

Link



Association for Spina Bifida and Hydrocephalus/ASBAH 20p

March/April 85

Cover Story:
See page 5



New — 32 page LINK!

**DISPART '85 : International Federation Conference programme :
SIGs : Bristol workshop : Holidays : Centre pages — Expedition to the
Sahara : Diary of a canal holiday : Hydrocephalus — problems, and
how to help.**

Inside — Application Form for the International Federation Conference

LINK 97

Once Weekly!



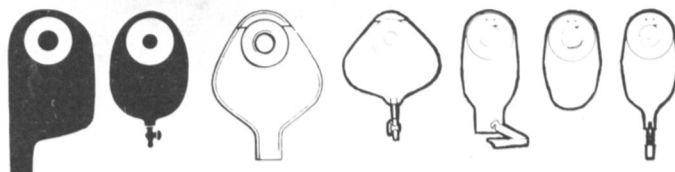
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and Hydrocephalus/ASBAH

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Hon Treasurer: Mr R H Smith

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relating to those with spina bifida
and hydrocephalus.

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Miss B Holland

Link Editor:

Mrs Susan Gearing

LIFT (Young ASBAH) Organisers:

Paul Cooper, BA

Ann Monaghan

A bigger and better LINK

AS THIS issue shows LINK is getting bigger and we hope it will be more interesting, entertaining and informative than ever.

It seems there's more of everything to include in LINK — news, articles, personal stories, medical advice and general information. So we have added another 8 pages and covered much of the cost of increasing the size by including more advertising.

Nevertheless there's a limit to what we can achieve in this way if we are to maintain an acceptable balance between advertising and editorial matter. There comes a time in the life of every publication when steadily rising costs of paper and printing means that the cover price has to be reviewed. We have decided therefore to raise the cost of LINK to 30p per copy from the September issue. The cost of postage and packing will be 25p.

This is the first rise for two years and LINK is promising to be bigger and better than ever before. We think it is an excellent value-for-money deal.

If you receive LINK direct from ASBAH, the new annual UK subscription for LINK from September/October 1985 (including p and p) will be £3.30. But don't forget that many readers in this country receive LINK direct from their own local associations which have their own arrangements for delivery and payment.

Subscriptions not paid in sterling

Payments made for LINK in any currency other than sterling incur extra bank charges for ASBAH of £3. So it is regretted that with immediate effect LINK subscribers who pay other than in sterling must add the equivalent of £3 to their subscription.

SUBSCRIPTIONS FROM SEPT. 1985

UK £3.30

Europe & Overseas Surface Mail £4.80

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All prices include post & packing.

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equivalent of an extra £3.

100th Issue

This September sees the 100th issue of LINK. We will be marking the occasion with a very special number.

Ideas for special articles would be welcome and, more generally, please remember that LINK is your magazine. It is a LINK between ASBAH, individuals with spina bifida and hydrocephalus, their families and the professionals. So, if you have any ideas for articles, features, if something has happened locally that you think might be relevant or if you just want to air an opinion, please do write to me.

The closing date for copy for the next issue (May/June) is April 5.

Sue Gearing

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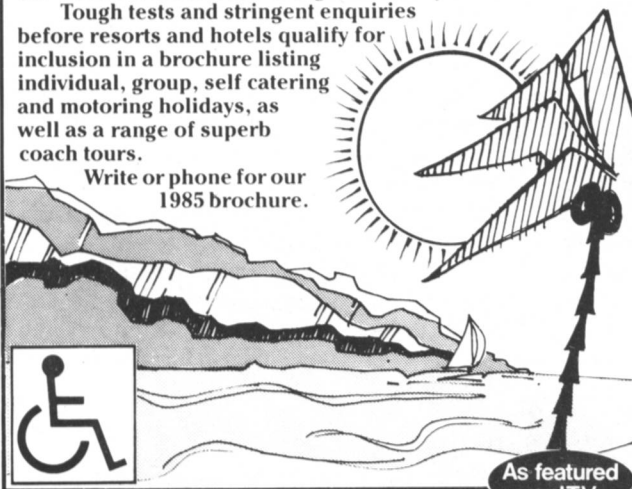
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1985
UNITED NATIONS
INTERNATIONAL
YOUTH YEAR



IYY

Working together for participation by disabled young people in the UN International Youth Year 1985.

Workcamp

THERE is a danger that even DISPART '85 will be another example of organisations providing for and making decisions about the leisure needs of others. This workcamp, at Werkenrode in Holland, is an attempt to overcome this.

It is hoped that about 50 young people, disabled and able-bodied, will gather together to produce their own aims and action plan on leisure. It will be held at the Werkenrode Institute at Groesbeck in Holland, July 27-August 3, and will cost about £100 per person plus travel. But it is hoped to obtain financial help.

The workshop will provide a variety of leisure experiences for assessment and discussion. If you are interested contact Paul Cooper LIFT Organiser at ASBAH.

LIFT Weekend

ABOUT 100 young people will be converging on Owens Park, Manchester for the second LIFT Conference (March 29-31). It promises to be a lively weekend.

Special Interest

COURSES ranging from fashion and driving, to cookery, outdoor activities, dance, drama and fishing are being held at Five Oaks this year. There should be something for everyone. For further information please contact Miss Moyna Gilbertson at ASBAH.

Independence

ASBAH is extending its Independence Training Courses for its own members to include other young disabled people. The first step is two one-day conferences, in London and the North of England, for staff of other voluntary and statutory agencies, to explore the best way of proceeding.

A WIDE variety of workshops and events has been organised for disabled and able-bodied young people during IYY by a consortium of charities working together — ASBAH, PHAB, the Spastics Society, Muscular Dystrophy, the Spinal Injuries Association and the National Bureau of Handicapped Students. They have come together under the one name DISPART.

The emphasis will not be on disability, but on youth. Each organisation has planned its own programme of events, although in many cases members of the consortium have worked jointly where areas of interest overlap.

There is also participation with able-bodied youth organisations to promote the theme of integration — organisations like the National Association of Youth Clubs, the British Youth Council, National Council for Voluntary Youth Services and the Scout Association.

Any young disabled person between the ages of 16-25 in Britain can get involved in International Year of Youth by taking part in any of the DISPART events.

* * *

THE SPASTICS Society has drawn up a list of events to carry them through the year. Many are national whilst each region has organised its own events. In the South East Region young people are organising a conference for other young people on the theme of employment.

Relationships

People Need Help—Understanding Personal Relationships is a one-day conference organised by the Spastics Society and SPOD, covering all aspects of personal relationships. Participation is invited from young people with disabilities. Details from Debra Ziegler, the Spastics Society. Tel: 01-636 5020.

Sharing

An Invitation to Sound, Vision and Action is designed for the sharing of ideas through the arts. It is an effective way of communication, participation and self-expression. A week of workshops, for up to 50 young people, disabled and able-bodied will explore the themes of IYY—participation, development and peace—using the media resources of Beaumont College, Lancaster. The young people will come from abroad, Beaumont College, other Spastics Society schools, local schools and colleges. Some places are open to general application. Details from Debra Ziegler, the Spastics Society. Tel: 01-636 5020.

Video

Coming In: A 14 Day Video Experience is a project organised by the Spastics Society and PHAB which offers active experience in all areas of video making, including camera techniques, scripting, research, sound and editing.

The culmination of the workcamp will be the shooting and editing of sequences which may later provide the basis of a PHAB video aimed at encouraging leaders of youth clubs to integrate young people with disabilities into their clubs.

A variety of entertainment has also been laid on. There are 16 places open to general application. August 10-24 at the Thomas Delarue School, Tonbridge, Kent.

Details from: Chris Davies, the Spastics Society. Tel: 01-636 5020, or Terry Thompson, PHAB. Tel: 01-388 1963.

COVER STORY: Chris Hopkins (left) and Andrew Evans with the Lady Jean Mackenzie and Tim Rice at the launch of DISPART '85 in London in January.

Mark aims for top in ice-sledging

MARK TONG is only 15, but he is already one of Britain's fastest ice-sledge racers. With him (in the picture on the right) is his coach, Stewart Skedge (standing) an athlete disabled by a shipyard accident 14 years ago.

Ice-sledge racing is the disabled person's equivalent of speed skating. The athletes race around a 400 metre ice track on special lightweight sledges propelling themselves with ski poles.

Mark, who has spina bifida and lives in Morpeth, Northumberland, competed in the European Open Championships in Holland in February, and will take part in the disabled winter sports World Championships in Oslo next year.

From Europe, to the world, to the Olympics . . . Mark and his coach hope he will make the British Olympic team for Canada in 1988.

Stewart Skedge a coach with the British Paraplegic Sports Society said: "Mark has the potential to become Britain's top ice-sledge racer. He is capable of everything the sport demands. He already has the stamina and we are working together to develop his technique".

Mark's mother said he had been lucky enough to have a lot of encouragement and support, including that of the North East ASBAH.

A group of physiotherapists in Newcastle started a Challenge Club for the disabled which proved an inspiration to Mark. His school — Pendower Hall — had also been very supportive and enthusiastic.

"It shows what a youngster can achieve given the right kind of encouragement. It is a pity that more disabled young people don't have the same opportunities" she said.



Mark Tong and Stewart Skedge

ASBAH launches sailing contest for young people

THE ever versatile Appeals department of ASBAH has entered the world of sailing.

Sue Stamps, now a member of the fund raising team — having formerly been a secretary in the department — is organising a contest to find the Young Yachtsperson of the Year.

This enterprising and entertaining contest starts in April when young people will be invited to take part in tests of seamanship in various regional locations.

Each young sailor is sponsored — in aid of ASBAH, of course — for the number of points he or she gains in the heats.

In September all regional winners will go to the finals in Cowes in the Isle of Wight from where the first Young Yachtsperson of the year will sail forth.

The Duchess will welcome members and supporters

FOR some time now we have been conscious of the fact that there are very few opportunities for us to thank our donors for their support and for them to meet our members; we are, therefore, particularly delighted that our Royal Patron Her Royal Highness, the Duchess of Gloucester has consented to attend a reception on April 25.

Guests at the reception will include regional representatives of LIFT who will have the honour of meeting Her Royal Highness and some of our major donors from whom the Duchess will receive cheques.

The reception will be held at the Forum Hotel, Kensington, who were so helpful to us when we celebrated our 18th Birthday there and who are once again demonstrating their support by allowing us to use the room without charge.

Douglas Jack our Commercial, Industrial and Trusts Fund Raiser is very busy contacting potential and proven donors and Paul Cooper is, of course, rounding up the LIFT representatives.

Moyna Gilbertson

Constance Activity Holidays

CONSTANCE is offering 75 places for disabled people on a holiday from July 20 — 27 at the National Star Centre near Cheltenham.

Activities involve English language, fencing, canoeing, horticulture, computers, drama, bridge, chess, archery, golf, arts and crafts, basketball and swimming.

The price of £149.50 is all inclusive of accommodation, meals, tuition, and special equipment etc. The holiday is open to physically disabled and able bodied people over 16. Applicants should be independent, as individual personal care is not provided.

Details: Constance Activity Holidays, 1 Lowther Gardens, Bournemouth BH8 8NF. Tel: 0202 304534.

Is it Maureen the first?

IS MRS Maureen Ashton the first spina bifida grandmother in the country?

Her grandson, Gary Lee Ashton was born on December 12 in Kent and was christened on February 10. His father is Mrs Ashton's eldest son.

Mrs Ashton, who has spina bifida and lives in Harwood, Bolton, has four children of her own — two boys and two girls whose ages range from 23 years to 4 years. They are all perfectly normal.

"It was much easier having the grandchild than my four" commented Maureen Ashton! She is a member of the local ASBAH in Bolton and Bury.

Lee wins himself a holiday

THE LUCKY prizewinner of the special LINK competition sponsored by Peaudouce is 30-year-old Lee Grayson of Orpington, Kent.

Lee has won a two-week holiday at Skylarks Hotel run by the Winged Fellowship in Nottinghamshire. He's taking the holiday this month (March).

The competition was based on a series of questions about places around the world. Lee's was the first correct entry opened.

Lee attends a Day Centre four days a week, and on the other day he has a Community placement at the home help office in the Social Services Department in Orpington.

He writes: "I am very interested in sports and play as many as possible, particularly table tennis. I am the captain of the table tennis team at the Magnolia Club, a sports club for the disabled in Orpington. We have entered the B.S.A.D. games and I personally have won several medals. Our club is the most successful for the disabled south of the Thames.

"My mother drives me to and from most of the places I go to but now thanks to BOBCAT (Borough of Bromley Call-a-Trip) which is our local Dial-a-Ride, for the first time in my life I can go places all by myself. Everyone connected with this transport is absolutely marvellous.

"I lead a very active social life and am a CB Breaker with the handle 'Ironside' and I am an active member of our local club.

"My mother and I saved very hard for five years and last year managed to afford a holiday in Israel which was absolutely



Photo: Bolton Chronicle.



Lucky Lee — winner of the holiday competition in LINK run by Peaudouce, the makers of Slipad.

wonderful. I do hope that soon they get some facilities for the disabled as it was very hard on my mother there, but we did enjoy ourselves".

Congratulations to Lee, and best wishes for a happy holiday at Skylarks.

ABOVE: The start of a new dance routine by members of the Kaleidoscope Club in Kearsley, Lancashire.

The wheelchair dance club is led by husband-and-wife team, Richard and Kath Reading both of them qualified dance teachers. Kath Reading has spina bifida and both she and her husband are members of Bolton and Bury local association.

The Club has proved so successful that members are now giving demonstrations.

Traditional dance steps have been adapted to manoeuvres for pairs of wheelchairs so members can now foxtrot, tango or waltz. They have also gone on to barn dances and modern sequence dancing, which has led to the demand for demonstrations locally.

The team is 12 strong and meets at Kearsley Leisure Centre. Secretary, Mrs Sylvia Higginbottom said "We hope other disabled people will get some encouragement from this and there is an open invitation to people in wheelchairs to join us".

Three of the dancers in the above photograph are members of the Management Committee of Bolton and Bury ASBAH: Christine Linguarth (4th from left), Richard Reading (centre left) and George Winstanley (second right) who is the local associations Sports Manager. Kath Reading is not, unfortunately, in this picture.

Mrs Baker makes prize cake

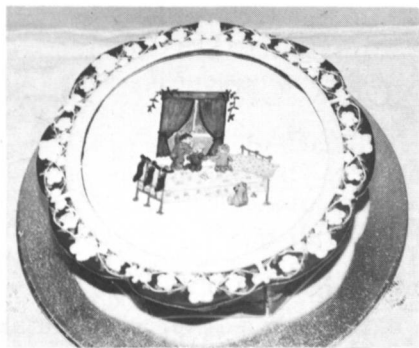
THE TOP of a very special cake (left) which raised £250 for ASBAH.

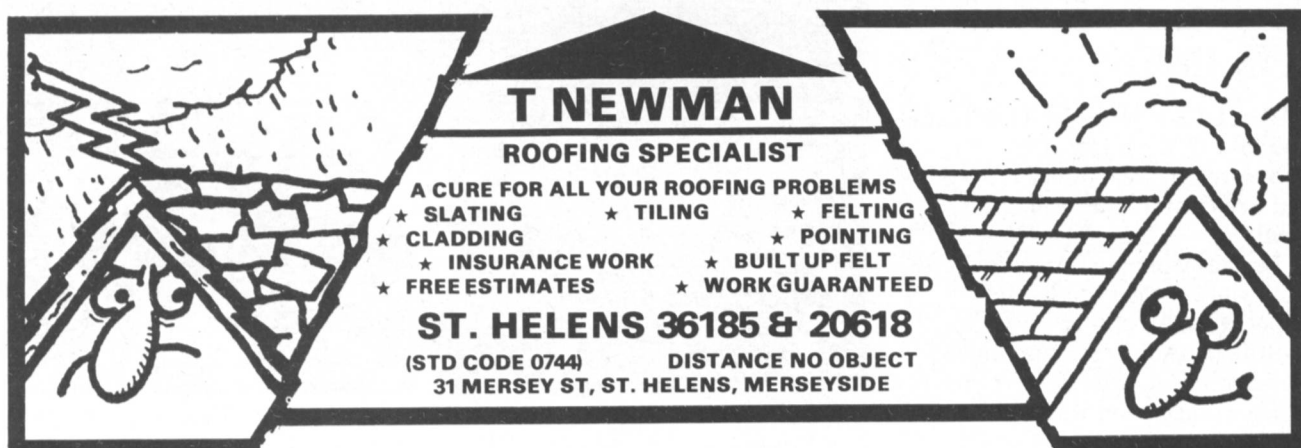
The sides of the cake are equally beautiful and it is all the work of Mrs Janet Baker of Hildenborough in Kent.

A neighbour told her she thought it was good enough to make some money for charity, and Janet whose middle child, Patricia, aged 3, has spina bifida plumped for ASBAH.

Her husband is the Principal Timpanist with the Royal Philharmonic Orchestra and they agreed that the cake could go to the Fairfield Halls in Croydon for their Christmas concert. Tickets were sold to members of the orchestra during rehearsal and to the audience during the concert interval.

The raffle was drawn on stage after the concert, and the result announced — £250 for ASBAH.





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MY NAME is Marcel van Kleef, I am 19 years old. I was born at home, my father took me immediately to the local hospital, but they were unable to help me and we had to go to the university hospital in Amsterdam. After examining me all day, they told my father that there was no hope for me!

Until I was 3 years old I was in and out of hospitals. For instance I spent one year in a childrens hospital where I learned to walk.

When I was 4 years old I went to primary school and after that to the normal junior school, where I stayed for one year. I had to leave there because the teacher found it too much work to look after me, also I couldn't participate in gymnastics, because they were afraid something would happen to me.

My parents had to send me to a special centre. I stayed there for 4 years and went back to the normal school again, this time for 2 years. I had to go back to the centre because I burned my behind (stupid me!).

After the centre I went to Werkenrode (near Dymegen). At Werkenrode you can learn a trade. I followed a course in metal work, but the only thing we learned was how to use a file, so I changed over the printers course and that I liked very much.

In my time at Werkenrode I had an operation on my feet. Afterwards I developed a fistel and for that fistel I have had 5 operations in 5 years. Last time it was suggested my foot should be amputated but I said I would rather be operated upon once a year than lose my foot.

After I finished at Werkenrode, I was at home for a year before I could start work in a social work place.

Last year I learned to ride a motorbike. The first time I had to take my driving test, they wanted a special health certificate because of my handicap. It took two months before they figured out what they wanted to know.

The first test I failed, but the second time I passed and I now ride a big Honda CX 500 custom!

My next move is to drive a car, I am taking lessons now and they want a special health certificate again, I wonder what they want me to do this time.



In International Youth Year a 19 year old from Holland gives us a brief insight into what his life is like.

'Last year I learned to ride a motorbike . . . next, a car'

At the weekends I go out with my friends. Mostly we go to a bar-disco. I always take my wheelchair with me, because I can't stand up for a whole evening. When it is busy I have got my own chair with me.

Sometimes people complain that I am in the way, but then I tell them that I have just as much right to be there as they have!

Greetings

Marcel van Kleef
translated by Marilyn Dain

Gloves on prescription

DESPITE what you may have heard to the contrary, disposable gloves are available on prescription.

They are supplied by Surgikos, and it is helpful to use the code on the prescription. There are three sizes each with a different code: small (code 3327D), medium code (3347D), large (code 3367D).

UNICHEM, the chemist wholesalers buy from Surgikos and can, therefore, supply chemists.

ASBAH gives its views on NHS drugs

WE WOULD like to reassure members that we at ASBAH have responded to the document *Limiting the Range of Drugs Prescribed under the NHS*. We know that many families and individuals with spina bifida and hydrocephalus are worried.

ASBAH was invited to comment on this by the DHSS, and we drew attention, in particular, to the availability of suitable medication for long term treatment, especially in the area of bowel and bladder management.

We also pointed out our concern about the restriction of vitamins on prescription before the results of the Medical Research Council's study are available.

. . . and ITV's 'The Practice'

We know that some members were distressed by several episodes of the Granada programme *The Practice* which portrayed the problems facing a young couple, when following amniocentesis they realised that their expected baby almost certainly had spina bifida.

The impression was given that no counselling or support would be available and there was no mention of any services provided by ASBAH. We have written expressing our concern to the Director General of the Independent Broadcasting Authority and to the TV Times and have submitted an article to Media Project News.

At the time of going to press we are unable to say whether ASBAH's comments will be published.

MOYNA P. GILBERTSON
Executive Director

Naidex

NORTHERN NAIDEX takes place at Harrogate Exhibition Centre on May 29, 30, 31. There will be displays from 150 companies and among other attractions Banstead Mobile Assessment Unit will be there. There will also be a demonstration track for wheelchairs. Admission to Naidex is free.

International Federation for Hydrocephalus and Spina Bifida

1985 International Conference — 25th – 28th September 1985

WEDNESDAY 25th SEPTEMBER 1985

TIME	SUBJECT	SPEAKERS
14.30 – 15.00	<i>Opening Ceremony</i>	
15.00 – 17.00	<i>Pre-natal Screening & the MRC Trial</i> <i>Genetic Counselling</i>	Professor I Cooke, University of Sheffield, Dept. Obstetrics & Gynaecology Professor K M Laurence, Professor of Paediatric Research, University of Wales School of Medicine

Chairman: Mr D M Forrest FRCS, Chairman of ASBAH's Medical Committee, President of the Society for Research into Hydrocephalus and Spina Bifida

Host: Mr Bjorn Rundstrom, President of the International Federation for Hydrocephalus and Spina Bifida

This will be followed by a panel discussion involving: The speakers, an ASBAH counsellor, a young person with Spina Bifida, the mother of a young child.

THURSDAY, 26th SEPTEMBER 1985

09.00 – 10.30	<i>Problems at Birth</i>	Dr Roger Bayston, The Institute of Child Health; former ASBAH Research Fellow; Dr E Charney, The Children's Hospital of Philadelphia
	<i>Later Development</i>	Dr P Tomlinson, Medical Officer, Lord Mayor Treloar School; Dr J. Lones, Vice Principal, Lord Mayor Treloar School.

COFFEE

11.00 – 13.00	<i>Spinal Fusion</i>	Mr Cheong Leen, Queen Mary's Hospital, Carshalton.
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Spina Bifida Occulta: Speaker to be confirmed.

Incontinence problems with Spina Bifida: Mr H Eckstein, Hospitals for Sick Children, Great Ormond Street.

Mr Eckstein would welcome a great deal of discussion, and would be pleased to receive questions in advance.

Chairman: Mr D Young, Royal Hospital for Sick Children, Yorkhill Glasgow, Member of ASBAH's Medical Committee.

Host: Mrs A D Smith, Executive Officer of the Scottish Spina Bifida Association.

During meal times there will be opportunities to view the exhibitions and various demonstrations.

13.00 – 14.30	<i>LUNCH</i>
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14.30 – 16.00	<i>Making Our Way — Controlling our Destiny.</i>	The speakers will comprise a panel of young people with spina bifida and hydrocephalus.
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Chairman: To be announced later.

Host: Moyna P Gilbertson, Vice President of the International Federation for Hydrocephalus and Spina Bifida, and Executive Director of ASBAH.

16.00 – 17.30 TEA & DISCUSSION GROUPS

During tea various discussion groups will gather in smaller meeting rooms, at the moment we anticipate that groups will discuss:

<i>Incontinence related to relationships</i>	Mrs H Gatfield — The Care Centre
<i>Developing Potential</i>	Mrs L Tuckey — ASBAH Counsellor
<i>Mobility in Life</i>	Mrs L Holgate — ASBAH Mobility Adviser
<i>Groups relating to the morning session</i>	Mr D. Forrest
<i>Self Help Groups</i>	Ms B Buda, Scottish Spina Bifida Assoc

Report Back: Chairman to be announced

FRIDAY, 27th SEPTEMBER 1985

09.00 – 10.30	<i>Employment Prospects</i>	Mr N C Clegg, Principal North Notts College of Further Education; Miss M Wingrove, young lady with spina bifida, currently employed by ASBAH
	<i>Computers in Life</i>	Dr Janet Larcher, The Spastics Society; Mr F Green, The Spastics Society

Chairman: Mr D M Bryant, Chairman of ASBAH

Host: Mrs D Dunning, Education, Training and Employment Co-ordinator ASBAH

10.30 – 12.30	<i>Employment Prospects</i> <i>Work Orientation Modules</i> <i>Setting up a Workshop</i> <i>Work Experience</i>	<i>COFFEE BREAK & DISCUSSION GROUPS</i> Mr A Macpherson, Principal, Lord Mayor Treloar School Mr D. Hutchinson, North Notts College Mr D Artingstall, Chairman, Midland ASBAH Mrs D Dunning, Education Training and Employment Co-ordinator — ASBAH
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Report Back: Chaired by Mr D M Bryant

TIME	SUBJECT	SPEAKERS
<hr/>		
13.00 – 14.30	<i>LUNCH</i>	
<hr/>		
14.30 – 16.00	<i>Fashion</i>	Mrs N Thornton, Director of Fashion Services for the Disabled. Yorkshire A young person
	<i>Travel</i>	Mr T Thompson, Director of Physically Handicapped & Able Bodied
	<i>Realistic Goals</i>	Mr Paul Cooper, LIFT (Young People's) Organiser — ASBAH
<i>Chairman:</i> Mr T Thompson		
<i>Host:</i> Mr B Sculley, Member of the International Federation Executive Committee		
<hr/>		
16.00 – 17.30	<i>TEA & DISCUSSION GROUPS</i>	
	<i>Life Styles</i>	Leader to be confirmed
	<i>Group travel & Exchange</i>	Mr T. Thompson
	<i>Grooming & Shoe Demonstration</i> , Miss M Small, ASBAH Disabled Living Adviser <i>(follow on from Mrs Thornton)</i>	
	<i>Activities at Five Oaks</i>	Mr J Stanton, Project Leader — Five Oaks
<i>Report Back:</i> Chaired by Mr Thompson		
<i>Host:</i> Mrs E Meyer, Member of the International Federation Executive Committee		
<hr/>		
In addition to the formal programme there will be an arranged visit to Five Oaks for any delegates wishing to go, an excursion demonstrations of mobility, wheelchair proficiency etc. There will also be an exhibition. Films and videos will be available.		
A social/entertainment programme is also being arranged.		

SATURDAY 28th SEPTEMBER 1985

09.00 *General Meeting*

Contributions from official delegates. It would be helpful to have notification about specific items in advance please.

12.30 – 14.00 *LUNCH AND DEPART*

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Nina and Pamela prove their value at work

A SHELTERED Industrial Group is a scheme whereby disabled people are given the opportunity to work for a normal weekly wage in a regular commercial or industrial setting. The number of people that can be employed under the scheme in any one location is between one and six.

There are three parties involved in a SIG.

- The Sponsor i.e. ASBAH who is responsible for employing the individual, paying wages and ERNIC
- The Host Firm which provides the job and working environment and pays the sponsor for the amount of work done
- The Manpower Services Commission who share the cost, that is the difference between the wages and the payment from the host firm, for the work done. The grant from the MSC is now 100% for voluntary organisations.

ASBAH has been sponsoring SIGs for about three years and the scheme has been very successful. The Association would like to sponsor more SIGs. However, the problem is finding organisations/ companies who would be willing to co-operate in the scheme.

Nina Unsworth has been sponsored by ASBAH under the SIG scheme for the last two and a half years. Nina's host firm is Lancaster Training Services (LTS) and after successfully completing a training period she began work officially in August 1982.

Lancaster Training Services is a training centre for drivers of Heavy Goods Vehicles and other industrial vehicles. Nina's work is mostly divided between general clerical duties and tachograph chart analysis. Nina says she has plenty of work to do, particularly now that the firm is expanding.

A number of young people are being employed by LTS under the Youth Training Scheme, and Nina has been involved with the administration.

Since September, LTS have been sponsoring Nina on a day release Business Education course in Office Technology at Lancaster and Morecambe Technical College. Nina has found the right balance in her college life. She finds her college course interesting and worthwhile — and also enjoyable. Although technically employed by ASBAH, Nina feels as much a part of the office furniture as the rest of her colleagues. She has certainly proved her disability has not prevented her from holding down a responsible job.

A more recent sponsorship under the SIG scheme has been Pamela Cox, who also lives in Lancashire. Pamela started work as a clerk typist in the Catering Department of Rossall School in Fleetwood. The School is an independent co-educational school comprising approximately 800 pupils.

Pamela, who works for the catering officer, finds her duties are many and varied. These include answering the telephone, typing correspondence and, once a week, she has to type all the menus for the staff and



Pamela Cox at work

pupils' dining rooms. Pamela has also been involved in helping her boss in the preparation of a book on large scale catering. This has involved Pamela in typing a great deal of the manuscript, including sample menus.

Pamela's office at the school was once a store room. It has been renovated into a comfortable and practical office with a typewriter, desk and fitted carpet! (Not to mention the kettle!). Pamela has found her colleagues very friendly and helpful and enjoys her work immensely.

Pamela is 'over the moon' about her job and there are certainly no complaints from her boss. The catering officer says she is very impressed by Pamela's work and is pleased to have such a pleasant young lady working for her.

DENISE DUNNING

Education, Training and Employment Co-ordinator

JOHN GROOMS HOLIDAYS

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For our new colour brochure, write to John Grooms Holidays, 10 Gloucester Drive, London N4 2LP. 01-802 7272.

Workshop has designs on the future

BRISTOL association's workshop opened just over a year ago, and already this small, but enthusiastic, craft team has had its first show selling £200 worth of goods, and taking orders of about £100.

The workshop, under the skilled supervision of Liz Luckwell, opens four days each week in a corner of a workshop/factory in Bristol where units are rented out to small firms.

Six young adults with spina bifida and hydrocephalus work there producing original, beautifully dyed rag rugs and wool rugs, many of them made to order. More recently they have become skilled at machine knitting and make knitted fashion vests.

"We are hoping to increase our knitted work and bring out our own design tops and skirts. We have a shop outlet in Bristol where we could sell them on a sale-or-return basis" said Liz. They have yet to come up with a good name for their merchandising label.

The workshop is working towards becoming financially self-sufficient, and the show that boosted their moral so much was held at Christmas at the weaving school at the village of Kingston Seymour, south west of Bristol.

Visitors were able to see the rugs being made and buy or order goods. One lady from across the other side of the Severn, in Chepstow, was so impressed that she made a special visit in February to the workshop and ordered a rug.

The members of the craft team are Julie Beese, Peter O Loughlin, Jane Williams, Paula Boon, Stella Rogers and Diane Bennett, all of them in their early twenties. They each go in for two or three days and get involved with several different operations—

dyeing (either with natural or synthetic dyes), spinning, weaving rag rugs using various different materials, and knitting. The workshop was fortunate enough to be given some knitting machines.

The work premises are suitable



Jane Williams (left) and Julie Beese look after the desk at the workshop's first sale and exhibition.



Stella Rogers proving to be adept at the art of spinning.

for wheelchairs and have a small canteen. The whole atmosphere of the place is busy, but relaxed.

Considering the shortness of the working day, the workshop can feel justifiably proud of what it has achieved. Liz Luckwell until recently was also responsible for driving the association's mini bus and collecting everyone in the morning from various parts of Bristol and taking them home again. Given the distances involved

work never started until latish in the morning and they had to start thinking about going home at about 4.30.

Since February the situation has been eased thanks to the help of Kingswood Voluntary Services who are providing a driver. This leaves Liz time to prepare and finish off work.

The team is fortunate at the moment to have the assistance of Mo Braithwaite who on her own initiative found out about the workshop, discovered she would be welcomed, and helps each day on a voluntary basis.

Bristol was the second local association to open a workshop. Midlands' has a bigger and more commercial venture, and Liverpool is concentrating on made-to-measure fashion for the disabled (see LINK Jan/Feb). Bristol's set-up is small, but has shown in the past year that it is meeting a real need and providing a good working environment for some of its young adults.

ASBAH's mile of money

DURHAM shoppers showed themselves to be generous on behalf of ASBAH when they put down £151 on the pavement in Durham Market Place for the Mile of Coins organised there in November.

It all came about because Durham Seahawk Venture Scout, Jill Robinson visited Five Oaks and

went back to her unit singing its praises. The venture scouts decided to do something for Five Oaks and the Mile of Coins was the result.

The money was received on behalf of Five Oaks by Sandra Wheatley, Field Worker for ASBAH. It has bought a much needed microwave for the centre.

Holidays start here . . .

Travelling abroad made easier and there's more on offer at home

FOR MANY people a holiday abroad is something they take for granted but for disabled people this has, in the past, been an impossible dream. Happily, this is no longer true and more and more disabled people are taking the opportunity to travel to other countries.

There are a number of companies specialising in holidays for disabled people either travelling alone or with family or friends. One such company is Threshold Travel Ltd, which offers a wide range of holidays and a door-to-door service which takes all the worry out of getting to and around your holiday resort. Winged Travel Fellowship is another organisation offering disabled visitors with special needs, the chance to go on holiday and have someone provide any extra support necessary.

Travel companies are also finally waking up to the fact that there is a whole untapped market of holiday-makers wishing to travel abroad, for whom just a little extra care and planning is necessary. Horizon Holidays produce a brochure for disabled holidaymakers, and Thomson Holidays offer a special welcome. These companies' brochures can be obtained from your local travel agent.

The Sol Hotel Chain, which has hotels throughout Spain, the Balearic Islands, the Canaries and Hawaii, has built hotels with the needs of disabled and elderly people in mind. Most travel brochures have details, or ask your local ABTA Travel Agent.

People wishing to travel independently should be able to get information about individual resorts and hotels from a travel



Activity holidays with the Calvert Trust.



agent. Ask whether the place is hilly, how many steps there are, if the area is accessible or not. This kind of information is contained in the Agents Hotel Gazetteer which is held by all ABTA Travel Agents.

Airlines are now aware of the number of disabled people who travel and may need some help. "Who Looks After You At British Airports" is a leaflet available from the British Airport Authority. It gives details of facilities available.

Many airlines have special on board chairs for disabled people and accessible toilets. Do check before you book with a particular airline to see what facilities and help is available.

Before you dash off to book that holiday a word of caution.

- Check that the facilities offered are adequate for your particular needs and disability.
- If you need help, take a companion or escort *don't* rely on the good nature of other holiday-makers, remember they are on holiday too.
- Take all medicines, dressings etc, necessary, to last the length of your holiday. You may not be able to purchase them or they could be expensive.
- Do make sure you have adequate insurance cover, not just for small emergencies, but also in case you have to be hospitalised or flown back urgently. Your Travel Agent should be able to arrange the ABTA Extra Sure Insurance which gives up to £500,000 cover.
- If travelling to an EEC country

get DHSS form E111 well in advance to arrange free medical treatment.

For people who feel like being a little energetic on their holiday or doing something different, there are a number of activity and special interest holidays. They include sailing on the river Fowey at the Churchtown Farm Field Study Centre in Cornwall, absailing at the Calvert Trust Centre in Cumbria and Gliding at ASBAH's Centre, Five Oaks in West Yorkshire.

Activity holiday are becoming more and more popular, enabling disabled people to stretch themselves and experience and achieve more than they ever thought possible. No longer has the person with a disability to sit back and watch others. With the help of experienced and encouraging instructors they can be the participants not the spectators, whether it is rock-climbing, absailing, canoeing, dinghy sailing, swimming, bird watching or nature rambling.

Some disabled people take to the high seas on board the 105ft brigantine Soren Larson run by the Jubilee Sailing Trust. The crew is made up of disabled and able-bodied people and it is a specially adapted boat.

If the calm waters of the canals are more to your liking 'Doubloon' is a narrowboat specially adapted for the disabled holidaymaker and family operating on the Staffordshire Canals (for an account of a canal holiday see page 22).

A more leisurely holiday is available at various centres including Five Oaks which in 1985 is offering a variety of courses including Fashion, Driving, Dance and Drama, and Fishing weekends.

If it's a self-catering holiday that interests you, you may like to find out about holiday cottages designed for disabled people. Details of these are in the free 'Guide to

Countryside Recreation for Disabled People' published by the Country Landowners Association (see page 27).

Whatever type of holiday appeals to you have a good time and write to 'Link' to tell us about it.

Below are the addresses of various organisations and tour operators offering holidays abroad, activity and leisure holidays, and information.

Holidays Abroad

Threshold Travel Ltd, Wrendal House, 2 Whitworth Street, West Manchester. Tel: 061-236-9763.

Chalfont Lines Holiday Information, c/o Kings Arms Service Station, Rickmansworth Road, Harefield, Middlesex.

PHAB, Tavistock House North, Tavistock Square, London WC1H 9HX. Tel: 01-388-1963.

Catholic Touring Association Ltd, 122 Coombe Lane, London SW20 0BA. Tel: 01-947-6991.

Pegasus Holidays, Freepost London SW5 0BR.

Winged Fellowship Trust, Angel House, Pentonville Road, London N1 9XB.

Travel Well, Carlisle House,



All set for a trip in a glider—part of a Five Oaks holiday.

8 Southampton Row, London WC1B 4RE.

Young Disabled On Holiday, 26 Chestnut Close, Aston, Hants.

Horizon Holidays—Brochure from your travel agents.

'Who Looks After You At British Airports' External Relations, British Airport Authority, 2 Buckingham Gate, London SW1.

Activity & Leisure Holidays

Church Farm Field Studies Centre, Lanlivery, Bodmin, Cornwall PL30 5BT. Tel: 0208-872148.

Kielder Adventure Centre, Jim

Wainwright, Low Craneclough, Kielder Water, Falstone, Hexham, Northumbria. Tel: 0660-50232.

Calvert Trust Adventure Centre, Little Crosssthaite Under Skiddow, Keswick, Cumbria. Tel: 0591-72254.

Jubilee Sailing Trust, Atlantic Rd., Eastern Docks, Southampton.

Staffordshire Narrowboats (Doubloon) Ltd, The Wharf, Newcastle Road, Stone, Staffs. Tel: 0785-816871.

Stackpole Trust Ltd, Project Director, Reaches Riant, Kelgetty, Dyfed. Tel: 06467-601.

SHARE Holiday Centre, The Director, Lisnaskee, Co Fermanagh, Northern Ireland. Tel: 03657-22122.

Five Oaks, The Drive, Ben Rhydding, Near Ilkley, West Yorks.

Further Reading

'Outdoor Pursuits For Disabled People' by Norman Croucher.

'1985—Holidays for the Physically Disabled' published by RADAR.

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Information Officer

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On the ferry from Algeciras to Ceuta, navigator Pippa Ribbans centre discusses the route ahead with other members of the Operation Sahara Safari expedition. Pippa, who has spina bifida, writes about the adventure on these pages.

Jackie Davies, aged 22, of Barry, South Glamorgan has spina bifida and had not been far from home for any length of time—not that is until last September, and *Operation Sahara Safari*.

Jackie was one of two young people in wheelchairs who took part in a 28-day expedition to North Africa. Also in the group was a boy confined to a chair, a young man who was completely blind, and four young people who were able to walk fairly well but occasionally needed to use portable wheelchairs. The rest had no obvious disabilities, but would probably hate to be described as 'normal'!

The trip had several aims. It was an exercise in self-sufficiency, and group living. It was a field trip in which useful soil samples and geographical notes were taken, and a good deal of film shot. It was also designed to change the public's image of disability, and to publicise the abilities of those people usually classed as 'disabled'.

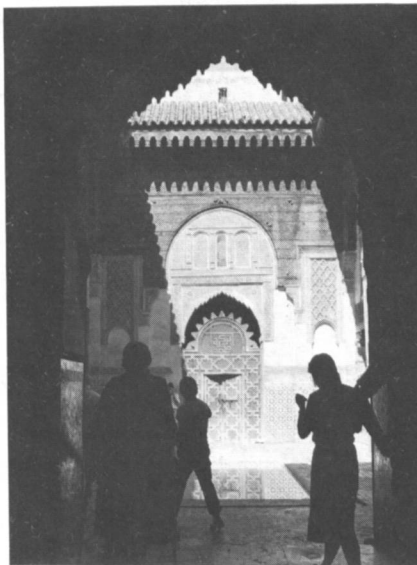
"Also on the expedition were a doctor, a health visitor and a hospital dietician, so we probably had better health care than at home" said John Reilly, Social Worker in South Glamorgan and the expedition organiser and leader.

The expedition was financed by the individuals themselves, backed up by the fruits of over a year's fund-raising.

The journey of 9,000 miles were undertaken in converted mini buses which really took the miles in their stride—apart from a bad start. One of the buses refused to start in front of the assembled 'send-off party',

Operation Sahara Safari: an adventure in independence

but after a delay of 1½ hours Operation Sahara Safari set off, and only one light bulb needed to be changed during the rest of the trip.



The magic of Arabia captured by the camera as members of Operation Sahara Safari visit this mosque in Fes noted for its mosaic work.



A night in the desert comes to an end, and John Reilly (centre) and Huw Lloyd pack up their tent ready for the morning.

Thanks to good planning and preparation there were no major problems. But that is not to say that the expedition was without its tensions, discomforts and mini dramas—like the night the cook's tent blew down at 2am, or the time when someone's catheter burst while she was asleep and ended up soaking everything.

School children in South Wales will have a chance to learn about the expedition first hand from those who took part. Jackie Davies plans to give a talk at Barry Comprehensive. A video was made, and the whole expedition was photographed by Nancy Roach. Her photographs, some of which are shown on these pages and on the cover, capture the flavour of the 28 days.

So, too, does the following account, written specially for LINK by another member of Operation Sahara Safari, Pippa Ribbans, who has spina bifida, and was at University in South Wales at the time:—

Despite to neglect dresses



Expedition leader (left) helps Denis Chadwick get off.



the excitement of each day, it is important not to neglect personal care. Expedition nurse Liz Gentle tends Mandy Glover's foot, inside one of the tents.



A donkey carrying water, shoppers, and Denis Chadwick in his wheelchair in the busy crowded streets of Fes. Denis is being guided through the streets by the expedition leader, John Reilly.

'... We camped in tents at perfectly ordinary camp sites and sometimes not in camp sites at all'

IT ALL began with a letter from SWASBAH informing me about a trip to the Sahara Desert, travelling overland via France and Spain. It was to be organised by a local Social Services Department. I was asked to contact SWASBAH if I was interested.

At the time I was twenty-one years old and studying geography at Swansea University. Geography and maps had always fascinated me and the prospect of travelling delighted me.

Naturally I contacted SWASBAH the very same day and before I knew it the project organiser, John Reilly, had asked me not only to go along, but also to plot a route and write a talk for schools—ultimately to be illustrated with rock and soil samples taken on the trip.

When I was contacted, I was living away from home. I had always tried to be independent and had been on camping holidays with my parents from a very early age. I was determined, on the expedition to be as much help to other people as I could be, since I had travelled abroad before.

The trip affected us all and probably affected our independence

and interdependence as much as anything. Some of our group, normally so dependent on other people, throughout the trip managed to cope better and better—proving time and time again that they could do anything given the chance to try.

Throughout the trip we camped in tents at perfectly ordinary camp sites (and sometimes not in camp sites at all) often with the most basic of facilities. The tents were shared between two or three people and one person slept in each of the two vans.

We had heard that the Moroccans were a little like magpies and were taking no chances!!

Probably our worst campsite problem was pushing wheelchairs over rough and stony ground but needless to say that was overcome by a bit of muscle! Toilets were often just a hole in the ground with footrests either side to stand on, but everywhere we went there were showers. Most of them were freezing cold but after a day of travelling, a cold one was better than nothing. The days we found hot showers it was a big scramble to be first in the queue—oh the bliss of

Continued from P.17.

warm water after a dusty day's drive!

Our driving days were short by comparison to some trips, 180 miles was definitely enough, but despite our tight schedule we wanted an hour for lunch and time for taking photos, without having to get up too early or eat our evening meal in the dark.

How all the planning fell into place as neatly as it did is a mystery to me but it worked most of the time!

There were days when, usually through lack of camp sites, we drove for longer, and tempers got a little frayed. I suppose we expected it, but we were always ready to kiss and make up and pack up for the off the next day in the best of spirits.

So far I have said very little on the countries that we visited. There was so much that was so different from the country that we live in that I could write a book on the subject. Rather than tell everyone what the people and their lands were like, I would simply recommend that everyone go and visit them themselves. Nothing can be perfect all the time but with a little perseverance it is amazing what one can do.

I don't know what we expected in facilities for the disabled abroad; we certainly didn't find wheelchair ramps everywhere! What the foreigners lacked in facilities they made up for in human kindness. Our chairs were carried up stairs and down stairs, by Moroccan Army personnel, Spanish police, ferry stewards (who were really super) and back in Britain at the motorway services we even got to use the staff lift—what an experience through the shop storerooms, the cleaners rooms, the kitchens, passages, in fact just about here there and everywhere.

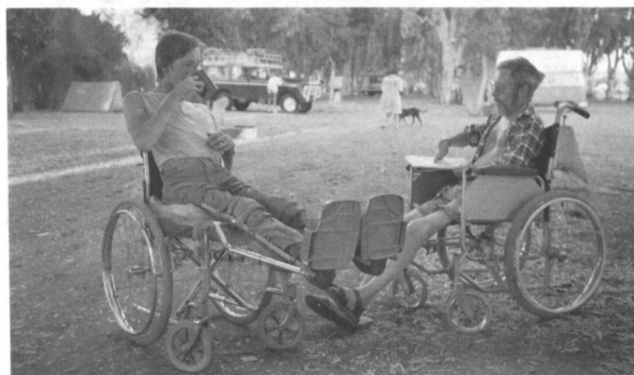
I don't think any of us would ever be worried about travelling abroad again with everyone's help given as freely as it was. We owed this marvellous trip to John Reilly, our organiser. Lets hope he does it again and again and gives lots more of us a chance to visit exotic countries and cope just like everyone else.

PIPPA RIBBANS

Relaxing by the pool-oasis at Source Bleue de Miski after several days of hard travelling. In the background is David Parker, and in the foreground Jackie Davies, who has spina bifida.



In the Fes camp site in Morocco Denis Chadwick (left) enjoys a cuppa while John Fane, a professional artist, draws a portrait of him.



The not so good side of the expedition—one of the vehicles needs a good firm push out of the sand at Erg Chebbi.

Jackie discovers new confidence

FOR Jackie Davies, Operation Sahara Safari proved to be 'the key' to a new self-confidence and independence.

John Reilly, the leader, explained that Jackie had never been very independent before, and had never really been away from home except for a local camping trip.

"After we came back she booked up to go to London to see the Flying Pickets. By broadcasting on the local media she asked for a helper to go with her.

"As it happened the arrangement fell through at the last minute, but she still decided to go ahead. She got her mum to put her on the train to London and did the trip on her own.

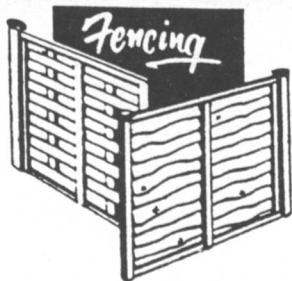
"She went backstage to talk to the Flying Pickets and ended up

having tea with them. She was put back on the train to Cardiff and when she arrived she rang up her mother to ask her to come and fetch her. It's something she would never have done before."

Morocco Expedition

THERE are 20 places for a 12-day expedition to Morocco—ten for disabled people, and ten for helpers, including two leaders. The aim of the trip is to examine the area where mountain range meets desert and to determine what effect this has had on the cultural development of Morocco. The expedition will be in November. For details contact: Debra Ziegler, The Spastics Society, 12 Park Crescent, London W1. Tel: 01-636 5020.

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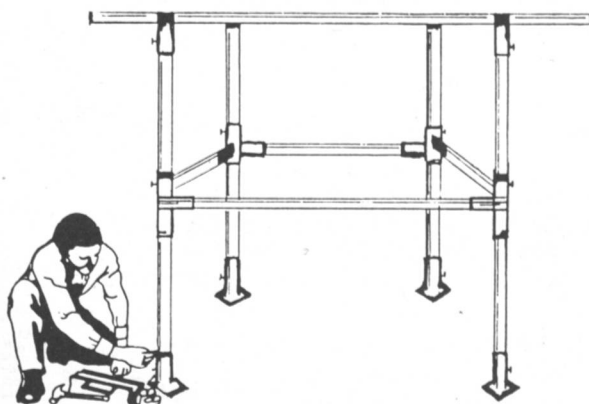
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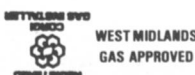
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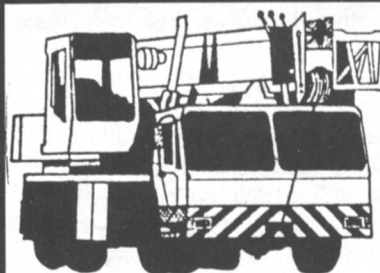
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Saturday

THE RAIN fell all day, from a fine drizzle when we left Kent to an unrelenting downpour on arriving at Dewsbury for a week's holiday on the Calder and Hebble Navigation. We had never taken a canal longboat holiday before so we were 'shown the ropes' by a member of staff from the hiring company, who gave us a hasty 'crash course' and then left us . . . nervously wondering what we should do next!! 'We' being myself, husband Brian, daughter Helen, aged 13 and son Richard, aged 11.

We were a little wary about taking such a holiday with Richard. He has spina bifida and is paralysed from the waist down and, therefore, confined to a wheelchair. He is also doubly incontinent. But we all liked the idea of a canal holiday.

At four o'clock it was still raining. Brian and I were soaked to the skin and chilled to the bone. We decided to 'heave-to' for the night and peel off our wet clothes—a hot cup of tea went down well. Bedtime was at an early hour.

Sunday

WE AWOKED to patchy sunshine. We had moored in a deep cutting, so walked along the towpath to investigate, listening to the fruity and lyrical song of the chaffinch. The cutting opened out to the rear view of houses and industrial premises. We climbed the cutting on our return to find a narrow piece of common land backed by houses. There was a fresh and spring-like smell of bluebells with droplets of dew glistening on the delicate bells—I picked some for the galley.

We breakfasted on cereal, rolls and coffee, then 'roped off' each of us taking a turn at 'driving' the boat. We all found the long 'bonnet' a little disconcerting! Most of the morning's journey was through the district of Kirkless. It was fascinating, yet strangely sad to see so many old warehouses and mills, derelict and almost forgotten.

Locks can be easily missed by the uninitiated! They are often at right or left-hand turns, looking very narrow and almost unused with green moss and grass growing from the damp timbers. One lock which we dismissed as being 'obviously disused' had water gushing from

Family takes to the canal boats

the rotting timber gates. (We were as green as the surrounding landscape!).

We continued upstream on the river until we ran into shallows, grinding sickeningly upon the gravel bottom. With quick thinking bordering upon panic we hastily reversed out and back-tracked to our leaky lock, whereupon I leapt onto the bank below and carried out a closer inspection. It was a working lock, it *had* to be, there was no other way to go.

We moored for the night beside a marshy paddock, wherein grazed two horses, one of which found our mooring lines of interest as an addition to its diet! Brian and I took a walk after our supper.

N.B. The preparing and eating of meals is no problem as the boat is equipped with pots, pans, cutlery, crockery and, of course, gas stove (with oven and grill) and sink with running water; everything neatly stowed away.

Monday

WE WOKE to a patchy threatening sky—it had rained overnight. Being able to climb up on deck and breathe the cool fresh air and smell the dampness of trees and grasses upon the bank was a real treat.

Arriving at Woodside Mills lock we found it to be very busy, with four boats passing through within a half hour or so. Whilst queueing we watched blue tits on a nearby stone wall.

At Salterhebble locks we were confronted with three in all. To novices like ourselves the negotiation of these appeared to be an insurmountable task so we moored below and reconnoitred. The first lock has a hydraulic lifting gate. I attempted to raise this slowly and painfully by windlass, until the lock-keeper came scooting along on

Messing about on the river sounds good. What is it really like? Mrs Penny Parfett of the Kent Association has lent LINK her diary of a recent family holiday on a canal boat. Son Richard, aged 11, has spina bifida. How did he cope? Read on. . . .



The Parfett family's home for a week

his motorised cycle frantically waving for me to stop. With turn of key and flip of switch the gate rose gently and effortlessly.

The lock-keeper then rescued me from struggling with paddle-opener with a pained look upon his weathered countenance! My apologies and nervous giggles were tolerated. At the second lock the keeper, again, assisted us and at the third the keeper's wife appeared as her husband retired into their cottage: we had disturbed his lunch.

At a 'Y' branch in the canal, we were undecided as to which direction to take. We told ourselves, if all else fails, we should read the map supplied with the boat! We had reached 'the end of the line' so to speak, of this particular canal. Here, we took on water and emptied the lavatory.

N.B. We found plenty of service points along the canal, all with fresh water, refuse and sewage disposal units and some with lavatories and fuel supplies.)

The rain continued in a steady downpour so we decided to remain at Sowerby Bridge for the night. It was nine o'clock before there was any let-up in the weather so it was at this late hour that Brian and I

decided to walk into town. There was still plenty of light but few people.

We found the remains of the old Rochdale Canal which had been culverted through the town. Here also was evidence of a once thriving industrial town, now in decline. Apparently, above the town, Rochdale Canal is navigable in parts and carries on to Manchester, some 92 locks distant.

Tuesday

WE AWOKE to an overcast and windy day, but at least it wasn't raining, so all four of us walked into Sowerby—well, three of us walked and Richard rode in his wheelchair and on any downward incline, *two* rode in the wheelchair.

We found the majority of shops closed. We did, however, find a busy market where we purchased meat, bread, which was still warm and smelled deliciously appetising, salad and fruit. By the time we returned to the boat, the sun was making one of its hitherto rare appearances.

We started on our return journey to Dewsbury. I was, in fact, able to dry some of Richard's clothing. Because of limited water supplied, we only carried out necessary laundry and as Richard's only mode of transport on the boat was shuffling on his bottom, his trousers acted as a mobile mop!

We, again, passed through Salterhebble Locks and decided to lunch below the locks, so I walked along the towpath looking for mint to accompany the lamb chops (without success!).

The sun was such a joy to see, so very warming and giving our surroundings a more colourful, pleasant aspect. We journeyed to Elland through a narrow stretch of the canal. Here we moored and climbed the steep hill to the shopping area—not a place for wheelchairs!

We arrived back at the boat to find another craft waiting to moor—we had apparently 'pinched' his spot. With abject apologies we roped off and moored approximately half a mile downstream, this time next to a 'promising' pub, and a cottage.

We later visited the pub where Richard 'downed' a pint of shandy (results could be disastrous) and on returning to the boat Brian slipped



Helen and Richard aboard

while lifting Richard on board. I stood on the towpath helplessly (laughing), while Brian hung perilously from the bow of the boat, one leg dangling overboard with Richard sandwiched between himself and the boat. The result of the accident was Brian had bruised his left leg and Richard his right knee.

Wednesday

I AWOKE at 6.30am to brilliant sunshine filtering through the curtained windows of the boat. At 7.30am I got up and walked back to Elland where I posted some picture postcards. The family was still sleeping soundly when I returned, so with offerings of breakfast the sluggards arose sluggishly.

The result of Richard's pint of shandy was evidenced by bedding draped over bow of boat!

The early sunshine gave way to ominous black clouds mushrooming high into the atmosphere bringing rain later which lasted until late into the evening. We moored at Brighouse for the night in torrential rain and played 'Scrabble' for an hour or so to the accompaniment of rain beating down onto the roof of the cabin and streaming down the window panes with condensation on the inside coming a close second!

Thursday

THE MORNING was overcast so I remained in bed until eight o'clock reading. After breakfast of coffee and toast—most breakfast being of coffee and toast, the cook being on short-time this week!—we made our way up to the bridge over the river Calder and found a very picturesque expanse of water. Later we visited an art gallery situated on a

hill above Brighouse in an old building overlooking the town.

We roped off after lunch beneath a brightening sky and continued our leisurely pace. We watched a kestrel fly off from the roof of a warehouse, then hover stationary above a meadow, then drop like a stone, then hover again a few feet above the ground. A few seconds later it rose again but had no prey in its talons. We saw many skylarks hovering above plants beside the canal and watched a water rat caught by the wash of our boat scrambling up the canal bank to relative peace and quiet.

We met oncoming traffic moving towards Brighouse, even less adept (or should I say more inept) than ourselves. On leaving the lock, their boat made straight for the opposite bank.

The countryside was again fairly industrialised and we met a dredger blocking our way through Shenley flood lock. As a weir was to our left we had only one option—to stop, which is easier said than done for novices such as ourselves.

Providence was on our side as workmen waved us through, having moved a large menacing dredging bucket which hovered above our heads as we threaded our way through moored barges.

We passed Thornhill power station and moored in a deep cutting (as we had done on our outward journey). Brian and I then took a walk up the hill where we had a superb view of the surrounding countryside of rich green, tinged with gold by the setting sun.

Friday

A SLIGHT 'nudging' of the boat awoke me: I found out later that it was one of the coal barges moving downstream. On its return it could not get past as it was then fully laden, so we swapped sides to allow it through on the deeper side of the canal. A dour-looking boatman steered his barge on its way.

Another coal barge came along fully loaded and we watched in awe and admiration as the boatman negotiated the locks. It had no more than two inches of freeboard and

Continued over page

Continued from page 23

Family takes to the canal boats

when in the lock had no more than six inches to spare front, back and sides!

Later that morning I 'combed' the canal bank for stinging nettles as a vegetable to accompany our sausages, mash and onions (nettles are delicious when boiled in a little water, or better still, steamed, tasting not unlike a mild spinach, with a little butter and pepper added, the family love it *and* it's for free.)

After our lunch we made our way towards Thorbury. We saw a pair of swallows splash about in the canal and then perch upon a wire fence to preen themselves. They looked quite comical with feathers all awry.

It was a day of brilliant sunshine with not a cloud in the sky. A thirst suddenly overcame us as we



Richard takes a break in the galley approached Thorbury and a canal-side 'pub. We were certainly in need of a drink after struggling with Richard, plus wheelchair over and under mooring ropes of other boats along a very narrow towpath and up a *very* steep incline.

A number of people kindly offered to help but we had to explain about the collapsible wheelchair which, for the uninitiated, collapses at the slightest touch, leaving helper with lone foot

rest in hand and overcome with confusion and embarrassment, and Richard clinging to half a wheelchair!

On such a delightfully sunny afternoon we couldn't resist a spot of sunbathing on the cabin roof.

Our leisurely pace returned us, regretfully, to Dewsbury which was now transmored by the late afternoon sunshine. What a difference from when we had left it last Saturday under a deluge of rain.

By 6.45pm we had loaded our tiny Renault 4 car and set off beneath a laden roof rack, making steady progress for Kent. It was just after midnight when we slipped between cool sheets upon familiar beds . . . I dreamed of deep canal cuttings, lush green meadows . . . and . . . hot relaxing baths . . .

N.B. An experience we would not have missed and would love to repeat. In fact, this year we are planning another such holiday but this time on a boat which has been specially adapted for wheelchairs!

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Hotel offers a warm welcome

THE TEN specially adapted rooms at the London Tara Hotel in Scarsdale Place, W8 have now been on offer for 18 months. And if the experience of the Sussex Association is anything to go by they are proving a great success.

A group from Sussex stayed at the hotel in December 1983. Afterwards one of them wrote:

"In a mad moment, we decided it would be fun to go to London for the week-end with a group of our older members, aged 18 to 30, and stay at the Tara Hotel in Kensington. It was fun.

"There were 29 of us altogether. We felt a bit overawed at first as the Tara is an 850-room, very modern hotel—but everyone was so friendly and nice to us that we soon felt at home. They didn't seem to mind at all our army of wheelchairs, our tail-lift vehicles blocking the front, our lack of formal clothes."

The enjoyment, it seems, has not

diminished with the passage of time and only recently Sussex secretary Margaret White recalled that those who went were very impressed. The only reason they had not been again was the cost.

The London Tara describes itself as a middle order hotel and its brochure admits, "those who are looking either for luxury or cheap bed-and-breakfast accommodation are unlikely to be satisfied".

Sadly, London is not a cheap city, but The London Tara does its best to help with an imaginative and very worthwhile Visitors Club. For a subscription of just £1 a year disabled people can join the club and secure priority booking and substantial discounts.

From April members will pay £24.50 a night for a single room while a double room works out at £19 per person per night. The prices include continental breakfast and VAT.

The normal rate is £43 for a single room and £52 for a double and that doesn't include the cost of breakfast.

There are now more than 900 members of the club and the hotel is getting booked up for the summer months.



The Visitors' Club

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If you wish to find out more about The Visitors Club write to 'The Visitors' Club', Juxon House, 94 St Paul's Churchyard, London EC4M 8EH. Tel: 01-248 9155 Ext 3172.

Publications

A Guide to Countryside Recreation for disabled people.

THIS FREE, 192 page, Guide contains a wealth of information about 400 sites around England and Wales where disabled people can participate in all kinds of countryside activities. There's information on nature trails, fishing, bird watching, sailing and visiting gardens and farms. The Guide also includes a number of self-catering holiday cottages.

Available free from The Country Landowners Association, 16 Belgrave Square, London SW1X 8PQ. Tel: 01-235 0511. New stocks should be ready by Easter.

How to push a wheelchair.

ALTHOUGH not new, this useful booklet may not have come to the attention of a lot of people. It is produced by the Disabled Motorists Club.

The booklet suggests that many wheelchair users do not make the best use of their chair. It gives advice on the best way of pushing yourself, on transferring from a chair unaided, on folding and storage, and on putting the chair in the car boot. It also gives tips to other people on how best to push a chair, and contains information on accessories and adaptations, and advice on choosing a suitable chair.

Please send 25p to The Disabled Motorists Club, West Midlands, Copthorne Community Hall, Shelton Road, Shrewsbury, Shropshire. Tel: 0743 68383.

Into Work—A Guide for Disabled People

RADAR has produced a loose-leaf information pack entitled *Into Work—A Guide for Disabled People*. The pack provides information and advice on all matters connected with seeking employment, from the first stages of training to the rights a disabled person has when he or she has obtained a job. Part-time

employment and sheltered employment are also covered.

Individual copies are available free from RADAR, (an SAE (10" x 7") would be appreciated.) 25 Mortimer Street, London W1N 8AB.

After I'm gone, what will happen to my handicapped child.

THIS BOOK, by Gerald Sanctuary, looks at the ways in which parents can prepare their children for coping with life without them. It deals with arrangements for making wills and setting up trusts in favour of someone who is disabled, and how to ensure that any money left to a disabled child goes to him.

Although intended mainly for parents of mentally handicapped children, and adults, many of the points are just as applicable to parents of the physically handicapped.

Published in the Human Horizons Series, Souvenir Press. Price: £5.95 paperback, £8.95 hardback.

New relief eases VAT burden on house adaptations

IN THE last year there has been much confusion concerning how the new VAT regulations, imposed in the April '84 Budget on building improvements, affect people who are adapting or improving a house or property to assist a person with a disability. Since the Budget there has been a widening of concessions on such works. Originally the VAT (Handicapped Persons) Order 1984 zero rated the following items only.

1. The supply to a handicapped person of bathroom, washroom or lavatory for the first time *on the ground floor* of the building where he has his private residence, and where such provision is necessary by reason of his condition.

2. The supply to a handicapped person of ramps or wider doorways or passages for the purpose of facilitating his entry to or movement within his private residence.

These provisions were very narrow, ignoring such vital facilities as kitchens, bedrooms, upstairs bathrooms, stair lifts, the adaptation of existing bathroom/toilet facilities, provision of shallow gradient steps at an external door, handrails and repositioning of doors.

After receiving many protestations and appeals concerning the fairly arbitrary and certainly mean nature of these concessions, VAT relief was widened to include:

All new bathrooms, washrooms and lavatories if they are to be the only such facility on the floor; adaptations to existing bathrooms, washrooms and lavatories.

While this is a slight improvement, the importance of the kitchen has still not been recognised. It is certainly hard luck if you are disabled and would like to do some cooking in the kitchen which is not accessible. The new relief is also no help if you live in a bungalow or a flat.

How to claim VAT relief

YOU SHOULD have discussed the zero rated works with the builder *before* the work started, so that you would not be charged for the relevant items.

If this was not done either go to your local VAT office or write to The Royal Association for Disability and Rehabilitation (RADAR), and collect a leaflet called 'Aids for Handicapped Persons' which lists zero rated items and contains a declaration indicating the intention to claim relief.

Give your builder this form and the invoice for the work and he should then amend the invoice and refund you with the sum of VAT charged for zero rated items.

RADAR's address is 25 Mortimer Street, London WIN 8AB. Tel: 6375400.

Short Stay Flat Opens in Wales

FROM MAY, National ASBAH is renting a wheelchair accessible flat in Cwmbran, South Wales from The United Kingdom Housing Trust. The aim is to give young people with physical disabilities the opportunity to try living in their own flat for a period of between 4-6 weeks. Shorter stays can also be arranged.

This flat is one of 59 units intended for young people and so has the advantage of allowing opportunities for integration. Included in the project is a communal lounge and there is a warden/caretaker.

The flats are close to the town centre which is very accessible for wheelchair users. Joyce Hodge, one of the South Wales fieldworkers, will be available to make daily visits if needed, and ASBAH will also be making use of the local statutory services.

ASBAH have agreed to rent the flat for one year, but this period can be extended if it proves to be as useful a facility as we anticipate.

The rent will be paid by the users claiming Housing Benefit, which in most cases should cover the full cost of rent and rates. If the flat remains empty ASBAH will have to maintain the payments.

After the young people have stayed in the flat, if they decide they would like to find permanent accommodation, help will be given.

If there is anybody in the South Wales area who might like to use this facility, please contact Siobhan Rowe at National Office.

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AS PROMISED, LINK now carries the main points of Leonie Holgate's talk at the ASBAH Study Day on Hydrocephalus, held in November. Mrs Holgate concentrated on the learning difficulties of young people with hydrocephalus and ways in which parents and professionals might help them to overcome some of these. Mrs Holgate is ASBAH's Mobility Adviser and is based at Banstead Place in Surrey. Two years ago she completed a three year research project for ASBAH into the effect of hydrocephalus on vocational and non-vocational training.

THREE of the most clearly identified problems of young people with hydrocephalus are lack of concentration, lack of speed and the tendency to be disturbed easily. Mrs Holgate listed the other main, though less immediately obvious difficulties:

Motivation: Because of the difficulty they find in doing so many tasks it isn't surprising that young people with hydrocephalus often lack motivation. This isn't their fault. They are battling against a lot of difficulties, and given the right circumstances can improve.

Poor spatial awareness: It is often difficult to judge distances—to know how far you are from a given object, and to be able to allow enough space or to appreciate the relationship of one object to another e.g. whether a chair is pushed under a table or standing proud of it.

Perseveration: Many young people with hydrocephalus find it difficult to stop a movement once started. For example, to stop the pencil at the edge of the page, if drawing a line across. This is known as perseveration. A rather different example is that they may persist in washing one limb and need reminding to move to the other.

Sequencing: It isn't easy to get things in the right order. This applies to thoughts, too. Young people with hydrocephalus may find it difficult to sort out facts in their minds and to see their way through problems.

Memory: Poor short term memory is sometimes a problem.

Transfer of skills: After being taught how to do something at school, such as how to get up in the morning, how to have a bath, or get

Hydrocephalus

Some of the problems and some ways of helping

dressed, when the young person goes home they sometimes find it difficult to transfer these skills to a new environment. It takes a while to get orientated. After a move it is likely that there will be a fall-off in performance for a while.

Perspective: Objects are often seen as flat, and not in perspective.

Midline: Another fairly common problem is the inability to cross the midline. In marked cases this may affect their reading. When the middle of the page has been reached they will return to the beginning of the line and so only half of the text will be read.

Talking: Parents can be enormously helpful right from the word go by talking to their children, and increasing their awareness of what is going on in the world around them, and in the home. Talk about the simplest of everyday things one does. This giving of information is important and will help make up for lack of experience of many children with spina bifida and hydrocephalus.

Repetition: Repetition is important in order to help the child understand what is expected of him. Repeat what you have said several times and talk in simple, short sentences when teaching a task.

Simple aids to teaching: Colour can play a useful part in helping to teach simple facts and simple jobs. For example when teaching left and right it can help to mark the left with one colour and the right with another. It is important to encourage the child to develop the use of both hands which often doesn't come naturally. Obviously the child must be properly stabilised so that both hands are free. This can prove very useful for the child later on and will help him to be much more successful and natural with tasks. When teaching practical

tasks it is often helpful to start at the end. For example if teaching how to make a cup of tea, start with teaching the final stage of pouring. Next time let the young person do the last two stages, and the next time the last three and so on. In this way he always ends up on a successful note. This is known as "backward chaining."

Check lists: They are a very useful aid to learning independence. They help to overcome memory and sequencing problems. In the very early stages pictorial lists may be used perhaps as a frieze around the bedroom. Progress later to written lists which may have to be quite detailed initially, breaking each task down into simple, small items. As progress is made a few headings may be all that is required but a list does provide a positive reminder which is very reassuring.

Experiencing: In order to build up a rich pattern in the brain, to understand the world and to develop confidence, the child needs to experience as many things as possible, to try things out, to see, to feel and to touch. This is an area in which parents in particular could be very helpful in bringing the world to their child.

Games: There are a great many simple and enjoyable games that can be of help. For the younger children any form of Hunt the Thimble encourages them to explore their immediate environment. Get them to describe where the object is e.g. under the chair, behind the vase, near the clock. Students at Banstead Place, where Mrs Holgate is based, are encouraged to play Pellmenism with a pack of ordinary playing cards. This is good for improving short-term memory. Use games involving shapes or peg patterns—Five in a Row, Connect, small hand-operated Space Invader games. These all require eye-hand co-ordination, and help with visual-perceptual difficulties and with developing appreciation of the diagonal. A visit to a Galts toy shop is probably worth while. You can start with something as simple as their Noughts and Crosses games. Games played with other people are more fun, and may also help mum and dad to appreciate better some of the areas of difficulty.

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Scottish Spina Bifida Association

Free leaflets are available from the Scottish Spina Bifida Association:

The Association; The Medical Aspects; Scoliosis in Spina Bifida; Employers' Leaflet.

<i>The Spina Bifida Baby</i> , By O. R. Nettles, MCSP, ONC	40p
<i>Growing up with Spina Bifida</i> By O. R. Nettles, MCSP, ONC	35p
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<i>Keeping Fit</i>	10p (Free to members)

Post and packing is extra.

Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW. Tel: 031-332 0743.

The Social Implications of Spina Bifida
By Margaret Woodburn

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