon when we arrived at the college track and Steven and I were soon wearing our shorts. Many of the St George's boys took a great deal of interest in us and some of them even did some last minute sponsoring.

Others borrowed our spare wheelchair and tried out the course for themselves. We worked out that we needed to do 48 laps round their 440 yard track to complete the 12 miles. When we started we were greeted with cheering and clapping from the St George's students.

We stopped for a rest after every 10 laps and our houseparent, Mr Slack, kept us supplied with drinks to quench our thirst as we went round. Supporters from our own school arrived in the school bus when we had just five laps to go.

They wondered who was pushing the fourth wheelchair. It was St George's own star athlete who soon realised that here was one sport he was no good at. We lapped him over and over again and he gave up exhausted after just 12 laps.

We were cheered into the finish 12 miles, and two and a half hours after we had started, tired but very pleased with ourselves.

We presented our cheque for £325 to Sergeant Saunders of the Welsh Guards at our Open Day on July 25.

*ONE LIFT member was looking forward to moving home when he decided to write to LIFT and explain what was in store. August 1 was the big day, when he would move into a house run for Jewish young handicapped adults by the Ranulf Association...*

## Moving into a new house

EVERYONE has a task in the house...cleaning the stairs, bathroom, toilet, kitchen, lounge, etc.

There is also a garden which, at first, we all will have to work at, as it is in a mess. Ugh! But when it is all clear someone, or probably all of us, will have a task there, whether it be mowing the lawn or tending the flowers.

There will be five people there...three boys and two girls, all living in.

I joined the group two years ago and have been on a training weekend with the group where we cooked our own meals and cleaned our place and got on with each other.

At the beginning there was a guy called Len who was in charge of our group. He left and we had two young girls, Margeurite and Ruth who took us and still do. They are really nice.

They run a club called Discovery to which I belong. It is associated with the house. We have a varied programme—discos, quizzes, outings to name but a few. The club is a Jewish handicapped one. We also have barbeques once a

year. Games, and art and craft afternoons have been on the programme and were successful. We have had speakers as well.

There is already one other house belonging to the group with youngsters living there, with whom I am very friendly. Two got married, moved out and one other moved in. The married couple are now living in Finchley.

I hope that many more housing associations will be set up and follow Ranulf's example.

**LIFT member**
**Kenton, Middx.**

# Parachuting: Andrea shares the excitement

ON SUNDAY June 20, Miss Lyn Mickelthwaite, a young lady who works in a paper shop near our house did a parachute jump at Flookborough in aid of ASBAH.

I went to see Lyn jump and this is how I felt...

I felt very excited as we waited for the jumping to begin. Suddenly a cloud came. My heart felt as though it was in my shoes as I thought of the disappointment the parachutists would feel if it began to rain and they could not jump.

Just as I really thought the whole thing was going to have to be put off until another day, they began. There were 14 parachutes of different colours. There were red, white, black and many others, including a brightly coloured one which was blue, yellow and white.

When they were high up in the sky the parachutists looked like tiny specks in the cloudless white sky.

I became more and more excited as each parachutist came down to the ground.

As each one came slowly down it reminded me of a bird floating softly down from the top of a tree. With the help of sponsors Lyn raised £336 for ASBAH.

**Andrea**
**LIFT member, Morecambe.**

**DIANE has a great friend in a wheelchair, and was moved to write this letter after reading a recent issue of a LIFT newsletter...**

# A friend —and an example

*'Sometimes when I see my brother playing, I feel sad because I cannot do the same. I don't like to go outside, because all I can do is sit there and watch him.'*

I READ this small paragraph in your 1981 Spring edition of Lift.

I have grown up with a disabled person, nearly all my life, in fact since I was about 3 years old. My friend has been in a wheelchair all his life, but can do just as much as any normal person I know.

From a very young age my friend has been very independent.

This, of course, was because of the determination of his parents that he was going to grow up and live as normal a life as possible.

My friend was never left watching if we were playing football or any other game for that matter. He was always made to join in. Although my friend is in a wheelchair my family and friends do not class him as being a disabled person.

So you see, if the parents want their children to be as normal as possible they should give them their own independence from a very early age. They should also treat the child the same as they would treat any normal child.

I also think it is a good idea if the parents try to get the child involved in some kind of club. The Scouts or Girl Guides would be a good idea as the child would be mixing with normal able-bodied people and this would give the child even more independence.

If I was to have a disabled child I would try to give him or her the independence that I think it necessary to live a life that is as near to normal as possible.

**Diane Lawler**

# NALGO guide is 'a first'

A TRADE union has published a special 'guide' to help bring about equal opportunities for disabled employees.

"Disability is no Handicap" is produced by The National and Local Government Officers Association (NALGO). The union says its the first of its kind.

The guide is designed to help local branches in the negotiation of equal opportunity policies.

The booklet points out that the unemployment rate is currently 16% compared with an overall level of 12%, and that the disabled in employment are to be found doing the least desirable, least well paid and least skilled jobs. Very few employers meet the 3% employment quota for disabled.

The booklet includes discussion of the Manpower services Commission recommendations for a new law to protect the employment interests of disabled people and to replace the quota system. The Government's attitude is covered, as well as the harmful effects of public spending cuts.

There are many recommendations for positive action. The booklet calls for tougher monitoring of the quota system and more severe penalties for non-compliance by employers. To encourage positively the disabled into employment, the appointment of a person with this responsibility is seen as an important priority.

The booklet ends with a list of sources of information and help for the disabled.

Copies have been sent to all NALGO branches. Members of the public may obtain copies from the NALGO Press Office, 1 Mabledon Place, London WC1H 9AJ. Please send sae (15 × 22 cm).

*The guest speaker at the Annual Meeting was Professor Richard Smithells, FRCP, Professor of Paediatrics, University of Leeds, talking on the subject...*

# Prevention of spina bifida: fact or fiction

**THE RESULTS of vitamin supplementation in aiding the prevention of spina bifida looked very impressive, Prof. Smithells told the Annual Meeting. His team had conducted research over a number of years. But they had not been able to carry out the research in the way they had wanted to originally, and, therefore, the effectiveness of vitamin supplementation could not be considered to be scientifically proven.**

Prof. Smithells explained the golden rules for conducting research properly.

'Rule number one for studies of this kind is that people who are to be studied should be allocated to one or two groups entirely at random. In the case of our research it was only mothers who had come forward to take part who were included, and this couldn't be considered to be 'at random', and there is some risk that women who came forward in this way had a lower risk of recurrence of a spina bifida baby.

"Rule number two is that neither doctor nor patients should know what they are taking. In our studies we knew what we were giving and the women taking part knew exactly what they were getting.

"Rule number 3 is that a control 'placebo' tablet should be used. We were not allowed to use 'dummy tablets' although we had them all ready for use.

"Because of these shortcomings, interpretation of our results is harder than it appears on the surface."

Referring to the proposed nationwide multi-vitamin trials to be conducted under the auspices of the Medical Research Council, Prof. Smithells said that in deciding whether these trials were necessary, one had to decide whether the small, residual doubt about the effectiveness of multi-vitamins was sufficient to warrant extensive and expensive trials of this kind, or whether it would, in fact, be better to proceed on the basis that the research so far had proved the case for multi-vitamins.

Prof. Smithells spoke to the Annual Meeting about the background to his research into vitamin supplementation. He said there had been a marked downward trend in the incidence of spina bifida since 1979, and this was not satisfactorily accounted for by the introduction of antenatal diagnosis and subsequent termination of pregnancy of spina bifida fetuses.

This downward trend and the consistent pattern, over the years, of increased incidence of spina bifida births to the lowest social classes, had given rise to the suggestion that malnutrition could be one of the factors leading to neural tube defects.

"By malnutrition I don't mean starvation or malnutrition in the Oxfam poster sense, but rather a deficiency of essential vitamins."

THE SIXTEENTH Annual Meeting of ASBAH was held at the British Medical Association in London on September 11 and was attended by local association members from all over the country, as well as professionals and friends of ASBAH.

Unfortunately, ASBAH's President and good friend, Lord Maybray King was unable to be at the Meeting due to ill health. However, he sent greetings to everyone concerned with the work, and his best wishes for a good year ahead.

ASBAH's Chairman, Mr D. M. Bryant took the chair.

Prof. Smithells said he felt it probable that the cause of neural tube defects was a lack of a variety of several different vitamins, rather than just one vitamin, or in certain people, the body's inability to absorb these vitamins.

Some of his early research showed that mothers in the two lowest social classes 4 and 5 had significantly lower levels of vitamin C, folate acid and riboflavin in their blood, and mothers of babies with neural tube defects had even lower levels.

These findings, he said, had led to the setting up of the first cohort of women for the multi-vitamin research. Out of the 200 mothers who had taken multi-vitamins since well before conception and into the early part of pregnancy, only one had a baby with a neural tube defect. This was well below the average of 5% recurrence for mothers who have already had an affected child.

Prof. Smithells said that a second trial using another cohort of women had now finished, but there had not yet been time to analyse the results properly. They would be published as soon as possible. However, at first glance, it looked as though the results were similar to those of the first trial, and the recurrence rate among the mothers who took part was reduced from the average of 5% to 0.7%.

Prof. Smithells also referred to a trial conducted by Prof. Norman Nevin in Belfast. 150 mothers took the vitamins and there was only one spina bifida birth. These results were very encouraging in view of the fact that Northern Ireland normally had the highest incidence of spina bifida in the world.

Is vitamin supplementation safe? Prof. Smithells posed the question himself, and answered it by saying he had no reason to believe it wasn't.

"The vitamins given to the mothers were not of meglopack proportions, and contained doses of vitamins very comparable to those recommended by nutritionalists. We have followed up a large proportion of babies born to mothers in the first trial, and they seem to have developed normally."

**IT WAS reported at the meeting that the Chairman of the Finance Committee, the Hon. Tom Manners, had resigned. The immediate past Treasurer, Mr R. M. Nichols, had agreed to succeed him.**

**ASBAH members relaxing after lunch in the impressive courtyard of BMA House, where they were attending the Annual Meeting.**

Photo: Philip Ridler.

# Working towards greater independence

**ASBAH's increasing support for young adults with spina bifida and hydrocephalus was referred to at the Annual Meeting by Chairman of the Executive Committee, Mr D. M. Bryant. "The emphasis is more and more on helping them to reach independence" he said.**

The Annual Report gives details of this increased activity, with the expansion of Lift—the young people's organisation, the setting up of ASBAH's own counselling service for young adults, the planned expansion of the independence training programme by forming Flying Squads to spread the word in schools, and the appointment of a Mobility Adviser to help give individual advice to young people about learning to drive and outdoor mobility.

Mr Bryant also spoke of ASBAH's awareness of the need to help young adults find suitable accommodation and employment. Despite the bad economic climate ASBAH was doing all it could, he said, to place people capable of carrying out some sort of work, in employment and supporting them as necessary.

Mr Bryant referred to some adverse publicity about ASBAH's fund-raising activities with Institutional Press. Following this ASBAH had decided to set up its own telephone selling activity 'in house' as part of its overall fundraising. "Already there are signs that it is doing well" he said.

"There is no doubt that we need increasing amounts of money, which are increasingly hard to find. Our activities don't usually come into the category of headline-hitting catastrophes that attract money. We need to go out and seek support and this takes a lot of hard work. Possibly, also, we have suffered from the lack of money generally available to charities."

# Keeping up the good work costs more and more

**IN HIS financial report, the Treasurer, Mr Howard Smith, said that the figures reflected a year of 'honest endeavour and hard work by all at ASBAH'.**

He reported a 40% increase in donations and said that income from special promotions was well up to a figure of more than £90,500.

Unfortunately, there had been an increase in costs too. There had been increased expenditure involved in the expansion of Lift and its specialist advice and information service, and on publicity and promotion work.

General running expenses such as rent, printing, etc. had shown an increase too. Altogether, there was a 32% increase in expenditure, said Mr Smith, and this led to a deficit for the year of nearly £49,500—more than three times last year's deficit.

However, a substantial increase in legacies came to ASBAH's rescue. These were nearly £190,000 compared with £134,601 last year.

The 'working capital' of the Association—the Accumulated Fund—stood at £351,479, an improvement of more than £140,000 on last year.

Mr Smith summed up: "The year under review shows a satisfactory position, but we cannot be complacent. Only through the exceptional income from legacies was the year a success. We may not be so lucky with legacies next year.

"With the planned expansion programme which ASBAH has embarked upon, plus inflation, there will be substantial 'material erosion'. We need to raise new money by new means and economise where possible."

Earlier in the meeting, Mr Bryant the Chairman, had said that ASBAH was 'feeling the pinch'. He said ASBAH had made a thorough review of the budget for the coming year and had cut out a number of projects which it had hoped to carry out, such as work to Five Oaks to provide more accommodation.

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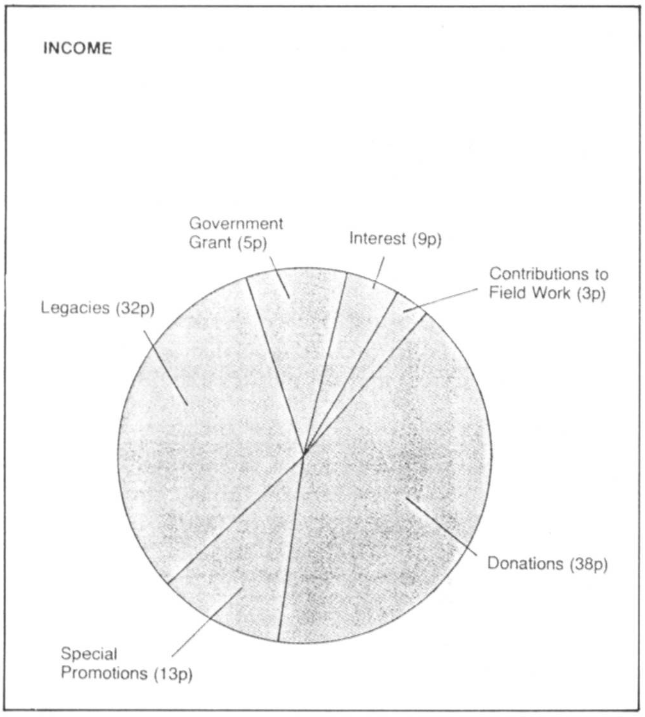
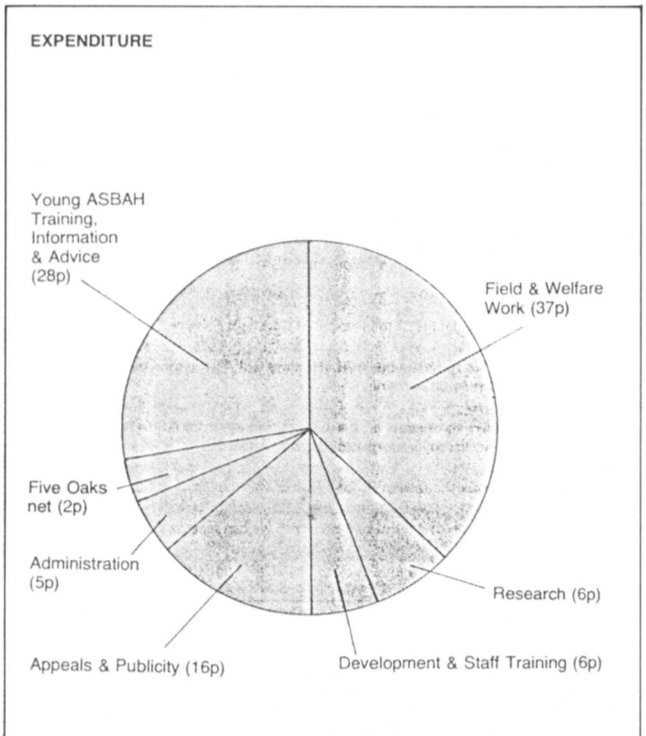
**AT THE Annual Meeting, three new members were elected to the Executive Committee: Mr G. Baxter, Mr M. Booth, and Mr D. Paul. The six members who were re-elected this time were Mrs J. Black, Mr D. M. Bryant (Chairman of the Executive), Mrs M. Clarke, Mr F. L. Dean, Mrs H. Payne, and Miss F. Seward MBE.**

# The cost of ASBAH's work

*THESE two diagrams explain where ASBAH's income comes from and in what ways it is spent, after allocating fair proportions of head office costs to each section.*





(The figures in brackets represent the number of pence in the £ relating to each item.)

# Mediscreen looks for talent

**THE NEW television production company, Mediscreen (reported on page 3 last LINK) is anxious to recruit disabled personnel as the intention is to have a staff of 50% disabled members and 50% able-bodied.**

It would like to hear from people, with or without, experience of the media, whom Mediscreen could send on appropriate production courses.

Anne Dillon from Mediscreen who spoke to the Annual Meeting said: "In particular we are looking for people who have never before had an opportunity to present themselves on the media."

She explained that the aim of Mediscreen is to project disability as an integral part of life. "We want to present programmes that the general public will find both interesting and entertaining" she said.

Mediscreen has a commission from Channel 4 to make four programmes about different aspects of disability. The first, in January 83, is on the subject of access. Mediscreen will provide proper follow up facilities so that anyone can ring up afterwards in response to something they have seen on the programme.

"We are also hoping to foster an international exchange of ideas, and are looking into the possibility of an international magazine programme" said Anne Dillon.

Anne Dillon can be contacted at Mediscreen, Brittanic House, Moor Lane, London EC2Y 9BO. Tel: 01-920 6241.

*Copies of the Annual Report and/or the audited Accounts will be sent on request. Please contact National Office.*

# Warning notices

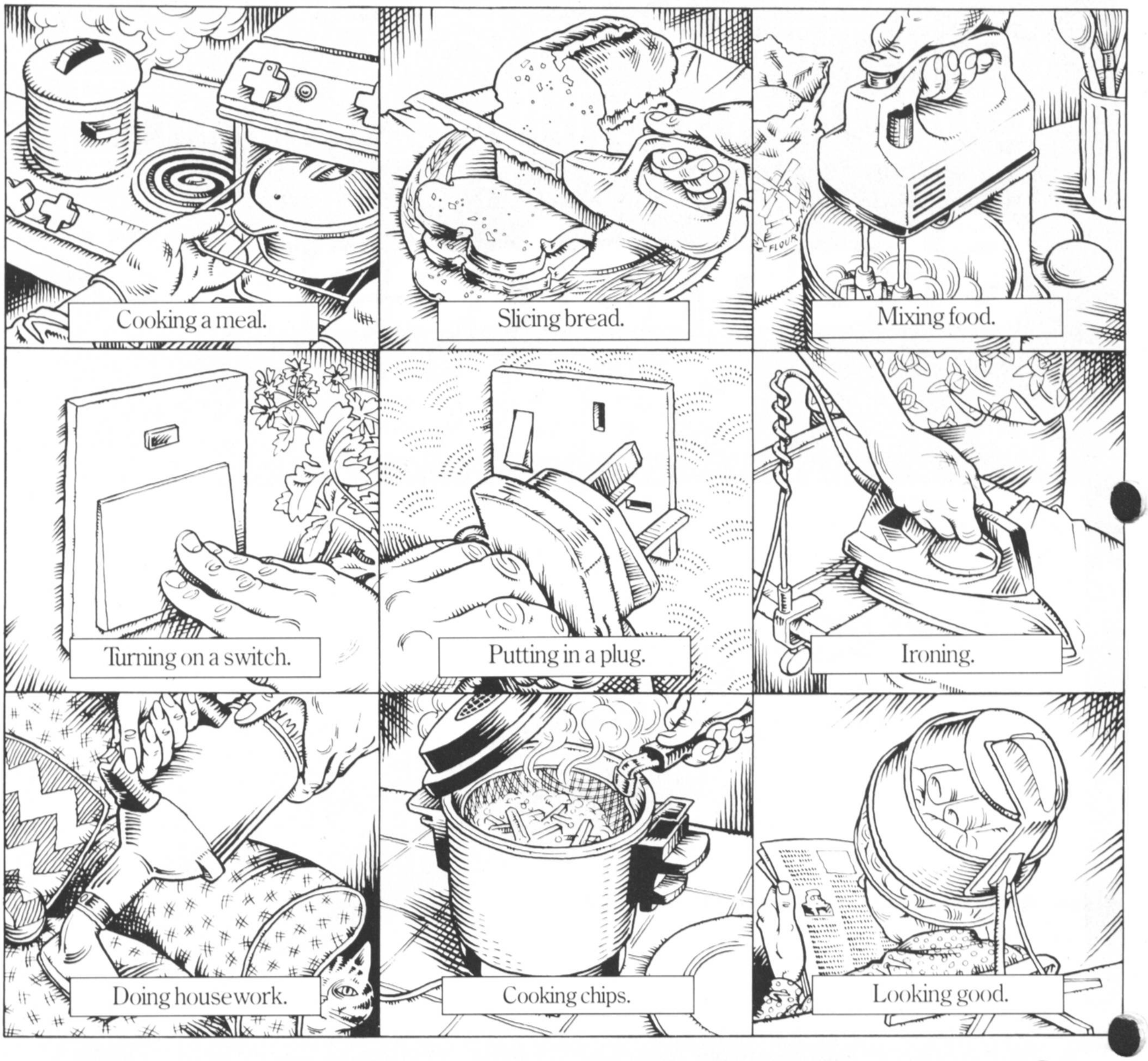
ASBAH has recently been advised of possible problems concerning two products currently on the market.

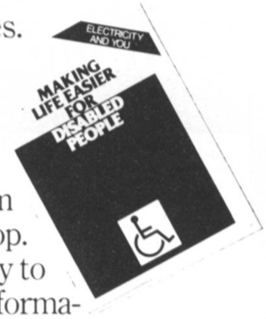
The first warning concerns 'Swedish Bath Grips'—handrails which normally clamp over the bath sides. Trials at the Institute for Consumer Ergonomics at Loughborough have shown that this type of grip, made by various manufacturers, lacks stability. It is recommended that Swedish Bath Grips should always be provided with floor fixing.

The second warning is about the Ortho-Kinetic Travel Chair. The Spastics Society has issued a safety circular about the structural failure of the telescopic bar in this chair. Ortho-Kinetics has decided to replace each and every telescopic tube assembly on all chairs in use in the UK. This applies to both 6301 12 inch and 6331 15 inch chairs.

If you know of anyone using a chair of this type, please ask them to contact the firm in order to have the telescopic tubes replaced. The address is: Ortho-Kinetics, Unit 24, South Hampshire, Trading Estate, Totton, Southampton. Tel: 0703 863629.


SURGICARE Trademark
Stomahesive™ Paste
For external use only
60g


Cooking a meal.
Slicing bread.
Mixing food.
Turning on a switch.
Putting in a plug.
Ironing.
Doing housework.
Cooking chips.
Looking good.


ELECTRICITY AND YOU
MAKING LIFE EASIER FOR DISABLED PEOPLE

*Meet Eileen Hobbs, a young mother with spina bifida, who against many odds is making a home and a life for herself and her son.*

# Mother and baby are both doing fine

**EILEEN Hobbs is a young woman with spina bifida who is looking forward to Christmas and the New Year, confident that she and her baby son, Malcolm, have a good life ahead of them.**

It's not easy to care for a baby when you are on your own, like Eileen after the break-up of her marriage. She's been able to cope through her own courage and determination and with the great love and support of her family, and with much practical help and friendship.

Eileen, 23, lives in a one-bedroomed ground floor flat in a pleasant area of Luton. It's in a small block set aside for elderly people, but through the help of her social worker, Mrs Webb, the council stretched a point and gave one of the flats to Eileen.

In fact, the elderly residents love having a baby around, particularly one who is as quiet as Malcolm.

"He has hardly cried at all from the day he was born" said Eileen. "The lady above me said she found it hard to believe that there was a baby here, he was so quiet."

**After she was married Eileen went away to St Loye's College, Exeter, and trained as a computer operator. She had passed her exams and was all set to return home and get a good job, when she found that she was pregnant.**

"I hope eventually I will be able to get a job in that line, but it's not possible now. Meanwhile I make a little money by making soft toys which my mother sells for me at a local factory."

Eileen's mother—and indeed the whole of this Irish family of one sister and two brothers, and father, of course—have been a tower of strength to Eileen. They dote on the baby and help Eileen in so many ways.

"My father, for instance, comes and takes him out quite regularly which gives me a break" said Eileen. Her mother thoroughly enjoys her role as grandmother, sharing the day to day care and feeding of Malcolm, her first grandchild. Fortunately the family lives nearby.

"I find I can cope quite easily with him, although he is getting very heavy for me to carry" says Eileen. But she solves this problem by putting him in the baby buggy and moving him round the house in this.

Eileen walks with the aid of sticks and has a chair for longer journeys. Her early childhood was normal. She went to a normal school and then to a convent and had no problem at all with walking, until she had an accident at the age of 10 and badly strained an ankle. This started a whole chain of operations—15 altogether—and she is paralysed in one leg. "I was supposed to have an operation on my shoulder, but we decided against it. My father said 'enough was enough'."

**She has great praise for her social worker. And particularly remembers the time Mrs Webb gave to be with Eileen when she went into labour. "She stayed the whole day with me at the hospital because my mother wasn't well at the time. She only went home when she knew that both I and the baby were well."**

Eileen had the baby by caesarian section, and after a few days in hospital, her social worker managed to get her into a mother and baby home in Northampton, where she was taught how to look after Malcolm. "I found I could manage him quite well so I went home early" she said.

**Eileen and Malcolm at the age of 5 months.**

Eileen's flat is situated right opposite a big park, where she often walks the baby. She can manage short distances without getting too tired.

She has applied for a Provisional Driving Licence and hopes it won't be long before she can become more mobile.

**ASBAH was pleased to be able to help Eileen. When they learned that she badly needed a washing machine, they provided the full cost, and this has made life much easier for her.**

She has also received support and encouragement from her local ASBAH—Herts and S. Beds—of which she is a member.

Malcolm is a blue-eyed active little boy, very advanced for his age, and obviously making the most of all the love and attention he gets from his mother, and her family.

# Railcard keeps on going

THE RAILCARD Scheme for disabled passengers will continue on its merry way for at least another 12 months. It was launched by British Rail as an experiment a year ago.

Costing £10 a Railcard lasts for a year, and entitles the holder to travel for only half fare—and an adult companion, too.

The 'disablement' qualification which entitles you to a card includes being in receipt of the Attendance Mobility, or Private Car Allowance, or if you are in the Motability Scheme.

Full details from post offices and stations. There is a leaflet on the subject—'Half-price train travel for disabled people'.

*ASBAH's Mobility Adviser, Leonie Holgate, needs your help*

# Successful drivers can put others on the right road

**IN MAY, 1982, I was appointed Mobility Adviser to ASBAH and became part of the Disabled Living Adviser's team. My interest is with the school leavers and their mobility within the community.**

Quite naturally there is a strong bias towards driving a motor car and most of the enquiries I have had have been about learning to drive, acquiring a car, transfers in and out of a car etc. Now I would like to turn the tables and ask for information from you.

I would very much appreciate hearing from people who have successfully passed their driving test. They can offer valuable assistance to aspiring drivers.

It would also be very interesting to hear from people who have found other ways of travelling around apart from driving. Some may be using a Batri-car or an electric wheelchair, others may utilise what the local services have to offer in the way of taxis or concessional cars.

I should be delighted to hear from anyone who feels that they would like to share their mobility experience. This can often prove beneficial to some who may be struggling.

The sort of questions I need to know the answers to are:

- Did you learn to drive in your own or your parents' car?
- Did your instructor have a car with hand-controls?
- If so, can I have his name, address and telephone number?
- How many lessons did you need to pass the driving test?
- Did you pass the test first time?
- Were there any special problems when you were learning to drive, eg. seating, judging distances, remembering instructions. How did you overcome them?

By answering these questions your knowledge and experience can be shared with others and it may be possible to put people in touch with one another so that they can give direct advice.

I do hope that I shall receive many letters which will be of enormous interest. You may prefer to phone in and I am at Banstead Place every Thursday from 9.30 a.m. to 3.30 p.m.

**Mrs Leonie Holgate, Mobility Adviser, ASBAH,**
**Banstead Place, Park Road, Banstead, Surrey.**
**Tel: Burgh Heath 56222.**

# ASBAH keeps in close contact with the 'vitamin trial'

THERE has been a delay in starting the nationwide 'multi vitamin trial' (as reported in LINK July/August) because all the necessary tablets are not yet ready.

One centre is starting to recruit volunteers, and it is expected that gradually others will follow suit.

ASBAH, aware of the concern and interest in these trials, and the difficult decisions that 'high risk' mothers may be asked to make, is maintaining close contact with developments. Rosie Horsfall, one of ASBAH's Disabled Living Advisers is keeping in touch with the individual centres. If anyone wants information or advice about vitamin supplementation or wants to talk things over, they are invited to get in touch with Rosie. Telephone her or write to her at National Office (tel: 01-388 1382).

LINK will carry fuller information about the trial in the next issue.

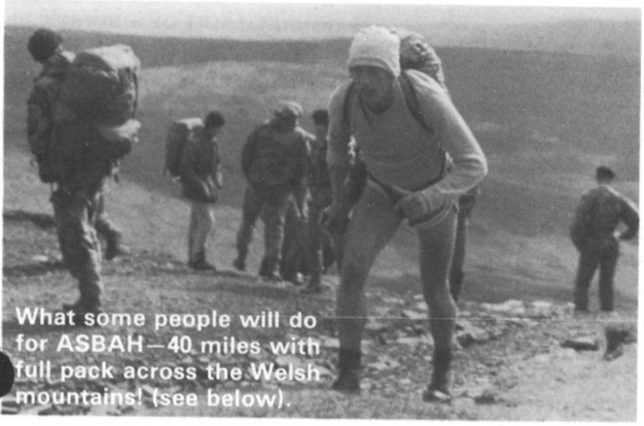
The aim of the trial is to determine once and for all whether taking extra vitamins taken well before conception and during early pregnancy can prevent the birth of a spina bifida baby to a 'high risk' mother.

Research over the past few years has indicated that vitamin supplementation does work, but the Medical Research Council, which is organising the trial, wants proper scientific evidence, before further steps are taken.

# Monopoly brings in real money

**Life in ASBAH's Appeals Department is always a frenzy of activity. However, over the last few months, we have surpassed even our own record for both frenzy and sheer inventiveness. If that sounds like boasting, here is the evidence to back the claim.**

On Sunday September 19, hundreds of Monopoly enthusiasts converged on Berkeley Square, Mayfair, for the first ever London Monopoly Marathon, organised for ASBAH by Fiona Isles and Madeleine Legg. The participants' task was to visit twenty-five locations which are represented on the Monopoly board but which also exist in real life! Some chose to walk, some to run, some went by bus or underground, some cycled and some chose to circumnavigate London in a bath called the ASBATH (ugh!). As in a normal Monopoly game, there were 'Chance' and 'Community Chest' cards, some of which simply said 'Go to Jail'—which meant five minutes hand-cuffed to the railings of Berkeley Square. All of the contestants were sponsored and an additional £30,000 was raised by despatching helium balloons sponsored by companies into the skies.



What some people will do for ASBAH—40 miles with full pack across the Welsh mountains! (see below).

## Calling out the troops

In addition to her work on the Monopoly Marathon, Fiona has been busy organising our second 'Mountain Express'. The rugged hills and passes of the Brecon Beacons were the scene for this forty mile 'yomp' with full pack, which started on the morning of Saturday September 25. Amongst the more than one hundred jompers were a number of Falklands veterans from the Second Battalion, The Parachute Regiment as well as from Twenty-Nine Commando (Royal Artillery) and from Forty and Forty-two Commandos (Royal Marines). There were also teams from RAF Hereford, London's Notting Hill Gate Police Station and the Cardiff Central Fire Station along with an array of bold civilians of both sexes. The winning team (Twenty-Nine Commando) completed the course in less than eight hours and, as Sunday morning dawned cold and wet, more and more teams romped home for bacon and eggs washed down with champagne. The Parliamentary Under Secretary for Wales, Mr Michael Roberts was present to award the trophy to the winners of this uniquely gruelling sponsored event.

**THE DAY the stars came out...Susannah York and Sally-Anne Howes at ASBAH's fashion show.**

**ORGANISER Barry Mishon (left) with two other celebrities who supported the occasion—Robert Powell and Nicky Henson**

## Model stars at Drury Lane

**Forming a complete contrast to the stark majesty of the Brecon Beacons is the plush magnificence of the Theatre Royal, Drury Lane, where, in September, ASBAH's Barry Mishon organised a fashion show under the title of 'Elegance is Fun'.**

Beautiful clothes provided by a range of leading designers were modelled by a dazzling array of celebrities, including Susannah York, Nerys Hughes, Carol Drinkwater, Hilary Tindall, Angela Douglas, Kenny Lynch and Nicky Henson. The opening sequence of the show was danced to the music of 'An American in Paris' as choreographed by prima ballerina, Lynn Seymour. 'Elegance is Fun' won ASBAH the praise of a glittering audience, some of whom had paid £15 for a seat.

*We'll have details of just how much these events raised by the next issue when all the sponsorship money has been received.*

## Thanks to the 'back-room boys'

Our Monopoly Marathon, the Mountain Express and 'Elegance is Fun' were all exciting events to organise. However, helping to make them a financial success has been the 'back-room' staff in our new Telephone Sales Department. Our sales team raised more than five thousand pounds of sponsorship for the Mountain Express in just one week. All in all, in a mere four months of existence, they have raised approximately sixty-five thousand pounds and look like going from strength to strength in their search for funds to boost ASBAH's work.

**Ian Morrison**
**Assistant Appeals Director**

# *'Happy birthday Thomas, love Mum & Dad'*

On Thomas's 12th birthday, his parents sent him this very special letter, which they have given LINK permission to reproduce below.

'His birthday was a great milestone for us and him. Perhaps if you could print the letter it may bring hope to other families now facing the problems we faced and conquered' said his mother.

Dear Thomas,

Many Happy Returns on this your twelfth birthday. We wish you lots of happiness. You have been discussing lately how you would like to be a writer when you are older. Do you know the secret of all good writers? Good writers always write about their own personal experiences, whether it is places they have visited, people they have met, or things they have done. You may feel at twelve you have not been to too many exciting places, met any exciting people, or even had anything exciting happen to you. Before reaching a hasty decision, can I ask you to look again at the people you know and have met.

The people who have come in contact with you have been all shapes, sizes, colours and religions, but what they had in common was the courage to accept life for what it is. Some people find disabilities hard to accept whether they take the form of blindness, deafness, loneliness or even the loss of limbs and speech.

### FIGHTING FOR YOU

Now start looking at yourself. Look how you have lived with your disability of being born with congenital hydrocephalus. How quickly you learned what you could do, and what you would never do. Look at your parents how they managed to live and adjust their lives around you and the daily thought that your shunt could block again. Do your brothers let you off in a fight? No of course not, you get the same abuse and punches. The only concession they make is not hitting you on the head. The fact you are included in abuses and punches leaves you in no doubt you are only one of five.

Have you noticed how your generation Thomas react towards handicapped people? They simply do not see the handicap, but the person. You know from personal experience they do not sit and compare disabilities, but rather discuss clothes, records, videos, sport, friends, school, and jobs. Now compare how *our* generation reacts. First reaction is of pity followed by the assumption that the handicapped cannot talk for themselves. You must have noticed how they talk over them but never to them. Because we are older does not make us wiser or kinder. Prejudice used to be associated with colour and religion, but can we honestly say we do not harbour prejudice towards the handicapped?

Think carefully of the ordinary people you have met who show they can accept their handicap. Remember those you met in youth clubs, hospitals and school—the sick and lonely people who kept their sense of humour in spite of the experiences they came through.

You have been told of your own personal experience in hospital time and time again. You had your share of operations Thomas, but none more serious than your second attack of meningitis and septicaemia. You were probably unaware of what was happening around you. Perhaps it was just as well. There were enough people fighting for you, praying for you without you adding to the worry. Those who were there will never forget the awful slow movement of the hands of the clock, as with each second it ticked away your chances of recovery. The wonderful work of surgeons who could only watch, hoping they had done enough for you, wishing the antibiotics would hurry and work. They knew the seriousness of the situation only too well. They had given you twenty-four hours to show some sign of recovery. One episode like that is enough to remember for ever no matter how long you live. Although your recovery was slow, to all involved it was nothing short of a miracle. That was your darkest spell, but you have had good spells of health to make up for it. That was when you and your family learned a valuable lesson, which they still try to remember, to live one day at a time.

### NEVER LOOK BACK

Before finishing this letter we wish to reassure you of our continual support and love. Now you are approaching your teens some questions will soon arise. Will I marry? Will I have children? Will I get a job? Will I live long? It would be stupid for us to answer yes to all these questions. No one has that assurance. We never got it ourselves so we cannot pass it on to you. We can only be there when you need us. We take from you what you have always given, your contentment of simple things. So never look back Thomas you cannot change it, look forward instead. Do not wait for others to help for their help might never come. Once again Thomas best wishes, have a Happy Birthday.

God Bless You,
All our love,
Mum and Dad.

# CLASSIFIED 'ADS'

**The advertising rate is:**
**£2.25 for up to 30 words. £3.30 for 30–45 words.**
**£4.50 for 45–60 words.**
**Please send remittance with your advert.**

**Adverts for the next LINK (Jan/Feb) should be in by October 5. Send to the Editor Mrs Susan Gearing (or telephone her on Langton 3351).**

### HOLIDAY ACCOMMODATION

**CAMBER SANDS.** Well-equipped and adapted chalet (sleeps 6). Bookings taken by Mrs N. Kerswill, 28 Ilmington Rd, Kenton, Harrow, HA3 0NH. Tel: 01-907 8526 (2–7 pm).

**HEYSHAM, Nr Morecambe.** Purpose built 6-berth fully equipped mobile home. Convenient and accessible for the largest wheelchair. Large bathroom. Details: Mrs H. Campbell, 9 Belton Road, Whitchurch, Shropshire. Tel: Whitchurch 3691.

**MABLETHORPE.** 2 fully equipped cedar chalets on Links estate. Sleep 6. Further details: Mr B Guest, 57 Bloxwich Lane, Walsall. Tel: Walsall 31725.

**WINTERTON-ON-SEA,** Nr Gt Yarmouth: 6-berth chalet. Indoor swimming pool, shop, play areas. Details: Mr R. Morris. Tel: High Wycombe 32184.

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

**BORTH Nr Aberystwyth.** 6 berth de luxe holiday home. Licensed site. Suitable for wheelchair users who live independently. Details: J. Carter, 1 Meadow Road, Craven Arms, Shropshire.

## Local Association changes

**THE FOLLOWING changes of Local Association Secretaries have taken place since the last issue. A full Directory will appear on the back of the next LINK.**

**CAMBRIDGE & DISTRICT**
Mrs P. Desborough,
Summerlin Farm,
62 Boxworth Road,
Elsworth, Cambs.

**EAST ANGLIA**
Now disbanded.

**HUDDERSFIELD**
Mrs Linda Foster,
7 South Croft,
Upper Denby,
Huddersfield, HD8 8UA.
Tel: Huddersfield 863006

**KENT**
Ms A. Hamlin,
32 West Street,
Gillingham, Kent.
Tel: Medway 573537

**LANCASTER, MORECAMBE & DISTRICT**
Mrs M. Dyson,
25 Royds Avenue,
Heysham, Lancs.

**LLANELLI**
Miss K. Bignall,
91 Old Castle Road,
Llanelli, Dyfed.

**SURREY**
Until further notice write to:
Mrs P. Holmes, (Treasurer),
11 Grove Road,
Ashtead.
Tel: Ashtead 76530

## Holiday Advertising

**Don't forget to send in your advertising for next year. You may like to advertise for the whole year (six issues). Please send payment with order. We have had to raise the rates very slightly but hope you agree that these are still very good value.**

### FOR SALE

**Leisure Wear:** White cotton **Tee Shirts** with green family symbol and words 'Support Spina Bifida'. Adult sizes, small, medium, large: £3.75 each. **Sweat Shirts** in reverse colours. Adult sizes, small medium, large, XL: £7.50 each, postage included. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks.

# ASBAH booklets etc . . .

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|---|---|
| *Your Child with Spina Bifida,*<br>by J. Lorber, MD, FRCP | 35p |
| *Your Child with Hydrocephalus,*<br>by J. Lorber, MD, FRCP | 35p |
| *Children with Spina Bifida at School,*<br>Ed. P. Henderson, CB, MD, DPH | 50p |
| *Sex and Spina Bifida* by Bill Stewart | awaiting reprints |
| *The Handwriting of Spina Bifida Children*<br>by Joan Cambridge and Elizabeth M. Anderson | £1 |
| *The Nursery Years* by Simon Haskell & Margaret Paull | 35p |
| *Little Joe (A Grandmother's story)* by W. Foster | 50p |
| Information leaflets | 100 for £4.00 |

Asian language translations of a Fact Sheet about spina bifida and hydrocephalus and ASBAH's work are available free from national office. Translations into Bengali, Gujarati, Hindi, Punjabi and Urdu. Welsh language sheets are now ready too. All available from ASBAH. (Special rates available to Local Associations.) Please note that postage is extra. Allow minimum of 15p per booklet.

**Scottish Spina Bifida Association Booklets**

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|---|---|
| *Growing up with Spina Bifida* | 35p |
| *The Spina Bifida Baby* | 35p |

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 × 30 in.** | **10p each** |
| **Best Foot Forward 15 × 10 in.** | **10 for 40p** |
| **For local publicity 15 × 10 in.** | **10 for 40p** |
| **Car Stickers** | **13p each** |
| **Plastic Lapel Badges** | **8p each** |

**All available from Appeals Dept.**—postage extra.

| | |
|---|---|
| **Film 'Appeal for ASBAH' 10 mins**<br>**16 mm Colour/Sound** | **£4 Hire** |

**The Appeals Dept. carries a range of fund-raising and publicity items, i.e. posters, pens, key rings, games. Send for list and order form.**

**Flag Day equipment** can be obtained direct from: Angal, 48a Holmbush Road, London SW15 3LE (01-788 5464).