Link

Association for Spina Bifida and Hydrocephalus/ASBAH

March/April 1989 Issue Number 121 30p

Association for Spina Bifida and Hydrocephalus (ASBAH)
22 Upper Woburn Place, London WC1H 0EP
Tel: 01 - 388 1382

Registered Charity No. 249338

Patron: HRH The Duchess of Gloucester

President: Sir Hugh Rossi, MP

Chairman: Mr R.R. Mackenzie **Hon. Treasurer:** Mr A.K. Stewart-Roberts

ASBAH has an experienced staff ready to help with any problems relating to spina bifida and/or hydrocephalus:

Executive Director.......Miss Moyna Gilbertson, *MCSP, FBIM*

Appeals Directors...............................Mr Douglas Jack, *MA*
Mrs Jenny Whiting

Assistant Director (Administration).............Mr Paul Dobson, *BA (Hons), MIPM*

Fieldwork Manager...........................Mrs Teresa Cole, *MICA*

Disabled Living Advisers..............Miss Mary Barton, *MCSP*
Mrs Leonie Holgate, *MCSP*
Mr Phillip Watson, *BA (Hons), RGN*
Mr Jamie Gilham
Mr Ian Laker
Mr John Naude

FIVE OAKS, ILKLEY, W. YORKS

Manager..Miss Joan Pheasant, *NNC*

Development Officer.................Mr Paul Cooper, *BA (Hons)*

Finance Director......................Mr Derek Knightbridge, *FCCA*

Services Director..........Mr Charles Spottiswoode, *BSc(Eng), MICE, C.Eng.*

Press and Publicity Manager.......................Miss Monica Hart

Research Officer.....................................Miss Pat Corns, *SRN*

Education, Training & Employment Co-ordinator.......Mrs Susan Fenton, *BA (Hons)*

Accommodation Officer.........Miss Carolyn Smith, *BA (Hons)*

LINK Editor..Mrs Sue Gearing

APPEALS DEPARTMENT

Deputy Appeals Director........................Mr Stewart Morrison

Appeals Administrator.............................Mrs Joan Chapman

Appeals Organisers.........Mr Richard Pool, Mr Jonathan Smith

ASBAH Publications

All available from National Office
Cheques payable to "ASBAH"

Young People with Spina Bifida and/or Hydrocephalus — Learning and Development (1985) *Leonie Holgate*.. £1.60
The Handwriting of Spina Bifida Children (1979) *Joan Cambridge, E. M. Anderson*.......................... £1.60
Spina Bifida and You — A Guide for Young People (1985).. £3.50
Sex for Young People with Spina Bifida or Cerebral Palsy (1984)... £1.75
Children with Spina Bifida and/or Hydrocephalus at School... £2.50
Life & Death-thoughts on bereavement (1983)...... 75p
Making our Way — individual experiences of young people with spina bifida and/or hydrocephalus (1984)... £1.20

BOOKLETS/LEAFLETS

General leaflet.. 5p
Housing: general advice for young people............ Free (60p for professionals)
Five Oaks leaflet... Free

All prices include post and packing

FACT SHEETS..up to 10 copies free
Translations of fact sheets are available into Welsh.

VISUAL AIDS
Slide sets and notes (12 slides) Living with Spina Bifida £8.62 inc. VAT
Video — Training video on Hydrocephalus (May 1987). Contact Information dept. for details of hire or purchase.

MAGAZINES
LIFT — for members of young ASBAH (LIFT)...................Free
Causeway — for contributors to ASBAH's work................Free

LINK SUBSCRIPTION
UK...£3.30
Europe and Overseas Surface Mail...................................£4.80
Air Mail..£10.80
All payments should be made in Sterling.
•Except in the case of LINK all the above prices apply in the UK only. Overseas rates on request

Editor's Note

GOODBYE FROM ME

My time as Editor of LINK has been rather like bringing up a child. Having "adopted" the magazine at an early stage in its life - issue no. 25 - contributing to its development and helping it to 'grow up', the stage of letting go is now here.

After 17 years it's time to let someone else take over.

It will be a great wrench for me. Writing about you, your trials and tribulations over the years has made me feel very close to many families. One of the least pleasant aspects of journalism is the way in which a reporter gets to know a family very well for a short time, and then leaves - very often never to see them again. But I haven't forgotten those of you I have met, and it has been good to renew friendships at conferences and meetings.

I think I have been longer at ASBAH London office than anyone else here today, although of course I have only ever worked part-time and from home.

Over the years there have been many changes. Some cynics may say that the situation in general for people with disabilities is much as it was 20 years ago, but I do feel there has been

Continued on page 4

On the INSIDE

NEWS

MEDICAL

LEISURE

DAILY LIVING

PLUS

FRONT COVER:

Rifa Begum looking pleased with her new sports wheelchair bought by her friends at Lliswerry Comprehensive School, South Wales and others - thanks to the special efforts of (from left to right) Donna Bromley, Marianne Holbrooke and Lisa Ennis. Lisa who has spina bifida raised £120 in a sponsored swim, while Donna and Marianne were sponsored for spending a day in a wheelchair. Photo: S.Wales Argus Ltd., Newport.

Link **is published by ASBAH (the Association for Spina Bifida and Hydrocephalus).**

Contributions to LINK by way of letters, news photographs, articles and opinions are warmly welcomed.

The closing date for the May issue is April15. Send to the Editor at ASBAH's London office.

GOODBYE FROM ME

Continued from page 3

progress and that there is a much greater awareness and acknowledgement of people with disabilities by the general public and authority than in the past.

One of the most hopeful signs is the way in which disabled people are starting to stand up and be counted and to take up the reigns of responsibility. It is a movement that needs to gain greater momentum.

I hope that in some small way LINK may have helped to increase awareness and to give families a much greater fund of information and facts about what spina bifida and hydrocephalus are, the implications, how to solve problems, where to go for help, and other useful information on subjects ranging from equipment to holidays.

In the past 17 years I have also enjoyed worked on a number of ASBAH publications - the writing and editing of *Making our Way* where I met and wrote about young people with spina bifida and hydrocephalus and their individual experiences, the editing of Spina Bifida and You and of a number of Annual Reports, and the launch and editing for a while of the newsletter of the International Federation of Spina Bifida and Hydrocephalus, *Federation Focus*.

One way and another it has been an enjoyable 16 plus years at ASBAH. I hope I will have the opportunity of meeting or hearing from many of you again.

Sue Gearing

If any of you would like to get in touch, I am the new Editor of 'Getting Around' a national montly magazine of interest to people with disabilities, which we are restyling and renaming. We hope to concentrate much more on leisure and sport. One of my first priorities is to get together a team of freelance contributors who are disabled or fully involved in the world of disability. How about it?

The magazine is at 111/117 Victoria Street, Bristol BS1 6AX

Letters

Cross border 'raids' - taking them seriously

I would like to convey the thanks of the Scottish Spina Bifida Association for your efforts in making readers aware of the situation regarding ASBAH members fundraising in Scotland (LINK Issue No.119). However I would be very grateful if you would allow me to clarify the situation and explain our concern.

In the first instance, we disagree that misunderstandings arise from activities such as John O'Groats to Land's End events. We do not seek any veto or control over these - indeed we wish to be free to operate them ourselves. Our National Office would be very willing to help and advise such ASBAH fund-raisers if possible.

However, cross-border 'raids' are another matter. These normally take the form of bus-loads of people descending on Edinburgh, especially at Festival time, and rattling cans for a couple of hours - all good clean fun.

Not quite. In Scotland such collecting is illegal. In Edinburgh charities are allowed one Saturday every two years, and if an organisation collects during someone else's time it could well lose all collecting rights. We are very concerned lest the authorities fail to distinguish between our legitimat use of time, and such cross-border 'raids' - after all, both are concerned with raising money for spina bifida. While I and my Executive, are sure most of these 'raids' are innocent of intent, I would appeal to ASBAH fund-raisers to avoid such actions, since the consequences to their Scottish counterparts could be very serious indeed.

Finally, I would like to point to another form of cross-border 'raid", one with which I find it hard to sympathise or to understand. During October this year our Executive Officer was informed that members of an ASBAH branch had been trawling for donations round Edinburgh legal offices. As fund-raisers are no doubt aware, a great deal of cash comes through legal offices in the form of legacies, etc. and we in the Scottish Spina Bifida Association are very careful to ensure that any ambiguities are kept to a minimum. For an ASBAH branch to fish in these waters suggests to us a degree of premeditation far beyond the innocent 'raid'.

I trust this goes some way to clarify the position, and explain our concerns. Our Associations have developed a long and harmonious relationship over the years and it is important that this continues.

On behalf of the Scottish Spina Bifida Association I would like to end by wishing all members of ASBAH a healthy, prosperous and successful 1989.*

Mr Donald H. MacRae
Chairman,
Scottish Spina Bifida Association.

*Mr MacRae's letter was sent in mid December, just too late for the January issue of LINK

One of the few

I read with great interest the article in the last LINK by Dr Bayston about "Treatment of shunt infections in hydrocephalus".

Three months ago I would have agreed with him totally, but last November our daughter Natalie was admitted to hospital very ill. She had all the classic symptoms of a shunt infection - vomitting, listlessness, very sleepy and a terrific headache; so ill, in fact, the doctors put an IV drip up and commenced antibiotics through that medium. They didn't want to remove the shunt until Natalie was a lot stronger and able to take surgery. All very good, but terribly frustrating when as parents we knew eventually the shunt would have to come out.

Not so, Natalie was one of the few that Dr Bayston wrote about. Her infection responded to the powerful

continued on next page

Mobility Week

Don't forget ASBAH's Mobility Week on July 3-8 at the Ludwig Guttman Sports Centre at Stoke Mandeville for 9-14 year olds.

The week will not just aim at wheelchair mobility, but will also include other subjects such as: incontinence management, personal care, self awareness, fashion, make-up and much more. We do aim by covering such a variety of topics and by offering personal attention to start to equip these children for life in its widest sense.

The cost of the week is £75 and will cover full board and lodging.

If you are interested in sending your child, or if you know of someone who would like to go and you would like further information, please contact either: John Naude or Ian Laker, Disabled Living Advisors at ASBAH's London office.

Free furniture

When ASBAH's London office relocates to Peterborough later this year it will not be worth taking the 'motley collection' of office furniture that staff are using at present.

As a once only offer - ASBAH is offering individual pieces of furniture - old desks, filing cabinets etc. FREE to anyone who would like them and would take them away at the appropriate time.

First refusal goes to ASBAH members and staff.

If you are interested contact Paul Dobson at ASBAH's London office.

FLORIDA HOLIDAY AUTUMN 1989

At the time of going to press there were still places available for the second departure - sixteen days from Oct 12-27.

If you want full details contact:

Panovista Travel, 78 Sea Road,
Fulwell, Sunderland, Tyne & Wear.
Tel: 091 5494444

?roblem share

The new LINK column where you can air your problems. If ASBAH can't find the solution, maybe other readers can. It's YOUR space so please do write in.

……

? My son is 18 months old and has spina bifida. He crawls well and is learning to walk with calipers and a rollator (which he hates at the moment!). He has never been constipated, and about five months ago he had gastroenteritis. Since then things have gone from bad to worse and the area around his anus is now always sore, if not bleeding, due to continued diarrhoea. I have tried every nappy rash cream on the market and more besides.

Has any other mother faced this problem? Thankfully he cannot feel any pain in the area, but I am now at the end of my tether worrying about it. I'm beginning to think his problem may be dietary.

A In some case following gastroenteritis a mild infection remains which can cause persistent diarrhoea. Firstly, I would suggest that the paediatrician is approached to perform a stool analysis to exclude this possibility.

If no infection is detected, another complication following gastroenteritis in young children can be milk intolerance. To determine whether this is the case, a referral to a dietician would be needed. This would have to be made by the paediatrician.

In cases of persistent diarrhoea, a very high fibre diet can sometimes help. The problem here with young children is that if a too high fibre diet is given, not enough energy is made available for growth needs. Again, dietetic input and advice is needed.

? ? ? ?

A reader from Milan in Italy, Susan Camassa, has posed several questions in the hope that they may be answered either by experts or other readers. ASBAH is looking at them and will be forwarding answers to her, but meanwhile can any readers help, based on their own experience and knowledge?

1. I would like to take my five year old son swimming, but bladder and bowel incontinence cause a problem. How do other readers cope with frequent 'dribbling' and irregular bowel movements for this activity?

2. My son has to be catheterised intermittently, sometimes we have to take planes or trains or find ourselves in situations where public toilets are extremely small, inadequate and sometimes unhygenic for any such operation. How do people cope in these situations where it is virtually impossible to lie children down without disturbing other passengers or arousing their curiosity?

3. How does one explain in simple terms the functioning of the shunt and the necessity to lengthen the internal catheter at intervals to a child who will soon have to undergo an operation, without frightening the child?

4. Do parents find that often teachers tend to misinterpret learning problems of children with spina bifida and hydrocephalus and easily attribute other problems which would normally be ignored if that child were normal?

Letters *continued*

drugs she was given and fifteen days later we took a more-or-less healthy child home to a wonderful family Christmas.

I had never heard of a shunt infection being cleared up in this way before without the need for surgery. We were told it doesn't happen very often, but just occasionly, caught at the right time, a bad infection can be cleared up by using powerful drugs.

So while I would never presume to know more than a highly skilled person such as Dr Bayston, as a parent, if using drugs can work and save weeks in hospital and the need for an operation, I'll try it again without the scepticism I felt before.

Ironically on January 2, Natalie's shunt blocked at both ends and required a shunt revision. We thought the infection had returned, but on tests of the line and shunt, as well as CSF, there was no sign of any infection and after two weeks in hospital, we returned home with a little girl sporting a new hairstyle!

Mrs G. Truscott, Oxford

Holiday offer

My husband, who suffered from MS, died last May. Having been secure in life and love, the expression 'life begins at forty' took a different slant. What to do now was not in doubt. As a carer, I know that taking a holiday can be extremely difficult because accommodation facilities for disabled people are not like at home.

I live in the majestically attractive Bronte countryside of West Yorkshire and my bungalow was hand picked and adapted for my husband's needs. I feel that I can offer those elusive facilities to anyone who has a mobility problem - ramp or level access, spacious rooms, fully tiled bathroom with level shower area and a Parker bath.

For further details please contact me on 0535 44221

Margaret Rhodes
Oakworth, Keighley,
West Yorks

Making room for God

First, congratulations on LINK. My husband and I think it is very good.

You have asked for letters. I am better at talking, but will have a go.

In LINK July/August, page 14 there was 'Not the end of the world - the start of a new one'. I was interested and it made my day on page 15 when Lorraine said she had faith as her strength. It must be difficult for those bringing up a disabled child without any faith in God.

We too have faith. The Lord does not always take our problems away, but gives us strength to overcome them. Many friends have prayed for us over the years, and in 1989, prayers are still answered.

So could you make a little more room for God in LINK? There must be many non conformist ministers and clergymen able and willing to write a few words for LINK.

Mother came too

In LINK, Sept/Oct, Nancy Robertson said many problems arose from young people being too dependent on their families. I agree, BUT, a lot depends on the family, especially mother. I know I was an only child. My mum and dad were wonderful, but as I got older I had the get up and go and wanted my own friends. Mother always had the last word. Many times she stopped me going out, or mother came too.

Now at the age of 62, I can understand her better, but that did not help when I was a teenager.

Mrs Mary Topper,
Storrington, Sussex

Regular reading about research

In reply to your Editor's Note issue no. 120:

My husband and I have taken LINK for approximately nine years. We have never written to you, not feeling we personally had anything to contribute.

In December 1979 I gave birth to a son diagnosed as having spina bifida and hydrocephalus. His life was not to be, and sadly in March 1980 he died.

We continued to take LINK hoping, as we still do, that one day the reason for his handicap will be explained to us. We, therefore, read your research articles regularly.

In 1981, we had another son, 'normal' and healthy. We were then told that a third child would stand a very high chance of being handicapped. We read with interest the articles concerning folic acid and Pregnavite Forte F.

When we decided to plan a third child, our GP found out all he could for us and prescribed the Pregnavite.

In August 1984, we had a daughter, again 'normal' and healthy. Whether the Pregnavite helped, we don't really know, but it was well worth trying and also helped with our peace of mind.

We feel there are probably a lot more people in the same circumstances as us, regularly taking LINK, but no longer able to contribute.

Keep reporting your research articles please and we will continue to be regular readers.

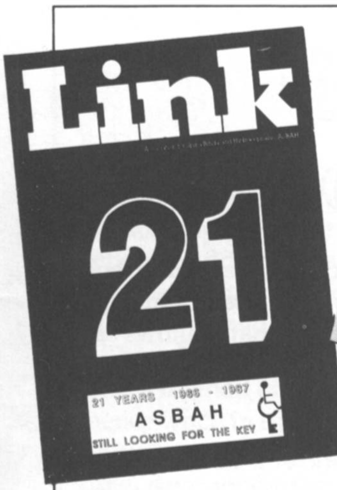
Jacky Foulger,
Woodbridge, Suffolk

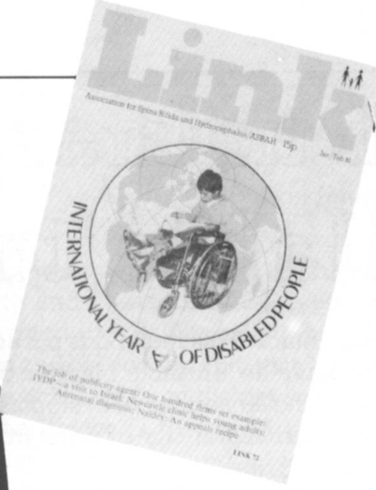
Stable conversion

Near Dorchester, Dorset. New two bedroom holiday cottage (one of four cottages in a stable conversion) ongrassland sheep farm. Designed throughout with the needs of disabled and elderly people in mind. Fully equipped including TV and video, washing machine dishwasher, microwave and electric cooker. Details: Charles Hammick, Higher Waterston Farm, Dorchester, Dorset DT2 7SW. Tel: 0305 848208.

Accessible hotel at Trefnant, Clwyd.

Opened this year, the hotel is wheelchair accessible and has some specialist equipment available if required. There are eight en suite bedrooms, including three family rooms. Many facilitie; tasty meals, with organically grown vegetables; nature trail. Details: Bryn Glas Hotel, St. Asaph Road, Trefnant, Clwyd, LL16 5UD. Tel: 074 574 868.





KEEPING IN TOUCH OVER THE YEARS

As Sue Gearing leaves LINK after nearly 100 issues, Moyna Gilbertson looks back:

AFTER 17 years and 96 issues of LINK, the time has come to say goodbye to Sue Gearing. For many people all over the world, families, people with spina bifida and hydrocephalus, professionals and friends of ASBAH - LINK has been a most important way of keeping in touch.

Looking back over these issues vividly demonstrates the growth and development of the Association and the wide range of topics which interest LINK readers.

It is difficult to pick out LINK highlights. There was the move to Devonshire Street in the winter of 1972, the 10th birthday celebrations, and ASBAH's 21. Then there were difficult topics, which had to be covered - 'Care of Newborn Babies' and 'Selection for Treatment' and in 1976 for the first time an article on 'Sexual Problems' recognising that the babies we first knew were growing up.

Every issue has included features about people mostly written by Sue and showing her devotion to her work, and her enthusiasm for making all of us feel that we have a positive contribution to make. Sue has rarely missed an AGM or Conference and she is a true friend. With the successful publication of her first book (on country walks) and the increased demands on her journalistic skills, she is now so committed that she has decided it is time to relinquish the Editorship of LINK.

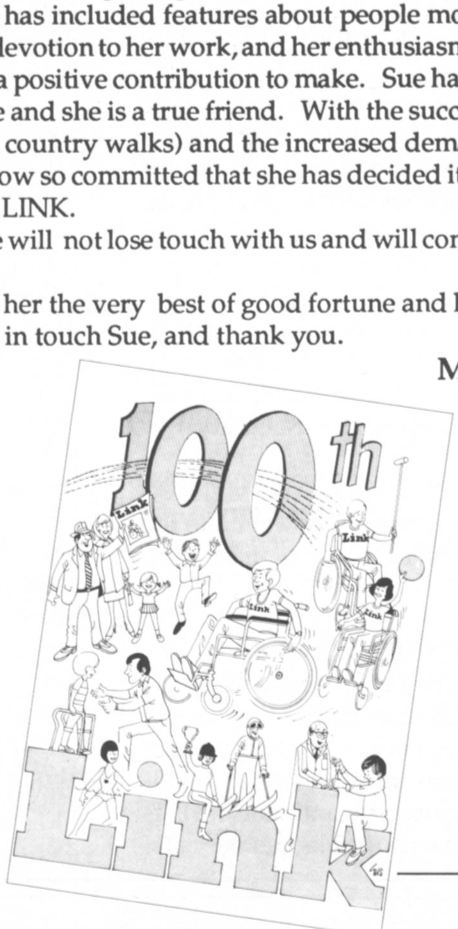
We hope she will not lose touch with us and will continue to contribute from time to time.

We all wish her the very best of good fortune and happiness for the future. Please keep in touch Sue, and thank you.

Moyna P. Gilbertson
Executive Director.

Left: one of Sue's favourite covers

Right: cover by cartoonist Gus - a good friend of ASBAH



Systems of urinary drainage available today

by Elaine Carter & Michelle Fullalove

based on their experience and knowledge of bladder systems and surgery for people born with spina bifida.

Both in their twenties, they work as nurses and have lived with ileal loop urinary diversions (bags) from childhood until 1983 when they both opted to try alternatives.

Here they discuss the advantages and disadvantages of these and other options.

The aims of all the systems are:

to allow our urine to drain freely from the kidneys, thus avoiding infection and kidney damage

to be free from urinary incontinence which is necessary for us to be able to socialise, attend school, work and make friends.

for us to feel comfortable with the system as part of ourselves.

THE FIRST METHOD to be tried for those who have not undergone surgery should be INTERMITTENT SELF CATHETERISATION. This is particularly suitable for the children of today. This is the passing of a thin plastic tube up through the urethra into the bladder to drain off the urine as completely as possible. Parents may start this for their children but the individual should be taught to do this for themselves as soon as possible to allow them to accept the procedure and be confident about carying it out.

This near ideal method seems to work for many children, occasionally with the use of muscle stimulant drug therapy; however, the side effects can be distressing such as dry mouth, blurred vision, rashes, hyper-activity.

The next method could be BLADDER AUGMENTATION which is the stitching of a piece of bowel on to the existing bladder, allowing a larger amount of urine to be stored.

Another possible method is CYSTOPLASTY. This is for when the natural bladder has proved to be unsatisfactory due to high pressure and reflex spasms causing uncontrollable leaking of urine. The operation involves making a cylinder-shaped bladder from intestine which maintains a low pressure and reduces incontinence. This option is only available to those with the bladder neck (Tri gone) intact. This method is particularly helpful to those who have an unstable bladder but whose sphincter is intact. The advantage of cystoplasty is that it allows safe and effective drainage of urine from the kidneys with no reflux of urine.

An option for those whose sphincter is not competent is the Brantley-Scott ARTIFICIAL SPHINCTER. The plastic sphincter is an artificial device used to achieve continence and is worked by a small pump placed in the groin which is squeezed flat. This deflates the sphincter cuff and allows the bladder to empty. In my experience this never worked and I had to squeeze the pump and catheterise at the same time.

I first had the Brantley-Scott sphincter at the same time as the cystoplasty. However, the sphincter became infected and required complete removal after only six weeks. Later I had the sphincter cuff implanted and was left incontinent for three months before the other components could be inserted and the device activated. But this still failed to achieve continence and it was found that the cystoplasty was contracting and causing spasm which in turn caused the incontinence. So then a patch of ileum (small intestine) was sewn into the cystoplasty and this prevented spasm and I achieved continence. However, the sphincter still did not work and I continued to self catheterise.

Four months later I had an infection at the site of the pump and this needed hospitalisation for intensive antibiotics and this seemed to clear up until five months later when I found I could not deflate the pump through pain at the site of the pump. This time it was found that part of the device had eroded into the urethra, possibly due to me having not deflated the pump prior to self catheterisation.

This again required total removal of the device. Following this I had an INDWELLING CATHETER and it was anticipated that the urethra would need repairing. But this I was told could not be done for some six months.

However, after six weeks I decided to remove the catheter to assess the level of incontinence and found that I was totally dry providing I catheterised regularly and was free from infection. This I feel has been an acceptable compromise.

Basically **the disadvantages** with the sphincter are infection and mechanical failure - the latter being less of a problem with constant updating of the device. Another aspect to consider is the psychological affect of having a small pump situated in the groin (the labia in women and the scrotum in men). Some women I spoke to found this difficult to accept, although the actual size is similar to that of a marble. Another consideration is that of child-

continued on page 9

Systems of urinary drainage

continued from page 8

birth. When I had mine inserted no-one with a sphincter had actually given birth and I was told that Caesarian section would not be a good idea as this might interfere with the device, although the doctors felt that natural childbirth would not be detrimental to the device.

The **advantage** of the device is that it offers a near normal method of urinary elimination and achieves continence whch in turn makes life easier for the individual. It mus be stressed that this option, although good for some, may not be the ideal for all. Possible candidates must be made aware of the complications.

Michelle Fullalove

If the bladder has had to be removed as in my case due to severe repeated infection or when incontinence is not manageable at all, then DIVERSION OF THE URINARY TRACT will be needed.

This means surgically moving the ureters so that they can freely drain urine from the kidneys into a substitute bladder. This substitute bladder must not leak and must be big enough to store the urine at low pressure until it is emptied into the toilet.

The urinary diversion can be of three types:

Firstly, the substitute bladder could be our LARGE INTESTINE which a few people are able to train to hold amounts of urine which are then passed along with their faeces. However, continence with this method can be difficult for people with spina bifida so I will say no more.

Secondly, the substitute bladder can be an UROSTOMY BAG stuck onto the abdomen over a surgical opening in the skin (a stoma). This system has probably saved many lives since the 1960s. The operation involves a short portion of intestine being moved to make a passage for the urine to flow from the ureters to the skin surface. This forms the stoma which sits like a 'cherry' on the skin of the abdomen. The bag is then stuck to skin around the stoma to catch the drips of urine and is emptied via a tap every few hours.

The surgery itself is relatively uncomplicated and if health is fairly poor might be the only possibility.

The other, newer urinary systems generally involve catheterising which may be less acceptable or practical for some people than using a stick-on bag which can be easily emptied. Long-term possible complications of the newer systems are not yet known either.

For this system - THE ILEAL LOOP URINARY DIVERSION - the long-term effects have been found to include gradual kidney damage, although this is not a problem short-term. Leakage of urine and sore skin under the bag are variable problems, lessened these days by better adhesives and bags, and by advice from stoma nurses.

Psychological acceptance of the stoma and bag varies even more. Those who have physical difficulties like leakage often find it harder to accept the system and vice versa. Acceptance in childhood is strongly influenced by family attitudes to the situation. It can be encouraged when the family sees the bag and stoma as positively helping the child's health and caring for it as a part of daily living. Childhood feelings stay with you, so a positive attitude then can help in forming friendships and relationships throughout life.

Thirdly, a substitute bladder can now be a POUCH-made surgically out of small intestine. It is inside the abdomen and is emptied by clean intermittent self catheterisation of a valve which keeps it continent. The difficult bit to get right is the construction of the valve. Various methods are used to make them out of more small intestine, appendix, ureter or fallopian tube. A repeat operation can be necessary.

"We are both well and happy with our systems - not wearing a bag feels better than we ever imagine"

I chose this option - KOCK POUCH - after long deliberations, for the following reasons:

I needed an operation - either for another ileal loop urinary diversion (mine was more than 15 years old) or this new system. I had felt positive about my stoma and bag. Neverthless, when offered a chance of a stoma but no bag I wanted to pursue it.

Over the previous five years I had had repeated kidney infections and poor kidney function. I hoped that this new system would prevent further damage since it was a second valve stopping reflux of urine and infection back up to my kidneys. I was concerned that success would need my ability to catheterise, so to see if I could cope emotionally with the idea, I practised catheterising my existing stoma.

Also the likely complications included leakage, in which case I could stick a bag on my skin as before, and, more long-term, stones might form and have to be removed needing a day in hospital.

In the event I had three operations before the valve maintained continence - for fours years so far. The pouch holds a pint of urine and then feels full, waking me if asleep. At first though I went mainly by the clock.

Catheterising takes about five minutes every three to eight hours. I catheterise where my old stoma was on the front of my abdomen. But now the stoma is just a quarter of an inch gap in a scarred bit of skin. Catheterising does need manual skill and concentration and can feel a bit uncomfortable.

So far my kidney function has been maintained and though urine infections occur I have not had the kidney infections which make me ill, nor any problems with stones.

Elaine Carter

Local Association Round-up

Sussex

New youth worker

Tony Westbury has started as a Youth Worker for Sussex local Association, working part time - 25 hours a week. Funded entirely by the local Association Tony, who is a graduate and sportsman, is studing for a Ph D part time.

He has worked at Chailey Heritage special school and at the Disabled Housing Trust in Sussex, and is interested in rock climbing, running, life saving, chess and rugby. His brief is to organise more weekends for the young people, to look at social and sports opportunities in different areas of Sussex and match them to individual members, and to do things LIFT did in the past.

Somerset

Telethon helps

The local Association has received £2,500 from the Telethon appeal towards financing a fieldworker - together with assistance from national ASBAH and money raised by Somerset itself. "We have been without a fieldworker for six years now and really are beginning to lose touch with some of our outlying families" commented Chairman George Earl.

Kent

Money-raising push

Karen Gold is gathering together as many sponsors as she can to support her on a wheelchair push in the Summer to raise money for the Handicapped Holiday Fund, which organises holiday breaks for those who need them. The push will be from Westerham to Biggin Hill on July 23. Sponsor forms from John Thunstrom: 0272 47474.

Hull

Young anglers

(Above) Prizewinning fishermen from Hull local Association with the trophies they have won in a recent fishing competition.

Mr Andy Gorman of the Blue Bell Angling Club organised the fishing competition and raised £750 from donations for prizes. The presentations took place at the Hull Golf Centre Club whose members helped to raise some of the prize money.

Twenty six people took part. The winner received £100.

Pictured (back from the left): Shelley Hebb, Stephanie Ellis, Philip Brown, steward Stan Furlong, Lee Edwards, Steven Wilson and Darryl Bulman; Paul Lister (left) and Janet Swainger in the front.

Bristol

Let's get together

Tolentino House isthis local Association's new centre for social gatherings. Family evenings are now a regular event for members as well as special evenings for younger ones with disabilities. It is hoped that members will come up with other suggested ways of making full use of Tolentino House as a 'social club'.

Lincolnshire

Nicola's special occasion

It was a day to remember for Nicola Cope of Reepham near Lincoln when she pushed herself down the aisle as bridesmaid for her brother Richard's wedding at Penge in Kent.

Nicola, 12, was able to 'catch up' on news of her friends and relatives. She was born in Beckenham and used to go to school in Chislehurst so she was back on her former ' home territory'.

Entente cordiale

Two French boys are looking for the chance to spend some time in this country......

One of the boys, aged 12, would like to spend a holiday here in July with a family with a young person similar to himself. He has minimal physical handicap but is incontinent of urine.

If anyone knows such a family please ask them to contact: Madame Buriot, Infirmiere Conseil, Association pour le Spina Bifida, 32 Ancien Chemin de Villiers, 94500 Coeuilly, Champigny, Paris.

Another boy would like to come to Britain for the Summer months too. He is mobile and incontinent. He knows a little English (onlyin the first year of English at school). The family would like him to stay for about a month and would be happy to have an English boy in exchange who is similar in the management of his disability.

If anyone is interested they should contact: Sebastian Tuacat, 26 Rue Marne, 94130 France.

NEW WHEELCHAIR SURVEY

A three year project to research powered wheelchairs is being launched by RICA (the Research Institute for Consumer Affairs).

There are glaring faults in the design of many powered wheelchairs which coupled with poor engineering and construction quality can mean daily discomfort and severe inconvenience, says RICA.

The project will cost about £250,000 - its biggest yet. A private trust is helping and RICA is also hoping for funding from the Department of Health, private trusts and Euro organisations.

The first step will be a survey of wheelchair users to find out their differing needs, and of the vehicles currently in use, their reliability and the standard of repairs and servicing available. The survey will look, too, at what sort of advice is offered by commercial and charitable sources, how users pay for the wheelchairs and how easy to use and maintain different models are.

Stage two will include user tests at Banstead Mobility Centre, an ergonomic evaluation of wheelchairs on the market, and engineering tests.

In 1984, RICA published a general guide to choosing and buying an outdoor powered wheelchair, but there's still little independent advice available and no truly comparative tests of wheelchairs have been carried out to offer users an informed choice, says RICA. It hopes to have a final report ready by 1990.

Newslines NEWSLINES Newslines

● A double decker intercity coach has been adapted for wheelchair users and passengers with a variety of disabilities.

It is owned an operated by Northumbria Motor Services of Newcastle upon Tyne. and used on the National Express Rapide service..it's the first to be used on a National Express route.

Details about the coach and times of operation from: Tony Kennan, Northumbria Motor Services Ltd., 6 Portland Terrace, Jesmond, Newcastle NE2 1QQ. Tel: 091 281 1313.

● Freedom Hire a new companyoffering families the chance to hire a roomy vehicle which looks like an ordinary saloon car but can take three adults plus driver and a wheelchair passenger.

The vehicle is a cleverly converted Renault Freedom. Freedom Hire is based in the West Country but can deliver and collect their vehicles anywhere in England and Wales at the normal hire delivery rates, and can provide a driver too.

Details from Roy Smith: 0278 760272.

● Peter Raynes, Founder of the employment charity 'Instant Muscle' will be joining PHAB (Physically Handicapped and Able-Bodied) as their new Director from April 1.

Mr Raynes, 56 who lives in Farnham, Surrey, had a varied career in industry focused on what he calls 'the people side' of business and in 1981 started 'Instant Muscle' which helps disadvantaged young people to start their own businesses. It now supports some 1,500 projects.

Door-to-door shopping service

Sainsbury's supermarket has scored a first by giving a local authority (Camden in London) a special bus to provide a door-to-door shopping service for disabled people in the borough. It is also paying for the first five years' running costs.

The photo shows Ossie Stuart, centre, Chair of Camden's Dial-a-Ride Management Committee who received the bus from Tony Trevethan, left, Sainsbury's District Manager and Rodney Woolliscroft, right, Manager of the group's new Camden store which opened in December. With them is Bill Budd, Camden's Mayor.

Mothe

COPING WITH MOTHERHOOD & DISABILITY

I was told "being pregnant and having a baby is a self-inflicted illness"

JULIE, 26, has a son aged four and a half. She has an ileal conduit and has had a leg amputated below the knee.

Julie said that the hospital which she attended during her pregnancy was not very supportive or encouraging and made her feel like a guinea pig.

Their attitude was not how they could help her, but rather what they could learn from her. Although she had given permission for student doctors to be present during examinations, she found on one occasion at least 30 students present, which she was not really happy about - she had thought it would only be 'a few'.

She did not have amniocentesis - she was not even offered one. However, she did have an ultrasound scan.

The general attitude was that she should not have a baby and certainly should not think of having a second child. It was actually said to her by a social worker that being pregnant and having a baby was a self-inflicted illness. She was not asked or advised about sterilisation.

The birth was by Caesarian although Julie was in labour for 12 hours. The hospital waited until her contractions were every two minutes.

They wanted to give her an epidural and it was Julie herself who said as she was spina bifida was this wise? To which they replied that in that case it probably was not! (in fact it could be very dangerous for someone with a spinal cord injury to have an epidural).

Julie's husband, Martin was present during labour, before the Caesarian, but no-one took his feelings into account or tried to calm him down.

When asked what her family's reaction to her pregnancy had been, Julie said it was very mixed - "but my mother was very pleased". She also said that her local doctor had proved supportive.

Mary, John and lively boys

When she took baby Adam home, practical help such as a Home Help etc. proved quite good, but she found that the worse thing was having no-one with whom to talk over her worries. She only found out about ASBAH a few weeks ago and wished she had known earlier.

She was unable to wear her artificial leg and was, therefore, not able to take her son to school as she has no wheelchair, so she contacted Social Services about this, but they were very unhelpful and unco-operative. So Julie contacted her local paper about the lack of provision and support for disabled mothers with able-bodied children. The paper published an article about Julie and the problems she was facing. Since this appeared in the paper, Social Services are doing everything they can. They are now telephoning her, rather than Julie telephoning them!

Left: Julie and husband Martin with their happy son Adam

Below: Adam and Julie having some fun together with bricks.

Photos on these pages are courtesy of *'Disability Now'*

er love

Personal accounts of bringing up children by four mothers who have spina bifida

"The hospital was marvellous and treat -ed me just the same as other mothers".

MARY, 36, has been married for nine years. She is deaf as a result of meningitis in childhood. she has two sons, one aged 3 and the other 8 months. Husband, John, disabled in a motor bike accident, uses a wheelchair but can walk with the aid of crutches.

MARY said she had good support and treatment while she was pregnant - the Consultant put her on multivitamins and advised on diet etc. The hospital was also very supportive and encouraging, although they had not had a pregnant woman with spina bifida before. They felt there was no reason why she should not have a baby. Mary said they were marvellous and that she was treated just the same as everybody else.

Towards the end of pregnancy, Mary was very big and this made transport difficult - she could get into their car, but could not get out again!

Mary was in before for three months when expecting Ben. She went in for a check-up and they said she had a chest infection - Mary feels it was not really a chest infection, but rather that she got so big that they became worried about how she would cope with breathing. With Matthew she went in a week befeore the delivery. When asked whether she wanted a natural birth or Caesarian, she said she wanted it to be natural, but that if anything went wrong, she was prepared to have a Caesarian.

Care was taken in finding out whether there was adequate help when Mary came out of hospital. She said that she and John were determined to do everything themselves to see how they would cope, and the social worker agreed to this, buytsaid if they needed anything they should let her know, but left the decision up to them.

However, it turned out all right and they managed very well on their own. Mary said the most difficult practical thing about having a young baby was just carrying the baby around as she could not do this. She had a special pram made to attach to the wheelchair, but this was too heavy and she could not push it.

They had no problems at night as both children slept all the way through the night!

Asked how they coped with Ben whenhe began toddling and running around, Mary and John said he was very good and did not run away - it is no fun running away if no-one is going to run after you!

Mary said that next door neighbours who have children let them come in and play with Ben.

Mary and John felt that when they had asked for advice, they had always had the advice they wanted, although people could put obstacles in the way. Again they said the hospital was very good and asked what **she** wanted, rather than what the hospital thought she should have.

Mary did feel that Social Services were watching them to see if they made any mistakes.

The family reactions were generally against them having a second child. Mary's mother never really came round to her way of thinking.

Mary has been stopped by one woman and told that a person like her should not have been allowed to have one baby, let alone two, but Mary said this was the only person to be so offensive.

"No more mistakes"

The only other incident along these lines was when she was being prepared for the Caesarian, the Sister asked what she was going to do about family planning as she could not have any more 'mistakes'. Mary replied that she had been married for nine years and that both babies were planned. ASBAH fieldworker, Mary Castle, was present during this exchange and said that although she felt the Sister's remarks were with the best intentions, the attitude was nevertheless very worrying and very offensive. The Sister also tried to persuade Mary to be sterilised, but Mary insisted on keeping her rights.

"I was told I was very cruel and selfish to have children"

SHIRLEY, 36, is a single-parent with two sons aged 9 and 11.

Shirley said her mother was not very happy at all when Shirley bcame pregnant with her first son, David, but she realises now that she was only worried about her and was very happy when he arrived.

When she was in hospital having her second son, Brian, one of the other mothers said that Shirley was very

continued on next page

continued from page 13

cruel and selfish to have children as they would have to live with her burden for the rest of their lives. However, Shirley said she did not make the decision to have children lightly. She was was able to walk when she had both children and worked until seven weeks before the first baby was born. Both babies were born by Caesarian.

Shirley was ill after the birth of her first son, David. They had moved into a new flat which was not ideal as it was half way up and she did not feel confident enough to take David out on her own. He was hyperactive and did not sleep through the night until he was five and a half years old. There was also not a lot of space in the flat for him to run around and let off steam. When they did have a house with a garden, they were able to make it safe so he could go outside to play. The house was in a flat area so she could walk to the shops etc. However, she did not have a lift for eight months, so had to go up and down stairs on her bottom and make sure she was organised with everything she would need downstairs.

When she did pluck up courage to go out with him she had pieces of string on each side of the pram attached to each wrist so the pram wouldn't run away.

Bathing the babies was not a problem when they were small. Shirley used a large washing up bowl on the tea trolley.

David was very good and always seemed to know that he should not run away fromher when he got bigger, but second son, Brian was quite different and would run away and take chances .

When David was five and Brian two and an a half, her marriage broke up and this did cause a lot of problems. She worried about whether she should keep the children.

Although she never had any outside pressure not to keep the children, Shirley said that she always had that fear and still does sometimes.

She said she felt people were watching her to see if she made any mistakes.

Since her husband left, the only support she has received from Social Services is a home help.

Shirley said her house always had loads of children in, and this had never really been a problem - they just accepted her as she is. But the reaction of other parents is sometimes a problem. When she went to the mums and toddlers group, one little girl wanted to go and talk to her, but mum kept pulling her away. The mother just could not handle it at all and it took quite a long time for her to come round.

When David first went to school, the headmistress could not cope with Shirley at all and would totally ignore her. When Shirley went to a school concert they had small, low benches set out. When Shirley asked if she could have a chair as she could not sit so low, she was told to get one from the other room.

"Whenever I took the baby to the clinic, the doctors and nurses always spoke to my mum and not to me as though I was incapable of answering"

TINA writes:

I am Tina Stubbs aged 19 and living in York. I found myself pregnant after the breakdown of a long-standing relationship.

Tina happily caring for her baby.

The pregnancy was a very happy one with no problems. Labour lasted just five hours and Cara Louise was born weighing 5lb 6oz. The post-natal period was uneventful except that my legs would swell up from time to time.

The consultant suggested to my mum that I should be sterilised. At that time I did not even know what being sterilised meant.

I found it was the attitude of professional people both at the hospital and in the community that caused most of my problems. They constantly doubted my ability to take proper care of my baby. When Cara Louise was three months old, they said she was not gaining enough weight and said she had the look of a 'starved infant'.

Whenever I took her to the clinic, the doctors and nurses always spoke to my mum and not to me as though I was incapable of answering any questions.

Luckily I have had my mum around to help with things that I have found difficult.

Cara Louise is now eight months old, a beautiful, happy baby and has brought untold joy and happiness into my life.

CHECK BEFORE YOU BOOK

The wheelchair symbol isn't always reliable

ON the face of it, there seems to be a reasonable amount of accessible holiday accommodation in this country and overseas - if the wheelchair symbol is to be believed.

But is it? Increasingly people who are disabled are finding that so called accessible places are totally unsuitable and an obstacle course. Choosing any kind of holiday is a bit of a lottery at the best of times, but if you are able-bodied it's not quite so crucial if the place you have carefully chosen and saved up for, falls a little short of the mark. But if you have mobility problems it can be quite disastrous. Moves are being made to 'upgrade' the wheelchair symbol so it really does mean something, but meanwhile *do check very carefully before booking.* Ask in detail whether there are steps, size of doors, size of bathroom, general layout of the place, and anything else you know that is vital to your every day freedom. Only you know what you need - so ASK, or better still, ifyou know someone in the area, ask them to go and look over the place. A visitor from Italy booked a so-called accessible holiday cottage in the West Country using one of the leading, reputable, holiday guides for disabled people. An English friend of his lived nearby and thought she would give it the once over first - just as well she did; it proved to be hopelessly inaccessible. "His holiday would have been ruined if he had come here all the way from Italy to this place" she commented. May be this checking of facilities is a service that ASBAH members in different parts of the country could do for each other.

A trip to remember

In the Summer of 1988 Lindsey Skelton-Smith went on the holiday of a life-time, to California, renowned for its sun, Disneyland, Hollywood and its hospitality.

She and others travelled with a group of carers, nurses,doctor, dietician, physiotherapists and others.

Here are some of Lesley's personal memories.

Lisa in Disneyland

THE PLANE: On the plane there was a small room where they kept all the wheelchairs. All the people in wheelchairs had to go and park in that room. One by one we were lifted onto the plane and once seated we had to wait for the other passengers to get on. On the trip, when I wanted to go to the toilet, Peter, a helper, and Pat took me. They had to carry me all the way down the aisle, into a small space and then into an even smaller space which was the toilet. It must have been very awkward It took more than 11 hours (not on the toilet) to reach America.

LOS ANGELES AIRPORT: We had to sort out ourselves and our baggage and lifting children off the plane took quite a long time.Mini buses then took us straight to the hotel. At the Hacienda Hotel Tracey and I found that our room had only one double bed, so Pat immediately changed the room so that we had two. Having unpacked, we went down to the pool to join the others.

DISNEYLAND: When we visited the was a parade to mark Mickey Mouse's 60th birthday. All the Disney characters were there. There were mice in aeroplanes, mice in boats and Mr Fox from Pinocchio actually shook my hand.We also went on a boat trip through an 'African' jungle.I took loads of photos and drunk umpteen cokes. It was a great day out.

THE POLICE STATION: We were shown around a police station by the Chief of Police. The cells were really disgusting especially the toilets in the cells. But on a nicer note, the policeman, on another occasion, invited three of us to his own home for a meal. After the visit to the cells I had my 'physio' and then we all went out to a pizza place

THE FILM STUDIOS: Another trip into the entertainment world took us to the Universal Film studios. There we saw the various techniques used in film making. We saw how they filmed a house on fire for television, all the stuff from Star Wars and Return of the Jedi and when the tram on which we were travelling drove inside one of the space ships, we saw space creatures firing laser guns. In one big dark studio King Kong leapt up beside the tram and started growling. It gave us all a fright.

HOLLYWOOD: Eventually we went to Hollywood and saw all the stars' names on the pavement. We

continued on next page

continued from previous page

of the kids started feeling a bit sick, probably because of the intense heat, so we went back to the hotel. The heat didn't seem to affect me : I just got a tan.

SEAWORLD: At Sea World we saw a show with dolphins and another with killer whales. They were in a huge tank filled to the brim. There was an awful lot of splashing.

I had had a terrific holiday and know that it was one that I will remember for the rest of my life.

Hugh on his champagne flight

High flying Hugh

On January 21 this year I flew Concorde. I checked in at Terminal 1 at Heathrow and then enjoyed half an hour before departure at a champagne reception. At 1.15, we all went to board the bus that was to take us out to Concorde.

After boarding the aircraft, the Captain welcomed us aboard.

At 1.45 pm precisely we cleared for take-off, and climbed steeply tol a height of 28,000 feet over the Bristol Channel, and continued to climb and increase speed until we reached our cruising speed of 1,100 m.p.h. at 58,000 feet.

We were then served a light cold lunch and champagne. Flying back towards London at 6,000 feet, we were summoned in turn for a brief visit to the flight deck.

My champagne flight was a wonderful experience - a once in a lifetime day out.

Hugh Davies, Cheam, Surrey, who works in ASBAH's Fieldwork office in London.

Michael Daniels enjoys the views in Malta

Maltese memories

A Venture Scout unit from Bristol for lads with physical disabilities decided to fly to Malta for their Summer holiday, but first they had to raise the money.

This they did in various ways - making and selling key rings, selling sets of towels, selling scrap metal, rceiving donations, a skittles match and sponsorship from swimming and a marathon pool game. In all some £1,500 was raised.

The Scout Association of Malta also offered help in the form of their Extension Advisor, Ivan Vella, who organised everything.

The holiday group eventually comprised 24 people including 13 Venture Scouts and Fellowship Members (six in wheelchairs) and six leaders.

The flight was booked with Paramount Airways. At Bristol Airport they were given special treatment by the staff. In flight, the captain invited those who could walk onto the flight deck to meet the crew and see them at work. Afterwards he went back into the cabin to explain to the others what was happening on the flight deck.

On arrival the group was met by Ivan Vella and family plus three buses on hire from the island's Physically Handicapped Rehabilitation Centre. Then it was on to the Youth Hostel at St Paul's Bay

The following night the group was invited to attend a camp fire by the Sliema Troop

During the next six days the group was taken on various trips which included Valletta's Grand Harbour and the island's Scout Headquarters, the President's Palace , the Island of Gozo, Mosta Dome (where a wartime bomb fell through the roof onto a congregation of 300 but did not explode) and the famous Blue Grotto.

They also met the President of the Republic at his official residence and were shown around. One of the Scouts Michael Daniels, says: " He was very pleasant man who told us of his own scouting days, before the war. He had his photograph taken with our group and we presented him with a plaque of the ss Great Britain".

Wherever they went the Bristol Scouts were greeted with friendship and hospitality and Michael says they are grateful to a lot of people at home and in Malta for enabling them to have such an enjoyable holiday.

HOLIDAY TIPS

Travellers need the best of advice before setting off. The International Aid for Disabled Travellers Club provides information on transport, accommodation, resorts, and facilities mainly in Europe and Scandinavia. Most of the information has been personally checked by members and the Club can carry out further checks on request.

Contact: International Aid for Disabled Travellers Club Ltd., Southern Area Office, 174 Caswell Close, Cove, Farnborough, Hants, GU14 8TQ. Tel: (0252 373688).

In 'a mad moment' Zem Rodaway decided to have a go at ski-ing for the first time with the Uphill Ski Club of Great Britain which caters for skiers with disabilities.....

On the slippery slopes - where the views are great!

Zem on skis - where has everyone else gone?

A year or so ago in a past issue of LINK, I believe I saw an article about the Uphill Ski Club. I thought then that the idea of ski-ing sounded fun and that I might give it a try some time.

Finally in a mad moment, I filled out an application form and have returned from my first ski-ing holiday in Kirchdorf, Austria.

We set off by coach from London on Friday January 13. Several friends had joked that there was no way they'd go on holiday on Friday the 13th, but thankfully their superstitions proved to be groundless. The journey by coach and ferry took roughly 23 hours. We arrived at the Alphof Hotel on Saturday afternoon and unpacked before dinner.

We shared very comfortable rooms with en suite bathrooms and a balcony overlooking the nursery slopes.

After dinner, we were fitted with skis and outriggers if necessary - boots had already been lent to us at a pre-holiday meeting.

Outriggers are elbow crutches on half skis - with metal teeth to act as brakes at the cut off end.

"The fact that I could not use my legs much did not seem to matter at all"

The following morning I had my first experience of ski-ing. I've never been very brave, and was relieved to discover that I was to begin totally on the flat, just getting used to wearing skis and using the outriggers. The outriggers are used to stop and turn, so the fact that I could not use myl egs much did not seem to matter at all.

As the week progressed, I was able to start from further up the nursery slope. One big snag was having to climb up the slope before I could ski down. However, there were plenty of willing volunteers to push people up in wheelchairs, or to carry skis up whilst I walked.

A few days later it was time to tackle the tow rope. This is a rope which pulls skiers up the side of the slope. I found it was quite tricky to keep my balance and not let go of the rope as it pulled quite hard on the shoulders.

My room-mate had a novel way of coping with this - she would sit on her skis and stretch up to the tow rope. My first few attempts ended in my collapsing into thesnow half way up. However, other able-bodied holidaymakers were very patient and understanding when any of us fell over and caused a bit of a queue or accidentally grabbed the wire which brought the tow rope to a grinding halt!

Towards the end of the week I was able to spend a half day ski-ing in St Johann. This was much more challenging than the nursery slope I had been on all week, but the views were fantastic!

Apres ski activities included free use of the hotel's sauna and whirlpool, swimming, a sleigh ride around the village, shopping trips and tobogganning.

There were 18 holidaymakers, and 10 'helpers', also four ski instructors who had experience of working with disabled skiers, plus a nurse and the 'doc', so there was plenty of help available.

One of the best aspects of the holiday was that everyone could progress at their own rate, and a number of different approaches were tried until the one most suited to the individual was found.

I was amazed at seeing that people who were much more disabled then myself could ski. However, for those who were unable to ski, there was also a sledge available, so that no-one needed to feel left out.

If you like a challenge, I could recommend ski-ing.

(There are a number of different ski resorts and opportunities to practise on dry slopes in this country).

The address of the Uphill Ski Club of GB is 12 Park Crescent, London WIN 4EQ. Tel: 01 636 1989.

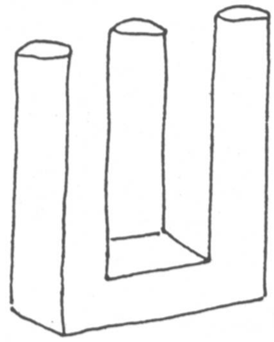
Hydrocephalus and the Senses

One of the best ways of understanding other people's problems is to attempt to put yourself into their shoes. For instance try using a wheelchair for an afternoon and it quickly becomes clear how much energy it takes and how many obstacles there are to bar easy progress. It is much harder to put on the subtle problems of hydrocephalus.

A high percentage of people with hydrocephalus, with or without a shunt, have problems with perception. Perception, very broadly, depends on the accurate interpretation of sensory input, eg. sight, hearing, touch. Providing a reasonably accurate interpretation is achieved, then an appropriate response can be made.

Eyesight problems are frequently noted in people with hydrocephalus. These may be of a physical nature such as a squint. The brain automatically suppresses the vision in the squinting eye in order to allow the other eye to focus sharply. If the brain did not do this, double vision would be present. However, when using only one eye, depth perception is lost and it becomes harder to judge distances and the speed of approaching obstacles. Try closing one eye and notice how much harder it is to estimate the distance between objects, one behind the other. If you drive a car, using only one eye makes it harder to judge the speed of on coming traffic.

Difficulties with visual peception are not easy tounderstand, but imagine how confusing it must be to see objects looking like this:



This must affect the ability to learn from visual material. Diagrams etc. could prove very confusing and wouldhave to be acccompanied by clear verbal explanations. A diagram of an electric circuit of some complexity would be hardto follow for most of us without a great deal of verbal assistance. Your husband presented with a knitting pattern would not have much success unless he were given careful instruction. Although these problems are not strictly the same as someone with visual perceptual deficit, the feeling of helplessness and, perhaps, annoyance would be the same. The diagram is clearly seen and the knitting pattern can be read but they do not make sense unless carefully explained.

Disturbances in interpretation of visual input may influence spatial awareness. This may result in apparent clumsiness or carelessness when, in fact, there are problems of understanding distance, position, perspective etc. We may occasionally experience these problems when hanging clothes on the line against the sky, thus reducing the clues concerning its position. You grope for the line and miss it but it helps if one hand is on the line while the other does the pegging. A child may have difficulty in putting a cup on the table because he misjudges the distance; the cup lands on the floor or balances on the brink. If one hand holds the table, increasing the awareness of its position, the other hand can then more accurately place the cup.

Children with hydrocephalus tend to learn by rote and repetition. They appear to have a facility with words. Because of this and also because they often spend much of their time with adults, their conversation appears mature. However, it is not always original thought they are expressing but stock phrases used at home and heard on TV.

Their thought processes are sometimes slow and they require time to assimilate and comprehend spoken messages. For example, if we hear a sentence in a language with which we are only slightly familiar, our response will be slow. We hear, we translate, interpret and then decide on our response which takes time. It is important when giving instructions to make them simple, short and repeat as often as necessary. Complex instructions should be broken down into small steps; ensuring response to one before going on to the next.

By feeling objects, without seeing them, we can recognise the shape, and the chances are, accurately name them. Fortunately this is a skill unaffected in many people with hydrocephalus. Therefore, allowing children to handle shapes as well as see them, or have them described, is helpful when learning. It makes use of the sensory inputs of touch, sight and hearing, bombarding the brain with information. Occasionally there appears to be apprehension or real dislike of handling certain textures - soft (feathers), slimy (mud), gritty (sand). Gentle persuasion may be needed to help them become used to and understand various textures. This aversion to certain textures is often seen in able-bodied people.

CONCLUSION

The brain is rather like a very complex telephone exchange. Signals come in and have to be sorted out and connected accurately in order that the messages eventually go to their correct destination. When the sorting centres are on go-slow, we all know what confusion can result, and this is seeimgly similar to the problems in hydrocephalus. Remember occasions when you have felt under threat - starting a new job, travelling in a foreign country, filling in a lengthy form full of jargon. There is a feeling of impending failure to get things right, anxiety and the fear of looking stupid in front of others. Nearly everyone tends to cover up with an attitude of bravado, but underneath feelings are very different. This must be a familiar experience for people who are constantly finding their surroundings and tasks hard to understand because some areas of their brain are on go-slow through no fault of their own.

They need time, patience and understanding and then it is quite amazing what can be achieved.

Leonie Holgate
Disabled Living Advisor

APPEALS NEWS

The Mayor of Blackpool presents the ASBAH Cup to Mr and Mrs McCarthy at the 1989 Pigeon Show

Encouraging support

ASBAH has been greatly encouraged by the recent generosity of British Petroleum which has provided sponsorship for a much needed service - BP has agreed to donate £15,000 over two successive years to fund the employment of a fieldworker in Dorset.

ASBAH is also very grateful to The Nuffield Foundation which has kindly agreed to contribute £5,000 to the Mobility Week being organised by ASBAH at Stoke Mandeville in July. It should prove an enjoyable and very practical week.

What a lot of chocs!

A giant box of chocolates, 20 lbs in weight and full of 996 separate chocolates, was one of the raffle prizes in ASBAH's bumper raffle at the British Homing World Show of the Year. It was donated by Woolworths of Southsea .

The Show took place at the Winter Gardens, Blackpool in January and once again the Royal Pigeon Racing Association's General Manager, Major Edward Camalleri, provided us with a prime site for an ASBAH stall from which a successful raffle was held (thanks to Richard Poole, ASBAH's mega star raffle ticket seller). There were various competitions involving teddy bears, especially a large one named Oliver who was won by a lady from the West Midlands.

Another diary date

As well as the Conversationalist of the Year on May 13-14, another date for the diary is Saturday April 29 when ASBAH's sponsored race day at Ripon will take place.

Trading is busy

Two new shops were opened at the end of the year - one at Ebbw Vale and the other at Portchester, Hants.

Both are tradingly busily -the latter having got off to a particularly impressive start, threatening ASBAH's 'league leader' amongst shops - the one at Fareham.

North to Alaska?

A number of embryonic projects are, as always, under review. At the moment these vary from a shopping centre promotion to a 1,000 mile husky dog expedition from Anchorage, Alaska to where the temperature at the time of writing is reported to be - 67 degrees F.

It need hardly be said that the husky dog expedition, if it comes, off will be organised for us rather than by us! It seems that there are strick rules covering such expeditions mainly to do with the welfare of the dogs rather than the human participants.

There is also a code of practice to cover such matters as finding a dead moose in what appears to be regarded as an Arctic clearway.

Steve puts his best foot forward

Steve Adams of Widcombe near Bath walked from John O'Groats to Land's End to raise money for children with various handicaps including spina bifida.

Steve presented cheques totalling nearly £3,000 to research into the cause of spina bifida and to Lime Grove Special School in Bath.

He hopes that he will have raised £4,000 by the time all the money is collected.

A tip from Steve to other prospective long distance walkers - the first half is the worse!

THE ORANGE BADGE ABROAD

An orange badge can be useful abroad, too. There are reciprocal arrangements that enable orange badge holders to use parking concessions in some European countries.

Contact: Department of Transport, Room C10/13a, 2 Marsham Street, London SW1P 3EB

LINK INDEX ISSUES 108-120

Below is a list of major articles that have appeared in LINK during 1987 and 1988 and in January 1989 - issues 108-120. If you'd like a copy of a particular article send your request with a stamped, addressed envelope to Miss Pat Corns at ASBAH London office.

ASBAH

		Issue No
Still Looking for the Key: 21 years of ASBAH		108
21st Annual Report and Meeting		112
Special Insert: The First 21 Years of ASBAH	Duncan Forrest, FRCS	113
Working towards a full fieldwork service for ASBAH	Teresa Cole	115
ASBAH Conference. Children with Spina Bifida/Hydrocephalus Grown Up		118

DAILY LIVING

Disability income - time for a change?	Disability Alliance	110
Are hospitals hospitable?	Sue Ripley	110
Microwave ovens - an aid to independent living	Joan Ransley	111
Honeylands support service for families in E.Devon	Philippa Russelll	117
Bath equipment	Jamie Gilham, Ian Laker	118
Loving ourselves and loving others - personal relationships	Pat Edser	119
Action in East Devon; meeting the needs of young adults	Sue Gearing	119

EDUCATION

The Education Act 1981; four years on	Denise Dunning	108
Residential further education for tudents with special needs	Alistair Kent	109
COMET (Concerned Micros in Education & Training)	Denise Dunning	111
ASBAH and conductive education	Moyna Gilbertson	112
Talking it through (using conductive education techniques)	Carole Sobkowiak	113
The Education Reform Bill	Denise Dunning	115

GENERAL

The Beaujolais Challenge		108
LIFT through France		108
The media and disability		109
The media needs more vision	Anne Karpf (The Observer)	111
The passage of a Public Bill through Parliament	RADAR	113
Disability radio - is it a good idea?	Andrea Fricker	114
Opposition to Alton's Bill		115
Launch of SATFA (Support After Termination for Abnormality)		115
Developing skills through toys - Christmas gift ideas	Mary Barton	119

HOUSING

Building the future together - Shaftesbury Society in Trowbridge	Sue Gearing	108
What has homelessness to do with me?	Carolyn Smith	109
International Year of Shelter	Carolyn Smith	109
LINK 'Special' on housing	Carolyn Smith	115
The changing role of Five Oaks		118

INCONTINENCE

How a bladder operation changed my life	Lisa Leeson	111
Penile sheaths	Ian Laker	116
Intermittent catheterisation	Jamie Gilham	120

LEISURE

Holidays -(international workcamps)		108
Report on LINK readers' holiday to Florida...		113,114
Holidays (Mobility International)		114

continued on next page

INDEX *page 2*

GETTING THE FEEL OF THE FARM

IN the heart of Derbyshire's Shipley Country Park is a traditional farming holiday and educational centre based in a beautiful Victorian farm, offering holidays for people of all ages including those with disabilities.

Farmcraft Holidays is an exciting learning experience and relaxation for young people who don't normally come into contact with the countryside and animals. The aim is to introduce them to farming via a hands-on experience. This involves learning about cows, pigs, sheep, bees, working horses, old farm machinery, hens, ducks and geese, rabbits, and to some extent farm crops. The farm's history and architecture is also discussed. For longer visits (five days) visitors are also able to learn about butter and or cheesemaking. The day to day schedule varies according to the weather, the farming season and the energy of the visitor. Everyone is encouraged to undertake much of the practical farmwork such as milking, feeding and mucking out. "We try to vary the content of the talks to a level and depth suitable for the ages and capabilities of our groups. Visitors are also welcome to join us for seasonal tasks such as haymaking and sheep shearing" said Pat Langham, who helps to run Farmcraft.

"About 20% of the groups that visit us are disabled in some way, either physically or mentally and many return year after year". A lot of the ground floor accommodation is fully accessible. Groups and families are welcomed for holidays of varying lengths.

Contact: Farmcraft, Shipley Country Park, Heanor, Derbyshire DE7 7JJ. Tel: 0602 305611.

The simple way to put you in touch with the largest range of Ostomy & Incontinence Supplies

As one of the longest established companies to specialise in the supply of Ostomy and Incontinence appliances we are pleased to offer probably the largest range of products all under one roof.

All leading makes are stocked including ● Downs ● Hollister ● Coloplast ● Clinimed* ● Simpla ● Eschmann ● Franklin ● Bard ● Redland ● Dansac-Combi ● Thackray ● Salts ● Birkbeck ● Translet ● Squibb-Surgicare. All types of barrier creams, plasters and deodorants. ● Catheters, leg bags and night drainage bags.

We offer a friendly and professional service to private individuals, Pharmacists and Chemists.

All products are stored in temperature controlled conditions in our large modern warehouse. A permanent Display Showroom enables you to see the most up to date appliances and qualified staff are always available for expert advice and information.

National Health Service prescriptions dispensed.

Call in, write or telephone:

NORTH WEST OSTOMY SUPPLIES

North West House,
62 Oakhill Trading Estate, Worsley Road North, Walkden,
Manchester, M28 5PT. Tel: Farnworth (STD 0204) 709255
Proprietor: Maureen A. Nuttall. SRN RSCN QN

The Versatile NIPPI

Mobility at your fingertips!

EASE OF USE
● drive from your wheelchair
● easy access
● controls within fingers reach
● automatic transmission
● electric start

FREEDOM
● go where you want, when you want
● at 25 + m.p.h. and 70 m.p.g.

SECURITY
● wheelchair locking system (seat also available) ● steel chassis safety frame ● three wheel stability ● free driver training ● free first year AA membership

LK3

Please send details of the NIPPI ☐
Please arrange a demonstration without obligation ☐
Name...Tel. ....
Address ....
....Post code..................

SPECIAL VEHICLE DESIGNS LIMITED SV
Ravenstone Road Industrial Estate Coalville, Leics LE6 2NB Tel: (0530) 810440

Martin needs support for holiday scheme in Cornwall

Martin Croucher, 30, paraplegic following a road accident 15 years ago has lived in Cornwall for over 10 years and is now hoping to build four holiday bungalows to fill a gap in what he describes as a real dearth of accommodation for people with disabilities in the beautiful West Cornwall area.

He is hoping to get as much support as possible in order to prove to the local Council that there is a need for this type of accommodation.

Martin writes: "I intend to build four purpose-built, fully accessible, self-catering holiday bungalows in the meandow alongside where my parents and I live. Currently there is nowhere in West Cornwall that is fully adapted.... Previously I tried to get planning permission for a similar scheme in 1986 but was turned down. I have decided to try again and am determined to take it all the way this time. .. The main thing I need to prove to the Council is that there is a need, and I am therefore writing to ask if you would write a letter, addressed to me, stating that you support the principal of the idea and stressing the need for accessible accommodation. Personally I have found accessible accommodation is easier to find abroad than it is in this country, therefore I am determined that people in such a position as myself will have the chance to explore this lovely part of the country...."

Martin Croucher, Brunnion, Lelant Downs, Hayle, Cornwall. Tel: 0736 740638

Advertising

FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS

Rates: £3 for 30 words max; £4.25 for 30-45 words; £5.50 for 45-60 words.

Cheque or postal order payable to 'ASBAH'

Adverts for the next LINK (May/June) should be in by April 15. Send to: The Editor , LINK, ASBAH, 22 Upper Woburn Place, London WC1H OEP.

HOLIDAY ACCOMMODATION

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

ISLE OF WIGHT. Very well equipped chalet with easy wheelchair access at **Brambles Chine, Freshwater.** Sleeps 6. Indoor heated pool, club, shop.Details: Ring or write: Mrs S. Gully, Old Princelett, Apse Heath, Sandown, Isle of Wight. Tel: 0983 863354.

SELSEY, Sussex. Six berth purpose built fully equipped mobile home. Ramp access. Site near sea. Pool, club, etc. Details: Mrs C. Bugden, 27 The Grove, Sholing, Southampton SO2 9LT. Tel: 0703 444921.

RYE HARBOUR, Sussex. Fully equipped mobile home, adapted for wheelchair users. Sleeps 4. Clubhouse on site. Details: Mr P. Borthwick, 170 Hollington Old Lane, St Leonards, East Sussex. Tel: 0424 51145.

SOUTH COAST. Very well equipped chalet with easy wheelchair access at Romney Sands Holiday Village. Sleeps 6. Many facilities including indoor heated swimming pools. Large clubhouse and entertainment provided. Very reasonable rates. Details - ring or write to: Mrs H. McLeod, 23 Harvest Ridge, Leybourne, nr. Maidstone, Kent. Tel: West Malling (0732) 840868.

WESTWARD HO!, North Devon. Holiday chalet. Sleeps 6. Excellent club. Swimming pool and shop on site. Near sandy beach. S.a.e. to Mr Oakley, 12 Farleigh Road, Perton, Wolverhampton. Tel: 751484.

WINTERTON ON SEA, Great Yarmouth, Norfolk. Six berth chalet bungalow, well equipped and on pleasant site with all amenities. Cooker, fridge, colour TV, toilet and bathroom. Heated indoor pool, shop, bar with live music, children's play areas. Cycle hire. Take-away food and snack bar. Details: Tel: Mr R. Morris, 0494 32184.

LOOE, Cornwall. Fully equipped, self-catering two bedroombungalow. Sleeps six. Site near sea with easy access to beach, shop and camp facilities. Easily accessible for wheelchairs. Details: Mr P. Cash. Tel: 0425 72055.

CHAPEL ST LEONARDS, Nr Skegness. Specially designed holiday chalet in its own grounds in the village. Private car park, grassed, safe play area for children. Four bedrooms: one double, one with twin beds, and two each with double bunks. TV. Near shops. Safe beach. Six miles from Skegness Details: Mrs J. Brook, 11, Standiforth Road, Dalton, Huddersfield HD5 9HD. Tel: Hudd. 21776.

FOR SALE

FORD ESCORT, 1.6 automatic. 3 door hatchback. AID hand controls. June 1983, 'Y' reg. 35,000 miles. Sienna brown. For sale: £2,995 o.n.o. Details: 01 674 7435.

EVERAIDS TURBO. Hydraulic, indoor and outdoor, and adjustable for sports use. Suitable for person up to 8 stone. Includes battery charger and sheepskin covers. Excellent condition. £1,500 o.n.o. Details: Mrs Sykes, 10 Littlemore Grove, Mirfield, West Yorkshire. Tel: Mirfield 493887.

VESSA VITESSE electric wheelchair with kerb climbers. Good condition. £500 o.n.o. Tel: Brighton 420687.

BEC RANGER outdoor kerb climbing electric vehicle. Suitable also as a golf buggy or business. Perfect condition. Used twice only: £800 o.n.o. Tel: 0322 65785 (Hextable, Kent).

BEC ELECTRIC 3 WHEELCHAIR fully controllable. 10 mile range. No effort needed. Fits into car boot. New batteries. Complete with automatic charger. Delivery can be arranged. £425 o.n.o. Tel: Martock (0935) 825075.

TENERIFE: Wheelchair accessible apartments to rent or buy in wheelchair friendly complex. Amenities include heated pool with hoist, restaurant, bar, physio, massage and other treatments; Flights and accommodation arranged. Video on request. *Details: Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middlesex TW19 5NX. Tel: 0753 685718.*

Dingle, Co. Kerry, Eire. Large four bedroom bungalow to let June to Sept. Accessible to wheelchair users. Three bathrooms. River on site. Fishing and several beaches nearby. Details: 063 98269 or write to: Mr Tom Kennedy, Ballingaddy North, Kilmallock, Co. Limerick, Eire.

Towy Valley, Dyfed. Self-catering on traditional farm in Dylan Thomas country. Wonderful location in secluded valley. Ideally situated for touring W.Wales - beaches, riding, golf, fishing and many places of interest nearby. Renovated barn adapted for disabled visitors. B & B and meals in farmhouse. Special diets. Tel: Tim and Sue Giles: 0267 88247 or write to Pantgwyn Farm, Whitemill, Carmarthen SA32 7ES.

DIRECTORY OF LOCAL ASSOCIATIONS

BARNSLEY
Mrs Marlene Haigh,
3a Birk Avenue,
Kendray,
Barnsley, S. Yorks, S70 3AE

BEDFORD
Mrs Elsie Bennett,
341 Bedford Road,
Kempston, Beds. MK42 8PX

BOURNEMOUTH,
CHRISTCHURCH & DISTICT
Mrs G. Lanning,
23 Seaway Avenue,
Christchurch, Dorset
Tel: Highcliffe 3255

BRISTOL
Mr G Egan,
54 Rookery Road,
Knowle, Bristol 4
Tel: Bristol 777942

BROMLEY
Mrs M Nation,
13 Ash Road,
Green Street Green,
Orpington, Kent.

BUCKS & E.BERKS
Mrs G. Ayres,
19 Park Lane,
Hazlemere,
High Wycombe,
Bucks HP15 7HY

BURY & BOLTON
Mr David Clyne,
51 Cuckoo Lane,
Whitefield, Manchester M25 5WQ
Tel: 061 798 7804 (after 4 pm)

CALDERDALE
Mr A L Crowther,
12 Elm View,
Huddersfield Road,
Halifax Tel: 0422 41497

CAMBRIDGESHIRE
Mrs Janet Douglas,
35 Kent Road,
Huntingdon, PE18 7JQ
Tel: 0480 56052

CHESTER & DISTRICT
Mrs P Ithell,
34 King Edward Street,
Shotton, Deeside
Tel: Deeside 811074

DUDLEY & WOLVERHAMPTON
Mrs Lorna J Wootton,
14 Leveson Road,
Wednesfield, Wolverhampton,
West Midlands, WV11 2HF
Tel: Wolverhampton 738724

ESSEX
Mrs V Roffe,
106 Thorpe Hall Avenue,
Thorpe Bay, Essex
SS1 3AS
Tel: 0702 584817

GLOUCESTERSHIRE
Mrs J A Wintle,
54 Borough Close,
Kings Stanley
Stonehouse, Glos GL10 3LJ
Tel: Stonehouse 2963

GRANTHAM
Miss Caroline MacCallum,
58 Redcross Street,
Grantham, Lincs. NG31 8BU
Tel: 0476 66085

GREENWICH
Mrs M. Mears,
29 Wellmeadow Road,
London SE13 657
Tel: 01 698 5567.

HAMPSHIRE NORTH,
W. SURREY & S.BERKS
Mrs Liz Selby,
The Old Police Station,
Woodbridge Road
Guildford. Tel: Guildford 571736

HAMPSHIRE SOUTH
Mr S R Baker,
12 Moorings Way,
Southsea, Portsmouth, Hants,
POY 8QW
Tel: 0705 819075

HERTS & S.BEDS
Mrs Fiona O'Loughlin,
55 Whitehicks,
Letchworth, Herts.
Tel: Letchworth 676706

HILLINGDON
Mrs S. Burns,
3 Goodwood Drive,
Northholt, Middlesex
Tel: 01 422 2102

HUDDERSFIELD
Mrs J V Brook,
11 Standiforth Road, Dalton
Huddersfield
Tel: 0484 21776

HULL & DISTRICT
Mrs G D Brown,
233 Cranbrook Avenue,
Hull. HU6 7TX
Tel: Hull 857165

JERSEY, Channel Islands
Mrs Mollie Buesnel,
Villa Acacia,
Sunshine Avenue, Five Oaks,
St Saviour, Jersey, C.I.

KENT
Mrs H. McLeod,
23 Harvest Ridge,
Leybourne,
Nr Maidstone, ME19 5LY
Tel: 0732 840868

LEEDS & BRADFORD
Mrs Jane Weston,
28 West Busk Lane,
Otley, LS21 3LW
Tel: 0943 465456

LEICESTERSHIRE
Ms Judith Bedford,
34 Wilson Street,
Highfields,Evington, Leics
Tel: 0533 531456

LINCOLN & MID LINCS
Mrs P Keyes,
Pinfold, Chapel Lane,
North Scarle, Lincoln
Tel: Spalford 781

LINCOLNSHIRE SOUTH
Mrs P Mason,
67 Boston Road,
Heckington, Sleaford, Lincs

LONDON N.EAST
Mrs B A Pierson,
18 Kingsley Road,
Forest Gate,
London E7 9PP
Tel: 01 472 8605

LONDON N. WEST
Mrs H Prentice,
37 Milton Road,
Hanwell, London W7 ILQ

LONDON SOUTH
Mrs S Cudd,
15 Woodvale Walk,
Elder Road, W. Norwood,
London SE27 Tel: O1 761 2400

MANCHESTER CENTRAL
Mr G Watson,
8 Bushnell Walk,
Manchester M9 2QH
Tel: 061 795 0029

MIDLAND
Mrs D Britt,
14 Court Road,
Sparkhill, Birmingham 11
Tel: 021 771 0371

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

NORTHAMPTONSHIRE
Mrs J Cockings,
57 Little Street,Rushden,
Northants

OXFORDSHIRE
Mrs Shirley Dale,
14 South Row,
Chilton, Didcot,
Oxfordshire

PRESTON
Mrs S Thompson,
34 Beatty Road,
Southport, Merseyside, PR8 6LB

ROTHERHAM & DONCASTER
Mr and Mrs D Barringer,
21 Coppice Gardens,
Broom Riddings, Greasbrough
Rotherham S61 4RE
Tel: Rotherham 560686

ST HELENS & DISTRICT
Mrs N Maddocks,
236 Rainhill Road,
Prescot, Merseyside L35 4LD
Tel: 051 426 3921

SALISBURY & DISTRICT
Mrs J Renshaw,
1 Philip Court,
Coronation Road,
Salisbury SP2 9DA

SHEFFIELD
Mrs C Crofts,
46 Busheywood Road,
Sheffield S17 3QB,
Tel: 0742 366033

SHROPSHIRE
Mrs A Ashfield,
35 Trenleigh Gardens, Trench,
Telford, TF2 6RN
Tel: Telford 612542

SOMERSET
Miss June Roberts,
1 Ilford Court,
Wiltshire Close,
Taunton

SOUTHAMPTON & DISTRICT
Miss T. M. Joplin,
4 North Road,
St Denys, Southampton S02 1NA
Tel: 0703 586498

STAFFORDSHIRE
Mrs J Davies,
8 Oakhill Avenue, Oakhill,
Stoke-on-Trent ST4 5NJ
Tel: Stoke 45365

STAINES, HOUNSLOW
& DISTRICT
Mrs M McGuigan,
Jesolo,
Lea Croft, Shortwood Common,
Staines, Middx
Tel: Staines 50854

STOCKPORT
Mrs S Silver,
1 Brookside Avenue,
Offerton, Stockport,Lancs

SUFFOLK
Mr David Lawrence,
69 Woodberry Way,
Walton on the Naze,
Essex CO14 8EW
Tel: 0255 675245

SUNDERLAND
Mrs Audrey Shepherd,
115 Holborn Road,
Sunderland
Tel: 091 528 3568

SURREY
Mrs J Straker,
Squirrels Leap,
Woodfield Lane, Ashtead
Tel: Ashtead 72009

SUSSEX
Mrs M White,
Averys,
Rusper, Horsham, Sx
Tel: 029 384 217

SWINDON
Mrs S J Trembling,
3 Church Place,
Swindon, Wilts

TRAFFORD & SALFORD
Mrs T Gaynor,
Davis Court,
Cyprus Street,
Stretford, Manchester M32 8AX
Tel: 061 865 0222 mornings only

WARRINGTON & DISTRICT
Mr S. J. Charlton,
36 Park Ave., Latchford,
Warrington, Cheshire, WA4 1DZ
Tel: 0925 38418

WESSEX
Mr T Poole,
123 Gerrards Green,
Beaminster,
Dorset DT8 3EA
Tel: 0308 862614

WHITCHURCH & DISTRICT
Mrs D R Calder,
3a Bridgewater Road,
Whitchurch Shropshire

WIGAN, LEIGH & DISTRICT
Mrs Pat Stridgeeon,
24 Greendale Crescent,
Leigh, WN7 2LQ
Tel: Leigh 676091

WIRRAL
Mrs M Hudson,
28 Stavordale Road,
Moreton, Wirral, Cheshire
L46 9PR

WORCESTERSHIRE
Mrs Frances Bourne,
20 Grafson Place,
Droitwich. WR9 8NQ
Tel: 0905 772971

YORKSHIRE NORTH
Miss Faith Seward,
45 The Paddock,
York YO2 6AW
Tel: 0904 798653

WALES

Llanelli
Mrs J. Davies,
40 Prospect Place,
Llanelli,
Dyfed.

Mid Wales
Mrs J Carter,
1 Meadow Road,
Craven Arms,
Shropshire SY7 9QY

North Wales
Mrs Barbara Meadow,
29 Sunningdale,
Abergele, Clwyd
LL22 7UB
Tel: 0492 824851

South Wales
Mrs Brenda Sharp,
38 Redbrink Crescent,
Barry Island,
S. Glamorgan,
Tel: Barry 735714

NORTHERN IRELAND

Mr J Rippey,
Long Eaves,
24 Tulleywiggan Road,
Cookstown,
Co Tyrone
Tel: Cookstown 62290

NON AFFILIATED ASSOCIATIONS

Blackpool & Fylde
Mr John Dewhurst,
62 Edmonton Place,
Bispham, Blackpool, Lancs

Beeston
Mr S S Goodfellow,
6 Cyril Avenue,
Beeston, Notts.

Cannock & Walsall
Mr Ken Hall,
17 Wallhouse Street,
Cannock, Staffs
Tel: Cannock 4847

Chesterfield
Mrs K M Tomlinson,
23 Hathern Close,
Brimington Common,
Chesterfield, Derbys

Cornwall
Mrs Wendy James,
17 Pergegon Parc,
Camborne, Cornwall
Tel: 0209 712191

Consett & District
M Broadley,
15 Girvan Close,
Burnside, E Stanley,
Stanley, Co Durham

Derby & District
Mrs A Hewitt,
St Merryn,
20 Burley Hill,
Allestree, Derby

East Anglia
Mrs L. A. Turner,
22 Windsor Drive,
Wisbech, Cambs
Tel: Wisbech 64483

Gainsborough & District
Mrs M Hawkes,
10 Turpin Close,
Gainsborough, Lincs , DN21 1PA
Tel: 0427 616807

Isle of Wight
Mr D Sprake,
Springfield, Town Lane,
Chale Green, Ventnor,
I.O.W. Tel: Chale Green 234

Lancaster, Morecambe
& District
Mrs J Murphy,
Garsara,
25 Hale Carr Lane,
Heysham, Morecambe LA3 2AE

Rochdale
Mrs Ann Lawton,
20 Spencer Street,
Chadderton, Odham, Lancs
Tel: 061 652487

Teesside
Mr J Gray,
Marchesi Centre,
Tollesby Road,
Middlesbrough, Teesside
Tel: 0642 814458

OTHER ASSOCIATIONS

SCOTTISH SPINA BIFIDA ASSOCIATION

Executive Officer:
Mrs Audrey Smith,
190 Queensferry Road,
Edinburgh EH4 2BW
Tel: 031 332 0743

IRISH ASSOCIATION

The Secretary,
Irish ASBAH,
Old Nangor Road,
Clondalkin, Dublin 22
Tel: Dublin 01-572326

Please will all local secretaries who want entries changed contact:
Mrs Sue Gearing,
LINK Editor at
ASBAH, 22 Upper Woburn
Place,London WCIH OEP
Tel: 01 388 1382