Link

December/January 1999
Issue No 179 Price 80p

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

The magazine for people with
Spina Bifida and/or Hydrocephalus

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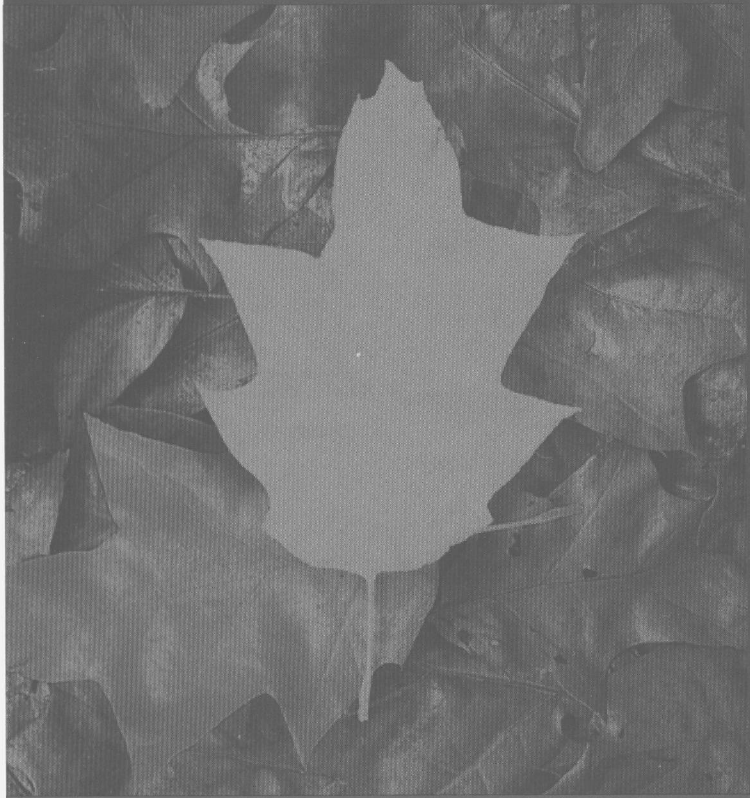

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New booklet designed for prospective mums with SB/H

A NEW pregnancy booklet – for prospective mums with spina bifida and/or hydrocephalus – has been published by ASBAH.

The 16-page booklet *(pictured right)* was researched by our staff with the help of ParentAbility and Jackie Rotherham, special needs co-ordinator, Liverpool Women's Hospital.

It is reinforced by the views, with photographs, of four women with SB/H who have experienced pregnancy, childbirth and motherhood.

The booklet contains information which is essential to know before you get pregnant and discusses antenatal care, prenatal screening and antenatal classes.

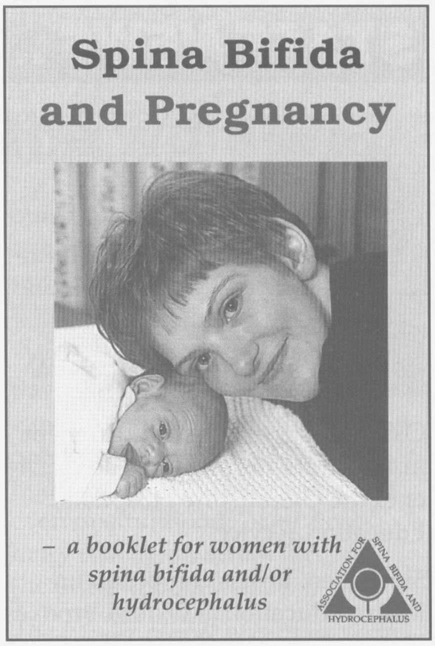
There is useful advice on continence management and other aspects of the disabilities which may be affected by pregnancy. There are tips on avoiding pressure sores, back pain and swelling of the feet.

The booklet takes women through the birth and afterwards, with pointers on making a birth plan, checking with your consultant to see whether a Caesarean birth is necessary, breastfeeding and going home.

Finally, there are two pages packed with further reading suggestions and sources of information.

- ***The booklet is free to people with spina bifida and/or hydrocephalus in England, Wales and Northern Ireland. It costs £1 a copy to all other UK orders.***

For overseas orders, the cost is £2 Sterling per booklet. When ordering by post from ASBAH Information Dept, 42 Park Road, Peterborough PE1 2UQ, please include a 9" x 6" stamped, addressed envelope.



Spina Bifida and Pregnancy

– a booklet for women with spina bifida and/or hydrocephalus

Local Association secretaries have already received a free copy in the post.

Euro-money first for *YVIA*

A EUROPEAN Commission grant of £26,000 was awarded to *Your Voice In ASBAH (YVIA)* for a pioneering international event in December which coincided with the annual European Day of Disabled People.

YVIA won the money to run a residential course aimed at arming disabled people with information about how to break down obstacles to their full participation in society and their own organisations. The event also helped with work on setting up a European Register of Disabled Trainers.

Partnering ASBAH in the five-day course in Leeds, were Leonard Cheshire Ireland, the Portuguese Spina Bifida Association and Mobility International.

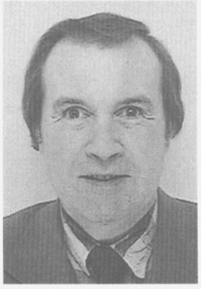
Contents

ASBAH is a registered charity

E-mail: postmaster@asbah.demon.co.uk Find us on the Web – http://www.asbah.demon.co.uk/

Cover: Patricia Millar hands over her Boyzone ticket, saving the day for disappointed Arlene Ronan. Full story on page 8. Picture reproduced with kind permission of Belfast Telegraph Newspapers Ltd.

STAFF NEWS .... STAFF NEWS .... STAFF NEWS ...



● A SPECIALIST adviser (education) has been appointed to cover the South-West, Wales and the Midlands.

Bruce Graham, who lives in Oxfordshire, took early retirement in 1995 from his post of head teacher of the Oxfordshire Hospitals Education Service.

Since then, he has completed an MA in Education at Oxford Brookes University, trained as an Ofsted inspector and acted as a member of the Independent Panel for Special Education (IPSEA).

ASBAH has now four part-time specialist advisers (education):

- Petrina Noyes – East & SE Regions;
- Joanne Grenfell – Northern Region;
- Lorna Johnston – Northern Ireland;
- Bruce Graham – non-regionalised areas.

● JEAN Black, adviser for Greater Manchester, and her husband Brian have celebrated their 40th Ruby Wedding Anniversary.

A buffet meal was held on 6 September at Flixton Football Club. Jean and Brian asked guests, wishing to mark the occasion, to make donations to Trafford & Salford ASBAH.

A total of £461 was raised which is ear-marked towards the running of the ASBAH office in Stretford, Manchester.

Jean and Brian were founder members of the Trafford Association 36 years ago. Both have served as chairman and Brian is now president.

● RACHEL Clark takes over from Shirley Hinde as adviser in Somerset.

Rachel's previous job was to set up and manage a resource centre giving community integration opportunities to adults with a physical or sensory disability.

She has also worked with deaf people as a volunteer and as a teacher in an adult education setting.

● ANNETTE Whitaker replaces Sue Ingham as specialist adviser (medical) for our Northern Region.

Annette has many years of nursing experience. As a volunteer, she has travelled extensively with the Across Trust, taking groups of disabled people to destinations in Europe.

● FAREWELL to Cathy Harrell, adviser for Leicestershire and Northamptonshire, who left in November.

During her three and a half years, Cathy became a valuable member of the Eastern Region team. In Leicestershire, she set up a spina bifida occulta support group – as featured in the last Link. *In Northamptonshire, Cathy was part of a multi-agency planning group which is producing a special needs insert to a booklet issued to every new parent in the county. The insert will include ASBAH's contact details.*

Two new workers for Kent

● TWO women have been appointed to find shortfalls in service provision for families in Kent following the local Association's win of a grant from the National Lottery Charities Board.

Development workers, Susan Bowles and Sarah Huntley, are conducting an audit of families to find out gaps in services and facilities. Once the audit is completed, Sarah and Susan will liaise with service providers to rectify any problems. They will also be starting some of their own schemes, such as parent support groups, as well as raising the profile of Kent ASBAH.

● CONGRATULATIONS to Geraldine Binstead, adviser for North Yorkshire, who gave birth to a baby boy on Friday 16 October.

WELFARE REFORM

PLANS to reform disability benefits have been outlined in *A new contract for welfare: Support for disabled people*, a consultation paper issued by the Department of Social Security on 28 October.

The main thrust is to limit the number of people with access to a non-means-tested income replacement benefit for disability or incapacity. This will be achieved by altering the contribution conditions for receipt of Incapacity Benefit (IB), to exclude claimants moving from Job Seekers Allowance onto IB (excluding 170,000 in the long-term).

The position of incapacity benefit is further threatened by the 'limited' means-testing proposal to reduce the amount of incapacity benefit received where a claimant has an occupational pension or 'similar form of income' of just over £50 a week.

The paper also outlines plans to abolish Severe Disablement Allowance for future claimants over the age of 20, while bringing those under 20 on to IB which is paid at a higher rate than SDA.

Disability Living Benefit on the whole remains relatively unscathed, although there will be no more 'life' awards. The Benefit Integrity Project is to be abolished, but the paper does not make it clear when.

Free summary from: Welfare Reform, Freepost (HA4441), Hayes UB3 1BR, tel: 0181-867 3201. Deadline for receipt of responses: 8 January 1999.

Cautious optimism for surgery in the womb

ASBAH has greeted with "cautious optimism" the news that a baby with a large spina bifida lesion, from the lower chest to the tail bone, has been successfully operated upon in the womb to minimise the spina bifida damage.

A report on the operation 23 weeks into the pregnancy was carried in the medical journal, *The Lancet*, on 20 November. The baby, operated on at Philadelphia Children's Hospital in the States, was six months of age when the report was written and was said to have passed all developmental milestones.

The surgeon, Scott Adzick, revealed that he had pulled flaps of skin over the lesion because he believed this would protect the exposed spine from chemical damage by the mother's amniotic fluid. An incipient Chiari malformation, detected by ultrafast MRI, had apparently disappeared by birth and he claimed he had protected the baby from hydrocephalus.

ASBAH said surgery in the womb was "very much the surgery of today" and the Americans appear to have managed to avoid post-operative miscarriage. However, spina bifida cannot be cured by operating on the foetus, though damage may be minimised.

"We approach the statement that the child's hydrocephalus was cured with some hesitation: many babies with spina bifida develop hydrocephalus in later years and even in adulthood," said Rosemary Batchelor, senior adviser (health and policy issues).

The Lancet report was of just one case, not a programme. The medical community would need to look at the long-term outcomes of a larger group of babies before pronouncing success.

The treatment is not yet available in the UK but, if all goes well with further cases, it could legitimately be regarded as a breakthrough and ASBAH would then expect it to be freely available, but only in a few specialist centres.

"Ultimately, prevention is better than the cure," said Rosemary. "All women should be taking a daily folic acid supplement before they conceive through to the end of the third month of pregnancy to help prevent their babies being affected by spina bifida."

Officers & Staff

Computer training for 10,000 disabled people

WORKABILITY, Leonard Cheshire's flagship project for its Golden Jubilee year, has been awarded £256,900 from the first phase of money for innovative schemes under the Government's New Deal for disabled people.

The Workability partnership will provide 10,000 people aged between 19 and 34 with free computer equipment in their homes, a 'buddy' scheme to help with training and help with job search. The first participants were given their computers and began training in July.

Initial training, based on national accreditation standards, will be offered on-line by two adult education colleges. Employment support will also be available to identify individuals' abilities, help with CVs, job applications and interview techniques and offer 'ready to work' courses.

The equipment and its licensed software will belong to the individual, who will also carry responsibility for insurance and maintenance and pay the cost of delivery of the equipment to the home. After the initial period of sponsorship, the client will also pay any Internet charges, and for phone bills from the first day of the programme.

The partnership includes Microsoft, voluntary organisations like ReCycle IT (computer refurbishment), AbilityNet (assessment and adaptations) as well as the Shaw Trust, Opportunities for Disabled People and CanDo (employment support).

Overall management is by Leonard Cheshire.

Lisa Hunt, one of the first people to join up, said: "I have not actually started my training yet, but I have received my computer and I'm having a go. I wish I'd had one years ago. It's lovely."

Lisa, aged 23, who has spina bifida and lives in Wednesbury near Birmingham, already does copy typing at home for RNIB. Once she has linked up with a buddy to help her through the training, she expects to improve her job prospects.

"At the moment, I use the computer to keep in touch with pen-pals and write other letters. I am looking forward to exploring everything else on the computer."

A major theme of Leonard Cheshire's jubilee year is the social exclusion of disabled people.

In May, the charity published a survey which revealed that nearly a third of people believe that people in wheelchairs are 'less intelligent' and that 41% believe that, if you are disabled, it is 'virtually impossible' to get a job.

Seventy-five percent believe that disabled people who work should remain eligible for benefits.

The jubilee year will end with the 'Enabled' Awards at the House of Lords on 15 December, given to reward examples of best practice from organisations which provide projects, products and services in the disability sector.

ASBAH teams up with Leonard Cheshire

'An exciting step forward' – Bryan Dutton and Andrew Russell sign the partnership agreement

ASBAH has teamed up with the Leonard Cheshire disability charity so both organisations can work together for people with spina bifida and hydrocephalus.

A new partnership agreement, signed on 6 November, will provide the framework for ASBAH offering advice and support to about 200 people with spina bifida and hydrocephalus associated with Leonard Cheshire.

Bryan Dutton, director general of Leonard Cheshire, said: "The recognition that each individual has differing needs and desires is the key to providing high quality care. This partnership is an exciting and important step forward."

Leonard Cheshire, now in its Golden Jubilee year, runs 130 services in the UK for disabled people. Most of its service-users live at home with the assistance of support workers, or in the community in independent and semi-independent housing schemes.

Other Leonard Cheshire service-users receive extra support in residential and nursing accommodation. Outside the UK, Leonard Cheshire runs over 200 support services in 50 countries.

Andrew Russell, executive director of ASBAH, said the partnership will provide numerous opportunities to strengthen relationships between the two organisations.

NEWS IN BRIEF

SPECIAL Schools in Britain is a new guide for parents wishing to obtain the best possible education for their child. It has over 1,500 entries from schools all over the UK listed in alphabetical, geographical and specialist facilities order.

Five copies are available free to the first respondents to any editorial featured on this book. Charity members can also buy the book at the reduced price of £5.00 each (cover price £8.99).

Information from Network Publishing, tel: 01527 834400.

Lift, ASBAH's free magazine for people with sb/h aged 14+, is available on audio cassette tape. If you prefer to receive *Lift* in this format, please call the Publicity Dept on 01733-555988.

ASBAH Information Sheets 1 and 2 – *What is Spina Bifida?* and *What is Hydrocephalus?* – are also available on audio tape. Other ASBAH Information Sheets are taped, on request, by our Information Dept at national centre.

ON AVERAGE, two babies every month are born with a neural tube defect (NTD) in Northern Ireland, the most common of these being spina bifida. The Health Promotion Agency for Northern Ireland has launched a major public information campaign that highlights the importance of folic acid in helping to reduce the number of babies born with an NTD.

Research conducted by the Health Promotion Agency showed that while 59% of women had heard of folic acid, many did not know about the benefits of taking it.

As well as TV and cinema advertising, over a quarter of a million copies of a free health magazine, posters and leaflets will be widely distributed.

Pictured at the launch are: Professor Nevin, consultant clinical geneticist, Northern Ireland Regional Genetics Centre, Belfast City Hospital Trust; Margaret Young, co-ordinator, ASBAH Northern Ireland Region; Douglas Smyth, chairman, Health Promotion Agency for N Ireland.

Help & Advice

Members seeking help and advice on any matters should make initial contact with ASBAH as follows:

Greater London, Berks, Hants, Kent, Surrey, West and East Sussex

ASBAH South East, 209 Crescent Road, New Barnet, Herts EN4 8SB. Tel: (0181) 449 0475. Fax: (0181) 440 6168. Regional Co-ordinator: Jo Francis.

Bedfordshire, Cambridgeshire, Derbyshire, Essex, Hertfordshire, Lincolnshire, Leics, Northants, Nottinghamshire, Norfolk, Suffolk

ASBAH East, ASBAH House, 42 Park Road, Peterborough PE1 2UQ. Tel: (01733) 555988. Regional Co-ordinator: Mary Malcolm.

Northern Ireland

ASBAH Northern Ireland, Graham House, Knockbracken Healthcare Park, Saintfield Road, Belfast BT8 8BH. Tel: (01232) 798878. Fax: (01232) 797071. Regional Co-ordinator: Margaret Young.

Cleveland, Cumbria, Durham, Greater Manchester, Humberside, Lancs, Merseyside, Northumberland, Tyne & Wear, North Yorks, South Yorks, West Yorks

ASBAH North, ASBAH House North, 64 Bagley Lane, Farsley LS28 5LY. Tel: (0113) 255 6767. Fax: (0113) 236 3747. Regional Co-ordinator: Joan Pheasant NNC.

Rest of England and Wales

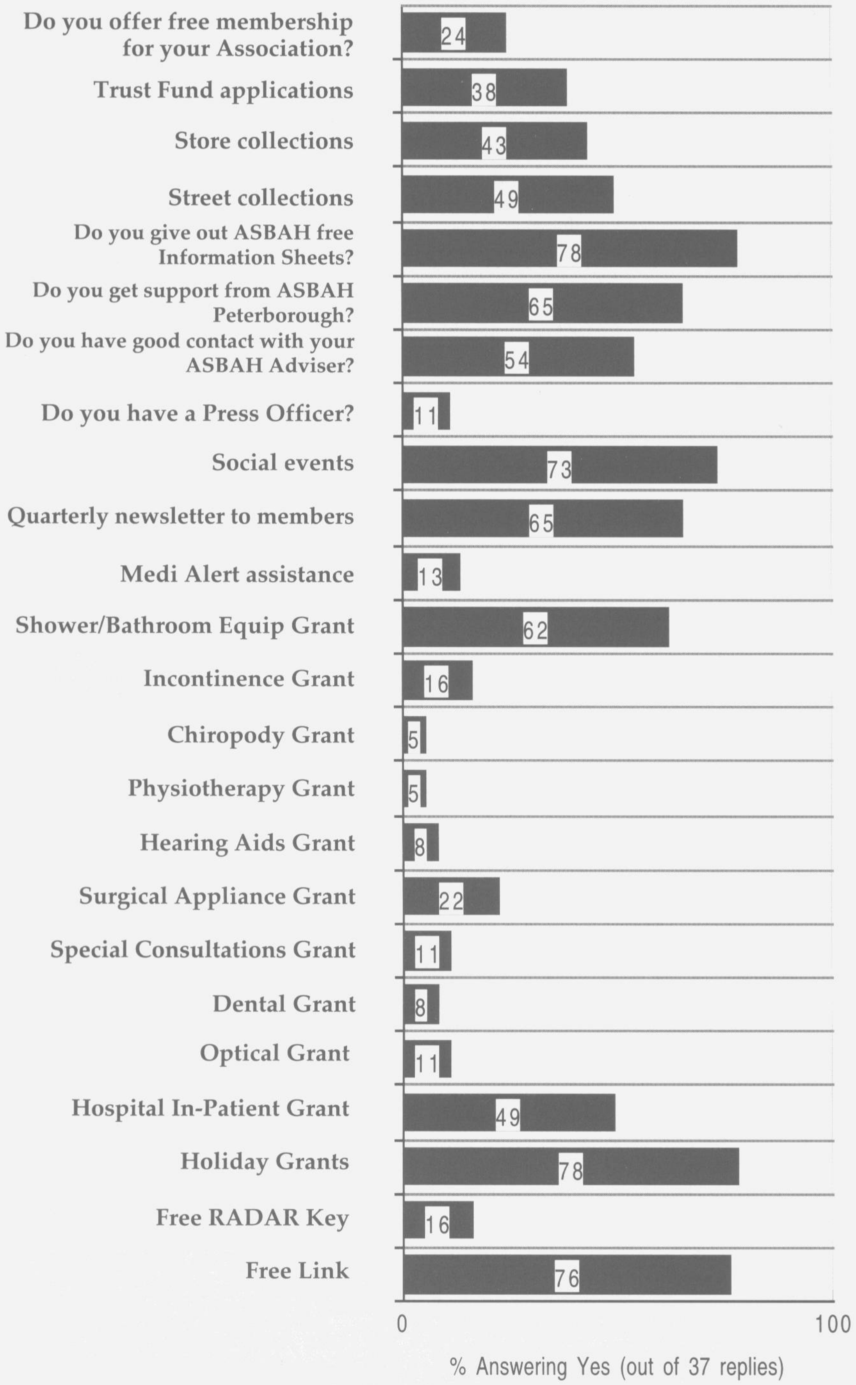
ASBAH National Centre, 42 Park Road, Peterborough PE1 2UQ. Tel: (01733) 555988. Fax: (01733) 555985.

ASBAH welcomes and appreciates the support of its commercial partners.

***Larkhall Natural Health** gives us 10p from the sale of each container of Cantassium Folic Acid tablets. These can be obtained in chemists and health food shops.*

***AlphaMed Ltd** makes a donation for every prescription order received, as a result of ASBAH's introduction, for continence and medical equipment supplies. Tel services floor, 01733-555988, for introductory Freepost envelope. Prescriptions for drugs or medicines should not be sent to AlphaMed.*

Bolton and Bury ASBAH questionnaire 1998



IN A BID to find out which local Associations provide what services, Bolton and Bury ASBAH earlier this year sent out a questionnaire to all England and Wales associations listed on the back page of Link. *Out of a total of 58 questionnaires sent out, 37 were completed and returned.*

The graph above shows the percentages of those 37 that offer particular services. It can be seen clearly from these details which areas have the lowest support.

Interestingly enough, services from national ASBAH appear to enjoy high average satisfaction ratings, though we are never complacent and are always looking for improvements.

LINK COVER STORY

ASBAH member gives up Boyzone ticket

A 12-YEAR-OLD Boyzone fan will have a Christmas to remember after being given a ticket to see her heart throbs by an ASBAH user group member in Northern Ireland.

Patricia Millar read in a Belfast paper that the schoolgirl – who has been struck by a mystery illness – had her view blocked by other fans when she went to see the band in Glasgow.

When Arlene Ronan's mum phoned the Scottish Exhibition Centre to complain, saying she had arranged the £350 treat to cheer up her daughter, she was told that Arlene would have to watch the fab five on the video screen instead!

Civil servant Patricia, a regular concert-goer who already had a ticket to see Boyzone, phoned up the band's Belfast promoter in a bid to buy a ticket for Arlene.

When 38-year-old Patricia learned that the concert was a sell-out, she and a friend decided to donate their tickets for the wheelchair area to Arlene.

Patricia said: "We were only too happy to give our tickets to Arlene. Those tickets cost as much as the others, so I don't see why disabled people are expected to put up with anything less.

"And when you have spent a lot of money travelling to a concert, it's a bit much to be told that you'll have to watch the band on a video screen."

After some persuasion, Arlene finally accepted Patricia's offer – but only on the understanding that she could return the favour next time the boys are in town.

Patricia, who has joined ASBAH Northern Ireland's user group in Belfast, is actively interested in access to public buildings.

"When I go to concerts and find there is a problem, I bring it to the management's attention," she said.

ASBAH survey results: media release 5/10/98

Disabled children denied help to overcome incontinence

EVIDENCE that health services, which should be helping severely disabled children manage their continence problems, are deteriorating in many parts of the country has been picked up by ASBAH in its annual snapshot survey of NHS Trusts.

The survey showed that many children with continence problems extending beyond normal potty training age now have to wait until their fifth or sixth birthday for free NHS supplies. ASBAH says they should be receiving continence pads for free by the age of three – the norm in two-thirds of trusts surveyed.

One trust questioned – Bolton Community Healthcare Trust in Greater Manchester – has pulled out altogether from offering free children's continence supplies to new clients.

Other trusts – S Lincs Community and Mental Health Services, North West Anglia Healthcare (covering the Peterborough and Stamford area), Oxfordshire Community, Scunthorpe Community – say they already operate a minimum age of five.

ASBAH found that at least two trusts have built in arbitrary, non-clinical hurdles before issuing free continence supplies:

- Plymouth Community Trust, while issuing pads at the age of three, says clients must first be receiving the care component of the Disability Living Allowance.
- Ravensbourne NHS Trust, Bromley, South London, requires the child to have a statement of special educational needs before issuing free pads at the age of three.

Julie Llewelyn, ASBAH's specialist adviser (medical), said: "Decisions to deny support to parents until their children are at school, or to refuse to support children altogether, will result in misery, isolation and despondency among people who deserve better. This survey gives direct evidence of deteriorating provision in health care for a population that tends to be less well-off and less likely to be vocal about their plight.

continued at foot of page 11

Continence wakes up a breakfast audience

By Tony Britton

ASBAH won a place on the *Today* programme, BBC radio's flagship political programme, when an item sparked by our annual survey of continence supplies was broadcast on 20 October.

The publication of the survey followed hard on the heels of a *Today* report three weeks earlier when Health Secretary Frank Dobson failed to deliver 'feel good' on the state of the nation's continence services.

ASBAH's annual snapshot survey, now in its second year, named NHS community trusts where we believe continence services to children have been found wanting. Several of the 75 trusts questioned this year failed to supply adequate pads and reusables from the age of three – when further potty training is not expected to bring about improvement.

In the earlier programme on 30 September, after hearing from the Blackpool father of two disabled sons, one of whom is doubly incontinent, presenter John Humphrys said: "Frank Dobson, that last case. It makes you want to weep. What is going on here?"

The Health Secretary, after a lot of wriggling, said: "This is the first time I've heard of this problem. First I heard of it was last night. I will look into it, see whether it is a general problem, but I don't think it is the case that things are generally in a decline."

The ASBAH snapshot survey, which was carried out in September, showed that all is far from well with the state of continence services to children.

There may not be a general decline but, in almost one-third of trusts questioned, for instance, children had to wait until their fourth or fifth birthdays before being given free continence pads. One trust even told us they were no longer taking on new clients below the age of 16.

ASBAH's survey prompted the programme to run a second piece on incontinence on 20 October – thought by campaigners to be an unprecedented development on a subject hitherto considered quite unsuitable for breakfast-time discussion.

The second item contained comments from executive director Andrew Russell, the mother of a child with spina bifida and the continence adviser for Oxfordshire Community Health NHS Trust.

The Continence Campaign complimented ASBAH on achieving the follow-up. Their national co-ordinator, Simon Hombersley, commented: "Your publicity coup resulted in the first sustained reporting on continence services by the *Today* programme."

Extracts from the

30 September 1998

Appearing: John Humphrys; Health Secretary Frank Dobson; Niall Dickson (BBC social affairs editor); Joe Stein (patient's father).

Earlier discussion with a Blackpool GP and hospital chief executive.

ND OK, let me move on to Joe Stein. You have two sons, one 28 and one 27. One has Down's Syndrome, the youngest has cerebral palsy. He suffers from asthma and he is doubly incontinent. What is your experience with him, with the NHS as it is today?

JS Before Christmas last year, he went into hospital and what I found was that we had to provide the personal care. Nursing was good. The doctors were excellent. But there was nobody there who had the time to bath him, to wash him, to feed him, to give him drinks and just to talk to him, look after him. And, with the incontinence service at one time, it was related to need. You got incontinence pads. Now what we are told is that you only need seven incontinence pads a day.

Well, he can't understand that he only needs seven. Also the incontinence sheets for the bed: at one time, there was 15 thicknesses of paper that absorbed urine, now it is down to three. Now, if that's not cutting corners, what is? So, if he leaks in the night, instead of it just being the spot where he leaks, he is now wet from his knees to his armpits.

ND Isn't that the matter, though, for the district nurse to decide how many pads are given, and isn't she making a clinical judgement?

JS It was, but now it has to work to a clinical budget.

RETURN TO THE STUDIO

JH Thank you, Niall. Frank Dobson, that last case. It makes you want to weep. What is going on here?

FD Well, it certainly makes you want to weep about the circumstances that the family face. But it is the case, and I've checked on this particular case, that the expert nurse, who deals with families on Merseyside in those circumstances, has absolute liberty to prescribe or allocate as many incontinence pads as she wishes.

JH But she told them she could not afford it.

The interview continued in much the same vein, only closing when Mr Dobson remarked that he did not think things were generally in decline.

20 October 1998

Appearing: Sue MacGregor (programme presenter); Niall Dickson; Rachel Johnson (Peterborough mother); Alison Barnsley (Oxfordshire Community Health NHS Trust); Andrew Russell (ASBAH); Dr Michael Blackmore (Dorset GP).

SM Now three weeks ago, you might remember, during the Labour Party Conference, we heard on this programme the harrowing tale of Joe Stein, the father of two disabled young men, who revealed that the number of incontinence pads he was allowed for one of his sons was being rationed. The Health Secretary, Frank Dobson, said it was a matter for the nurse in charge to decide, but he did promise to look further into the matter. Well, our social affairs editor, Niall Dickson, begins his new report with a reminder of the exchange on the programme between Mr Stein and Frank Dobson.

JS At one time as you needed them, you got the incontinence pads. Now what we're told is you only need seven incontinence pads a day. Well, he can't understand that he only needs seven.

FD This is the first time I've heard of

Change to non-disposables a cause

AN ASBAH specialist adviser has reacted strongly to the "appalling" situation in which an NHS trust has decided to stop issuing disposable continence products.

Oxfordshire Community Health NHS Trust is supplying non-disposable pads to all new service-users, or disposable products up to the value of the reusable product. Existing clients will remain on their current supply until their reassessment is due.

Julie Llewelyn, specialist adviser (medical), is especially concerned about children with continence problems who would be refused entry into schools if their parents were unable to afford to buy disposable pads out of their own pocket.

Julie wrote a strident letter to the chief executive of Oxfordshire Community Health NHS Trust, Jill Rodney, in which she pointed to the monetary and health implications of the trust's decision to withdraw free disposable pads.

Julie commented: "Rows of buckets neatly labelled are not an option [in schools] because of Health and Safety rules.

"[Schools] will also not agree to transport soiled nappies back home with the child. Therefore, this leaves families with no option but to buy disposables. With restricted income, this becomes impossible to fund."

Although Julie received a swift response from the chief executive of Oxfordshire Community Health NHS Trust, it appeared to be a standard letter which failed to answer her main point.

Today programme

this problem, or the first I heard of it was last night. I will look into it, see whether it's a general problem, but I don't think it's a case that things are generally in decline.

ND That's not a view shared by Matthew Johnson's mother. Matthew is four years old, has spina bifida and is doubly incontinent. The NHS in Peterborough, where he lives, used to provide nappies for disabled children from the age of three, when most children become dry, but Matthew's mother has been told there will be no help until he is five.

RJ I was pretty mad because Matthew doesn't fit into conventional nappies anymore and so I've got no choice but to order them, and they're very expensive. It costs me now £63.25 a month.

ND Rachel Johnson is not on a high income. Much of the disability allowance she receives for Matthew has to go on incontinence products.

RJ My son was born with this condition. He needs nappies as much as he needs medicines and other things that he has, and it's just not fair that we have to pay a fortune.

ND Rachel's case is no exception. Many NHS trusts and health authorities have imposed restrictions of one kind or another. All say they will make exceptions, but in Coventry to get pads patients have to be physically or learning disabled, doubly incontinent or dying. In Bolton, some patients are having to wait more than a year to get pads. In Plymouth, you have to be on Disability Living Allowance to qualify. And Alison Bardsley, of the Oxfordshire Community Health NHS Trust, says they are now only supplying reusable pads, even though she accepts they are not suitable for everyone.

What about if they're poor and it costs a lot of money to put these things through washing machines all the time?

AB The trust accepts that there are individual exceptional cases and that we do, you know, take those into account.

ND Does that mean that anyone who was on benefits would automatically be allowed to have disposable products?

AB No, because unfortunately, obviously, we have to come within our budget, so it would not be simply on the fact that you haven't got a washing machine.

ND Some restrictions may end up being a false economy. If disabled children are given the right help and aids when young, some will become continent, but the director of the Association for Spina Bifida and Hydrocephalus, Andrew Russell, says overall the service is deteriorating, which means more than just expense and inconvenience.

AR Poor service is dangerous as well as undignified, and can present dangers to kidney function, risk of infection, risk of pressure sores, and we're finding that the trusts are introducing what we would see as arbitrary criteria.

ND And to make matters worse, the Government has just closed a loophole which allowed the NHS to avoid paying VAT on incontinence products. In places, the effect has been devastating, as Dorset GP Dr Michael Blackmore explains.

MB The waiting list for incontinence supplies in Dorset has gone up from about two weeks at the end of last year and now it's five months, and this is entirely because the budget has effectively been reduced by 15% because the trust now has to pay VAT on the supplies to patients which formerly it didn't.

ND The Government has ordered a review of continence services. It's due to report next year. In the meantime, there is evidence though that vulnerable patients are suffering delays, hardships and inappropriate help. The organisations that represent them want to see strong direction from ministers to ensure that, at last, this Cinderella service is given the priority it deserves.

for concern

The letter, from Miss Rodney, stated that the policy review had taken place due to increasing pressure on the continence budget. By changing to non-disposables, she states, the trust will be able to meet the needs of all clients who meet the criteria for the service.

Miss Rodney added that Oxfordshire Community Health NHS Trust hopes that national standards will be set following the national review of continence services, announced by Health Minister Paul Boateng.

Disabled children denied help,

from page 9

"Many children with spina bifida have a neurological condition which makes them dependent on continence pads and reusables until appliance-free management can be introduced when they are older."

ASBAH executive director Andrew Russell added: "The senior managers of too many NHS trusts could be far better informed about disability, and rely on the relatively weak voice of disabled people, compared with other groups, which allows them to escape their duty as health service providers.

"Poor continence services are dangerous to severely disabled people, and it is a disgrace for community NHS trusts to be cutting these services. Fortunately, Health Minister Paul Boateng recently agreed to review these services nationally, and may put a much needed rocket behind local senior managers."

The impossible *is*

by Christine Helliwell

MEDICAL knowledge about spina bifida was not as advanced as now when Christine Helliwell was born in 1947.

The doctors told her parents that she might be severely mentally and physically disabled; that she would never reach a high level of education, neither was it likely that she would ever work. Her parents were told that it would be possible for them to quietly let her fade away. Fortunately for Christine, they insisted that she had an operation which closed the lesion in her spine.

Today Christine is proud to have achieved total independence. She has a full-time job working as an analytical chemist and her own flat – doing all her own cleaning, washing and shopping.

In PART TWO of a series based on Christine's autobiography, she describes her determination to gain an education to degree level.

TWO HOURS a week was the sum total of the education allowed to me as a child. If you were disabled you were regarded as a cabbage and were not worth educating. Fortunately, I had good parents who taught me to read, write, do simple arithmetic and tell the time.

By the age of six, my parents had managed to talk the education authority into letting a retired teacher educate me for two hours a week. I remember the first day very well and I was not impressed. With her she had brought a large box containing cards on which were labelled drawings of mother, father, brother, sister, other members of the family and many objects. Being able to read well for my age, I was disgusted. She must have got the message as the cards never appeared again.

Due to my disability, it was thought there would be little chance of me working, so needlecraft made up a large part of my education. At an early age, I embroidered a needlecase for my mother. Many more pieces of embroidery and tapestry were to appear. If I could not work, at least I would be able to make my own clothes and Christmas presents, so it was thought.

At the age of 10 and a half, my parents and GP got me an interview with the headmaster of a local school. I was accepted, with reluctance, I felt, for a three-month trial period. I was placed in the lowest class and found myself ahead in some subjects but very behind in others. History, geography and science subjects were completely new to me.

After six months, I went to a secondary modern school. I sat next to a tall, slim, dark-haired girl called Patricia Robertshaw. She became a very good friend of mine and still is to this day. Children can be cruel. I was made fun of due to the way I walked. Patricia helped me through the hard times.

Yet, in spite of the cruel words and mimicking of how I walked, I never regretted attending a normal school. I feel sure that if I had attended a school for the disabled around 1957 my education would have been poor. I had been motivated to reach the same standards as the able-bodied and wanted to stay that way even if I had to fight twice as hard to do it.

I attended the secondary modern school four and a half days a week. The other half day was spent at the school clinic where I had to have physiotherapy. This was to help straighten my legs for walking and make my arms and shoulders strong, so they would do what my legs would not. The other part of the day was spent at heated swimming baths where a physiotherapist taught me to swim, which also strengthened my legs to help me to carry on walking.

While at school, I lost a considerable amount of time due to illness and hospitalisation. Pressure sores were a frequent problem. I once had to have a skin graft. During such times away from school, I tried to keep up.

I took part in every subject except sport, during which time I did the homework I had asked for to help me catch up. By my final year at school, I had caught up so much that I was awarded a special progress prize.

I left school with no qualifications and I began working for a print firm, making carrier bags by hand. There was a further education college close to where I worked, so I decided to enrol for evening classes and study for GCE 'O' levels. Over the next few years, I gained O' levels in biology, chemistry, English Language, English Literature, and social and economic history. I took many of the exams lying down or kneeling as I had many pressure sores at this time, due to lack of sensation below my waist.

My attendance at lectures, too, was largely spent kneeling on the floor. I felt embarrassed the first time this had to happen but got used to it in time. I also had to slip out of classes to go to the toilet and I was always frightened of missing something. During exams someone had to go with me to the toilet.

My interest in science subjects grew. I was over the moon when I was accepted for the job of laboratory assistant at A H Marks in Bradford. Soon after joining this company, I was given day release to study Ordinary National Certificate in chemistry. I passed my first year, but failed my second. My boss thought I had worked so hard for the exam that, if I took it again, I would probably fail, so I finished college.

However, after a year's break, I decided I wanted to continue with my education and, under my own steam, started studying for a science and technology degree with the Open

possible

University. I had only got 'O' levels so I had to work for two foundation courses which is the equivalent of about five 'A' levels.

About half-way through my degree course, I was invited to a mayor's reception at the Leeds Playhouse, which marked the success of those students who had overcome some illness or hardship, as well as the usual academic pressures, and were doing well in their degrees. I had pressure sores on my heels at the time, so I was presented to the Lord Mayor and Lady Mayoress of Leeds wearing plastic theatre slippers.

Just before Christmas 1985, I received [illegible] letter telling me I had passed my degree. It was a most marvellous Christmas present. The degree ceremony, which took place the following June at Leeds Town Hall, was unforgettable. I wore a navy blue gown with a light blue and gold hood, which looked very smart. My sister Sheila and her friend, Joe, followed my friend Glynis Wrigglesworth and me into a pub behind the town hall for a celebratory drink. The pub was full of Open University graduates.

My first own home

I stood and stared round the room. Surrounding me was an old chest of drawers, on which stood a music centre, a two-seater settee and two chairs, a formica-topped table with a wooden chair, and a second hand black and white television standing on a low wooden table. This was my first day in my own home.

My own home. I was feeling slightly nervous but very excited. Would I be able to look after myself? I was determined to have a good try. My parents had told me I could return if I found it too hard to cope on my own.

The back-to-back terraced house was situated in a narrow street, not far from the main road. It had a large living room, reached by the only entrance to the house. Upstairs, there was a large bedroom and a very small bathroom. Above this, was an attic which I used as a storeroom.

The house did not possess a kitchen but had a sink behind two large doors in the living room. The gas cooker was at the top of the cellar steps. There was a door at the top of the cellar steps to stop people falling down. The fridge had been put down in the cellar. At a later date, a washer and a freezer were also put down in the cellar. It was not an ideal home for a disabled person, but it felt like Buckingham Palace to me.

I moved there in January 1974, at the age of 27. As I had not made contacts with the local church, I decided to find out if I could get a Sunday paper. I was directed to the George Hotel. I felt like a queen as I slowly walked down to Brighouse. I was on top of the world. On my return home, I spent the afternoon cleaning my new abode.

I was soon to find that my parents were feeling a little anxious. For the first few weeks, they were on my doorstep quite a lot. I think they were relieved when I had a phone put in.

I had just started my job at A H Marks – not just any job but work that meant I could be trained to degree level. I now had an aim and a meaning to life: exams to pass and interesting work to do. Like most people I would have to get up early in the morning and not return home until late afternoon. This work was with able-bodied people and I felt I was, at last, being accepted in an able-bodied world.

A home of my own, a full-time job and almost total independence gave me a feeling of excitement and contentment.

From house to flat

The terraced house which I had taken out a mortgage on six years before, gradually became too much for me. My ability to walk was getting worse and the steps throughout the house were wearing me down. I could no longer carry the vacuum cleaner up and down stairs easily. The steps down to the cellar, to reach the fridge, freezer and washing machine, were very dangerous, especially when I was carrying things.

So I contacted the council and put my name down for a ground floor flat. Soon after Christmas 1985, I was offered a new flat only four streets away from my terraced house. It did not take me long to go down to the council offices for the key. And, as soon as I saw it, I knew it was for me.

Christine Helliwell at work as an analytical chemist (1981)

I knew it was going to be hard managing both rent and mortgage together, but felt the chances of being offered such a flat again were small. Immediately, I went back to the housing office and signed the forms.

Over the next few weeks, I emptied my house and chose furniture from it that would fit into the flat, which was much smaller. Curtain rails were fitted, carpets were laid and I had the gas cooker taken out and replaced with a worktop dual microwave to make room for a fridge/freezer.

I was now using a bright red battery car to get around Brighouse and to go to church. As I had nowhere to keep it, the housing department gave me permission to have a shed built for this little car. This car has proved extremely useful to me. I have become affectionately known to local children as 'that girl in Noddy's car'.

Royal invitation

When I was 41, I was invited to a Buckingham Palace garden party, in recognition of the bravery of my vow to lead as normal a life as possible, despite my disability, and for what I had done as a Brownie leader for children from deprived backgrounds. On a beautiful, unforgettable day in July 1989, I had tea in the palace gardens and saw, at close quarters, The Queen, the Duke of Edinburgh, Prince Charles, Princess Diana and Princess Anne.

£140,000 to support our work

ASBAH has been enjoying the fruits of success in two major fund-raising events – with over £140,000 on its way to support our work.

The week-long GMTV *Get Up and Give Appeal* in mid-summer raised £90,152 for each of the five charities involved, including ASBAH.

Our vice-president, Claire Rayner, and 15-year-old David Proud went on stage at the Apollo Theatre, Hammersmith, on 24 September to collect our cheque from *Dr Dolittle* star Phillip Schofield *(see picture right)*. David was featured in one of the GMTV appeal films.

This followed a hectic week in July – when ASBAH members and staff round the country joined in an early morning of fun at Alton Towers, the Staffordshire theme park, and helped run the appeal telephone answering service at BT Tower, central London, and at Alton Towers.

Then, on 2 October, appeals manager Donna Treanor with colleague Paul Wootton joined TV personality Anthea Turner at the Grosvenor House Hotel, London, to represent ASBAH at the annual Swaps Ball.

A top-hatted GMTV cheque presentation to ASBAH. Sharing the moment are GMTV presenters Eamon Holmes, Lorraine Kelly and Ross Kelly

Flashback to a busy week – Mary Malcolm and Lynn Thomas, from ASBAH, (foreground) taking telephone pledges during GMTV's Get Up & Give Appeal

A total of 1,200 City dealers and traders sat down to dinner and then danced through the night at this £100-a-head event in order to raise money for two charities.

Anthea Turner and *EastEnders* star Ross Kemp (Grant Mitchell) assisted with an auction and raffle of major prizes, the proceeds of which will be split equally between the two charities.

ASBAH is expecting to receive £50,000 from the Swaps Ball, which will be put towards a new hydrocephalus research project.

Michael rows the boat for ASBAH

A 63-year-old man rowed 45 miles down the River Wye – from Glasbury on the Welsh border to Hereford – in two and a half days to raise money for ASBAH.

Michael Blanchard, of Broadway, Worcestershire, rowed 12-19 miles a day, converting his dinghy into a make-shift tent to camp over-night.

The hotel consultant raised £370 for ASBAH thanks to sponsorship from family, friends and two local businesses.

Intrepid oarsman Michael Blanchard rows down the River Wye for ASBAH

PHOTO COURTESY OF EVESHAM JOURNAL SERIES

Hnn
Hydrocephalus
Network News
Winter '98/99

Woman fights her benefit review

A WOMAN with hydrocephalus has been stripped of Disability Living Allowance in a review by the Benefits Integrity Project – even though the effects of her disability have not changed since DLA was awarded last year.

Angry and upset, the woman is now appealing against the DLA review which she blames on a report from her GP which assumed she was more physically able than she is, and did not appreciate the problems she has in tackling everyday living tasks.

In March 1997, Karen – not her real name – was awarded the High Rate Mobility Component and Middle Rate Care Component of DLA. Her application had been backed up by a locum doctor who came out to see her.

Despite having done well academically – with an MA and a lecturing qualification – Karen, aged 30, cannot stand on a chair to change a light bulb, cannot chop vegetables or carve meat and is unable to ride a bike. She falls over outdoors, when tired, and has fallen when alighting from buses and trains.

As this issue of *HNN* went to press, she was hoping to finally pass her driving test after having regular lessons over 13 years with four instructors.

Holding down a job has also been hampered by her disability which slows her down when sorting papers and learning new tasks.

continued on HNN page 2

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Launch of BIH rare condition support group

HELP is at hand for people with a misunderstood and disabling condition which can leave them feeling alone and depressed.

In July, ASBAH helped three women to set up a support group for people with Benign Intracranial Hypertension (BIH). Twenty-six people had joined the group as this issue of *HNN* went to press.

Despite its name, BIH is far from benign – often striking people in their mid-20s and completely altering their lives. The first signs may be sudden weight gain and/or sight problems.

Although not the same as hydrocephalus, BIH is characterised by raised intracranial pressure, often associated with sight problems. The raised intracranial pressure may be relieved by the insertion of a shunt and/or by lumbar punctures, or sometimes by drug treatment.

Since the launch, there have been articles about the group in the disability press. A new information sheet published by ASBAH is being sent to individuals, neurological units, GPs, disability information centres and family centres.

For more information contact: Lyn Rylance, ASBAH National Centre, tel: 01733-555988.

Turn to HNN page 6 for more

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ASBAH's Hon Consultant on Hydrocephalus: Dr Roger Bayston MMedSci FRCPath, contact through ASBAH's Services Dept 01773-555988

Woman fights DLA benefit review

from HNN p1

She believes all of these problems – coupled with a recent spell of depression – were overlooked by her GP due to the fact she has undergone no surgery since she was a child, and because of her academic achievements.

"My GP didn't ask to see me before filling out the DLA medical form. According to him, I am miraculously cured."

She added: "My mother and I have now been to see him and it was clear that he assumed I could cope with cooking as I had been to university – not realising that I'd been helped by others. Although recognising I had a weakness down one side of my body, he hadn't associated this with walking problems.

"Based on the information given by my GP, the DLA adjudication officer says I am not so severely mentally or physically disabled that I need a carer or help with mobility, neither am I so severely mentally or physically disabled that I can't prepare a meal, need help outdoors, or require attention during the day or at night.

"But nothing about my disability has changed since last year and it is not going to change."

Karen has recently completed a Legal Practice Course and, although she failed the final exam first time around due to having insufficient time, the course has made her more aware of her rights and given her confidence to ensure she has a fair hearing – even if it means going to tribunal.

"What has happened to me with BIP has given me a cause and has made me even more determined to pass my exams and become a solicitor to help others," she said.

Staff profile

EDUCATION ADVISER FOR EAST AND SOUTH-EAST REGIONS PETRINA NOYES ....

has at least one high-flying ambition – to learn to pilot an aeroplane. Not content to keep her feet firmly on the ground now that she is mum to sixteen-month-old Cameron, Petrina has been inspired to become mistress of the airways by a friend.

Petrina says: "Learning to fly is quite a complex thing to do but I had a friend who did it and she described a flight she made from Newcastle across the Pennines to the Lake District and it sounded fabulous.

"My husband Shaun enjoys parachuting but I'm not brave enough to actually jump out of a plane but I would love to fly one."

TV drama uses hydrocephalus storyline

CASUALTY, BBC TV's Saturday night medical emergency series, scrambled into action on ASBAH's front lawn at the end of October.

The episode, screened on Halloween, contained a story about a schoolboy who became dangerously ill – after his mother and grandfather overlooked classic symptoms of hydrocephalus.

The boy, who had been suffering daily headaches and blurred vision for weeks, had stopped complaining after his grandad, a retired GP, insisted that the boy was just pretending he was off-colour in order to skip games at school.

The boy hurt himself during a cross-country run when he failed to find his footing on a plank over a ditch. At Holby General Hospital, listening to the patient and sensitive observation in the accident and emergency department identified the underlying cause: the boy had hydrocephalus, in his case caused by brain tumour.

Tony Britton, ASBAH publicity manager, said: "This brilliant piece of drama captured what we've known for years – that even doctors can fail to identify the symptoms of this little-understood condition. And delay in bringing it to the attention of a specialist neurosurgeon can result in increased morbidity, or even be fatal."

ASBAH used the occasion to launch its newly revised Information Sheet – specially prepared for GPs – on the causes, symptoms and treatments of hydrocephalus.

Details about how doctors can obtain the sheet have been posted on our website – *www.asbah.demon.co.uk* – and the leaflets will be sent in print form to GPs, if their patients inform us that their doctors really need to know more. *Contact Services Dept at our national centre in Peterborough if you would like your GP to be sent the revised Information Sheet.*

ASBAH has a separate hydrocephalus alert card for people whose condition is treated by the use of shunts, which stresses the importance of getting to a neurosurgical unit within four hours of the onset of acute symptoms.

Kylie's big push for £783!

A GO-AHEAD youngster completed 10 laps round a local park on her tricycle, raising more than £780 for ASBAH.

It is the fourth time that 10-year-old Kylie Pratten has done a sponsored tricycle ride for ASBAH. The total amount that she has raised over the years is a fantastic £1,200.

Backed with pledges from her family, friends, neighbours, companies and her school, Kylie pedalled round Haverstoe Park in her home town of Cleethorpes.

PHOTO COURTESY OF GRIMSBY EVENING TELEGRAPH

GREAT ORMOND STREET HOSPITAL 'OPEN DOOR' POLICY

If parents want to access London's Great Ormond Street Hospital in an emergency, they should speak to the nurse of the ward rather than the registrar.

The nurses run an 'open door policy' which the registrars are not always aware of as they are on a rotation from other hospitals.

True story

By Karen O'Rourke from Stokenchurch, Buckinghamshire

IT WAS 19 May 1995 – the day that changed our lives completely.

Our son Liam had been to out-patients' for a check-up after a minor operation earlier that year, when the consultant we were seeing noticed that Liam had a large head and arranged for us to be transferred to another department.

When we saw this second consultant, we chatted about Liam's development and he said he didn't think there was anything wrong, but he would do an ultrasound scan through his fontanelle just to make sure.

We went down to the Special Care Baby Unit where the scan was done. To our horror and amazement, Liam was found to have hydrocephalus.

A CT scan was done a few weeks later and when we saw the scans, it was then that we realised the extent of Liam's problem. He was just 10 months old.

We took the scans and a referral letter to another hospital specialising in neurosurgery. After many out-patients' appointments and visits to our health visitor to record Liam's head circumference, a date was given for a shunt to be inserted.

The staff on the children's ward were marvellous and put our minds at rest that Liam was going to be OK. We saw various consultants, paediatricians, anaesthetists – all explaining what was going to happen to Liam while he was having the operation. We were shown a shunt which helped us to understand the situation and what he was going to have to live with for possibly the rest of his life.

While they were doing their checks, one of the consultants noticed that Liam's legs were stiff and put it down to his hydrocephalus and he said he would keep an eye on them after surgery before investigating further.

We had a very restless night. We were so worried about what Liam was having to go through and at such a young age.

The day of surgery arrived and there was a slight delay in taking Liam for his operation which added to our anxiety – we just wanted to get it over and done with. The surgeon was the consultant we had seen many times in out-patients so, at least, it wasn't a stranger we were handing our son over to.

We can't remember what time Liam went down to theatre. All we can remember is Phil (my husband) taking him to the anaesthetic room and coming out seconds later saying he was asleep. We were told to be back on the ward within 45 minutes ready for when he came round. We walked to the canteen and had a drink and bought some sandwiches for later as neither of us felt like eating anything then.

After 20 minutes, we went to the parents' room just outside the children's ward. Suddenly we saw the surgeon walking down the stairs opposite. My heart almost stopped beating – had something happened to Liam?

He smiled at us and sat down. My heart was still going nineteen to the dozen while he told us that all was well. There had been more fluid than he was anticipating but there were no problems. Then we heard Liam crying as he was brought back to the ward.

He wanted his mummy and daddy and he didn't know where he was or who he was with. Once he was 'back with us', he settled into a sleep. I didn't know how to hold him. All I wanted to do was cuddle him up close and never let him go but I was afraid to touch him. The shunt had been put behind his right ear. It drains down to his tummy so he was cut there as well. It was a nightmare – we wanted to hold him tight so that he didn't fall off our laps but we just couldn't. We managed, somehow.

The day seemed to drag. The nurses came in and out all day making observations, giving him his medication and fussing over him.

Liam made a fantastic recovery over that weekend. The nurses couldn't believe how quickly he was back to normal. He was laughing, playing, eating, everything he was doing before.

On the Monday, Liam was checked by the consultants and, with some feedback from the nurses, it was decided that he could go home.

At an out-patients' appointment, six weeks later, the consultant checked Liam's legs and decided to refer him to another hospital. Apart from that, Liam had recovered well.

In November, we saw the other consultant who suggested that a physiotherapist would be able to help Liam.

The physiotherapist was part of a hospital assessment team which kept a check on him.

The first visit by the physiotherapist was 2 January 1996. She gave us guidelines on physiotherapy we could do for Liam on a daily basis and came to our home once a week to check on progress and move on to the next step in getting him to walk.

Liam had intense physiotherapy on his legs. He wore day and night splints made specially for him. These were plastic moulds of his feet and ankles which were attached with Velcro straps. He also had (and still has) leg gaiters which are made of a denim-type material, again with Velcro straps which wrap around his entire leg.

At 20 months old, Liam was still not walking. The physiotherapy continued and visits to a hydrotherapy pool were suggested.

On a positive note, an MRI scan showed Liam's shunt was working correctly and the consultants hope no further shunts are needed until he is a teenager.

After discussions with the assessment team, it was decided to go ahead with 'serial plastering' of Liam's legs. This entails straightening the legs and feet to a comfortable point and plastering them. The plasters were to be changed every fortnight for six weeks to keep the stretch. This started in October 1996.

Liam was in severe pain for the first fortnight. He was very miserable and couldn't sleep. We wondered why we had put him through so much agony.

When we went back to have the plasters changed, we discovered, to our horror, that no padding had been put on Liam's heels, resulting in disgusting black sores. Everyone in the room was very distressed but I knew I had to be strong and allow them to put on more plaster as this was perhaps the only way of getting his legs straight.

The next set of plasters was reviewed in seven days and we were met then by a gentleman from the surgical appliances department who decided that new gaiters should be fitted instead to help to keep the stretch on his legs.

Amazingly, after only three weeks, Liam's legs were straight! Things seemed much better – the light at the end of the tunnel was finally beginning to flicker!

Liam O'Rourke

In February 1997, Liam joined a local play school where he was very happy. Then, in May 1997, he took his first steps. Just a week away from his third birthday, it was the best birthday present he could have wished for. We were all overjoyed. We are sure he was spurred on by seeing other children walking and running around.

After Easter, he started a local nursery school with extra help at playtime and for gym.

Liam's physiotherapist sent him for gait analysis, after which it was decided to try ankle-foot orthosis (AFO) splints again – like the very first he had had fitted.

It has been a long, hard struggle for Liam and for those connected with him, but he has found an inner strength and the determination to get where he is today.

Every day when we get that fantastic smile, the pain of watching him suffer just goes away. If Liam can cope, then so can we.

BIH Group – the founder members say why they think the group is so important

Liz Galfskiy, Hampshire: WHY a support group for benign intracranial hypertension (BIH)? It's been a hope and a dream, an idea born from annoyance, frustration and desperation.

A few years ago, I saw a 16-year-old girl have a lumbar puncture, then being told she had BIH. The doctor just said it wasn't anything to worry about: lose weight and, in time, she would be fine. What a load of rot!

She was alone, ill and very upset, her parents at home miles away with no transport and five younger children. The ward staff had little to offer.

I just put my arms around her but seemed at an utter loss for how to help her. There was no organisation to refer her to, no simple explanatory leaflet, no telephone helpline, no reassuring details of research work, no sure knowledge of what future treatment would be best: just agreement that family and friends wouldn't have a clue about what was wrong and the possibility that her GP wouldn't know anything about the condition either.

Why would anyone be surprised if depression, despondency and comfort eating followed? I had had a similar experience: the loneliness, the isolation, nobody who understood or could make sense of my condition.

Since then, I have taken every opportunity to develop my knowledge. It's been an uphill struggle while having over 30 lumbar punctures and 18 operations.

ASBAH has now produced a poster, a fact sheet, an entry on the Internet and there is more in the pipeline. I am just so enthusiastic but hindered by illness.

We have started. Now there is something for people diagnosed with BIH, it must continue. We must **Support, Inform, Take notice of people Under Pressure.** I am convinced that there are many frightened and depressed sufferers who are made to feel like freaks – let's try to reach them.

So **SITUP** and find out about BIH.

Lynne Minister, Croydon, Surrey: WHEN I was first diagnosed, nine years ago, I was surrounded by people on the ward who had other people to talk to with similar conditions to their own. I had no-one to talk to who really understood.

I got into a low state and depression set in. If I had had someone to talk to, I wouldn't have got so low.

If I can help other people not get so low as I did, then I feel I am helping.

I would also like the group to get some fundraising going so that we can get some research done on BIH.

It is all about changing attitudes and educating people, including GPs.

Donna Draper, Little Yeldham, Essex: WHEN I first wrote to ASBAH, you knew no-one else with the condition but you took me under your wing. After my article about low pressure in *HNN*, Liz Galfskiy got in touch, and both Liz and Lynne have kept in touch with me and we have supported each other.

Two years before my BIH was diagnosed, at 18, I was told by my GP that my violent headaches and weight gain were due to depression. If I hadn't been taken to Addenbrooke's Hospital in Cambridge, where BIH was diagnosed, after collapsing at work, I would have lost my eyesight.

There needs to be much more awareness about BIH – perhaps an Awareness Day held in a conference centre.

Hydrocephalus Network News
Hnn LETTERS

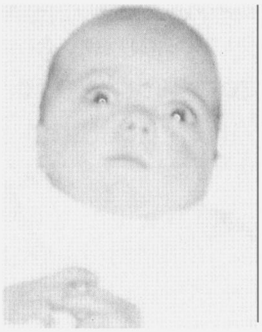
MY DAUGHTER Sophie was born 14 weeks premature on 14 April 1998. She was on the ventilator for nine weeks, on and off. She had two heart operations as she was born with a heart murmur.

She had another operation to have a feeding tube fitted. She then suffered some brain damage (bleeding in the brain) and developed hydrocephalus. She had a VP shunt inserted which needed revising the following week as it wasn't in the right place.

Sophie had to stay in hospital for 14 weeks before being transferred to our local hospital for a further five weeks.

Since coming home, Sophie has been up and down. She has been in our local hospital twice. The first time she had two green toes which were treated with antiobiotics. Then, a week later, she was very irritable and crying. We wondered if she had a shunt blockage, so we took her back to our local hospital which couldn't find anything wrong, so she was transferred to a larger hospital. Here they did a scan, various tests and an x-ray but couldn't detect anything, so we took Sophie home.

In the meantime, Sophie did settle. But when we next saw the consultant paediatrician, it was discovered that Sophie had two bilateral hernias and an umbilical hernia on her tummy button which was getting bigger, so he made an urgent referral.



Sophie Booth

She had been vomitting after feeds, for which we were given Gaviscon for her reflux, which has helped.

In October, Sophie had the three hernia operations. She was in a little pain when she came home, but she is a fighter. All of us have been through a lot.

We are concerned because the consultant paediatrian said she may have cerebral palsy, but we won't know for sure until she is just over a year old.

We hope Sophie has had the last of her operations. She seems to be doing really well since the operations were done. She has started eating solids and is putting on more weight. She sees a physiotherapist and occupational therapist every fortnight and they are pleased with her progress.

We would be very interested to hear from other parents who are, or have been, in this position. We would like to know what to expect.

Ian and Elaine Booth
60 Maybush Road
Wakefield
West Yorkshire WF1 5BA

Please send your letters, *True Stories* and feedback to:
Rosemary Batchelor
***HNN* Co-ordinator**
ASBAH, 42 Park Road
Peterborough
PE1 2UQ

We have had a request from a reader in Devon for adults with hydrocephalus to write in if they have experienced discrimination at work – either in job applications or promotion opportunities.

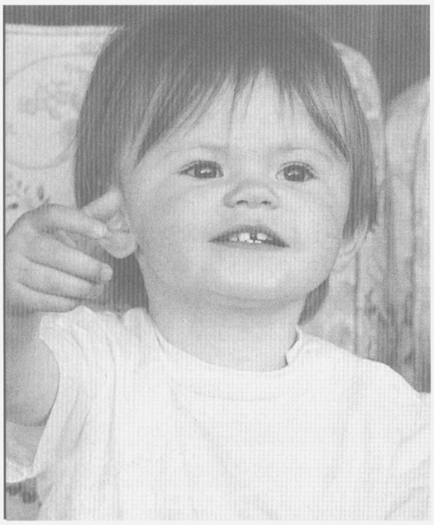
We can publish letters anonymously, if preferred.

What's in the Dec / Jan Link

Link ***is ASBAH's main magazine. Subscription details from National Centre.***

True story

By Rosemary and John Wormington from Redditch



Frances Wormington

FRANCES Ellen Wormington was born on 28 April 1997. She was perfect at birth and passed her eight-week check without a problem. At about 10 weeks old her eyes started to look strange – at times you couldn't see the bottom part of the iris and she became generally rather unsettled.

When she went for her second lot of injections at three months, the health visitor thought that her head looked rather large. When she measured it, it was the size of a six-month-old. We had noticed that her head had grown but, seeing it happen gradually, we had not thought anything of it.

At first, I did not realise the seriousness of the situation. We were due to go to Wales the next day on holiday. I could not take it in when the doctor said that he would have to refer us to a specialist straightaway. Our GP was excellent. He examined Frances and said that she had hydrocephalus but that it did not appear to be caused by spina bifida.

He rang the local hospital and got an appointment for us for the next day. He offered to call my husband as he could see that I was in a state of shock and, when my husband arrived, he told us both as much as he could, whilst trying not to alarm us.

At the hospital the next day, Frances had an ultra-sound scan which confirmed that she had hydrocephalus. The consultant got straight on to the Birmingham Children's Hospital and by 3pm Frances was there, having a CAT scan. By 5pm, we were told that she had a brain tumour and that they would probably operate the next day.

It was later decided to wait a few days and, although we were reassured that the operation was fairly straightforward, it was obviously an agonising time for us and our families.

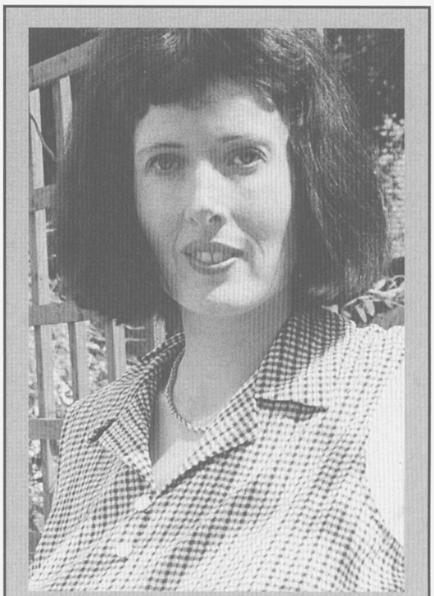
Frances came through the operation but ended up staying a further six weeks in hospital because the brain still appeared to be producing too much fluid. She had a shunt fitted and was eventually allowed home after we had learnt how to feed her with a nasal-gastric tube as she was taking virtually nothing by mouth.

Frances is now one and a half. We had a special birthday party for her to celebrate her first year and to thank all the wonderful family, friends and medical staff who have supported us.

We cannot stress how grateful we are to our GP, our health visitor and all the staff at Ward One at the Birmingham Children's Hospital. They really have been super. It seems such a pity that not everyone seems to get the same help and support. I know it is early days yet and that Frances will have to have further treatment but we are hopeful that she will have a full and active life and this is mainly thanks to the prompt and effective actions taken by all concerned.

Hnn – Annual subscription rates (four issues a year) are: £2.00 (UK); £5.00 European and overseas surface mail and £10.00 by airmail.

If you are not sure when your subscription is due, please phone Lynn Thomas in ASBAH's Services Department on 01733-555988.



The twins' tale

Part Two of Ann Wright's pregnancy diary

ANN Wright, who shared the first part of her *Pregnancy Diary* in the last *Link*, gave birth to beautiful twins on 7 October – a month earlier than expected.

Robert Peter and Chloe Ann are not identical as they grew from two separate eggs and have two very different personalities.

The last few weeks of Ann's pregnancy were hard, mainly due to the extra weight she was carrying and the effect this had on her legs. But she enjoyed the labour and now, after the birth, can look back on the whole pregnancy and labour experience with satisfaction.

Ann, from Waterloo, London, says: "I think what Stuart and I have done is brilliant and I would like to encourage others to go for it as parenthood is such a wonderful experience."

This is the final part of her pregnancy diary.

Saturday 8 August

Week 27. Trip over a rug at my mother-in-law's house. Start to 'spot blood' an hour later so we ring the hospital and I'm taken in. I'm devastated to think I might lose the twins. Have an emergency scan and the twins' heartbeats are monitored. Everything is OK but I'm admitted. I am given steroids to help make the babies' lungs grow faster in case my fall brings on premature labour.

I'm having a lot of sickness which is relieved by Stuart rubbing my back.

Monday 10 August

Afternoon: Stuart and Samantha leave early. I have a very bad headache, no-one knows why. I'm given painkillers, then sleeping tablets, neither of which work. In the end, I put a cold flannel on my head. I'm told to stay in hospital.

Tuesday 11 August

My headache has cleared.

Have a scan at 9.40am. I've been concerned that I'm so small. But the scan shows the twins weigh about 2lb each. This makes Stuart and I feel very happy.

I'm not feeling too well when I go back to the ward. They check my temperature and look at me as if to say 'you're staying in,' but I want to go home. It's so hot in the hospital. The staff, though, have been brilliant and having my own room makes such a difference.

Tuesday 18 August

Week 28. See my GP about my headaches. She doesn't seem to know much about my shunt. She tells me to go to St Thomas' at 1pm where the twins' heartbeats are checked. One heartbeat is picked up straightaway but they can't find the other one, at first. It's nice to be reassured that the twins are OK. I'm asked who I normally see regarding my headaches and I know it would be better for me to go to Kings College Hospital, where I normally go regarding my hydrocephalus. I'm given painkillers and allowed home.

Friday 21 August

Week 29. Routine appointment with midwife to check twins' hearts, take my blood pressure and weigh me. I now see a midwife once a week and a doctor at St Thomas' once a fortnight. This time I see a different midwife who thinks there is blood in the urine, so sends it off for testing. I look forward to the result as I've been feeling unwell.

Tuesday 25 August

Appointment with obstetrician at St Thomas'. Two courses of treatment are prescribed for my urine infection – a strong one to kill the infection and a milder one to take through the pregnancy.

Thursday 27 August

Week 30. Have a scan to check size and position of twins. Although I've lost weight, and only weigh as much as I did when I started the pregnancy, they are happy that the twins are putting on weight. The larger one is well down with its head pointing downwards,which makes it difficult to measure its head. The scan operator also checks my kidneys and these seem OK.

Tonight Stuart and I have a wonderful experience. I rub my tummy gently and feel a length of arm or leg pushing against me. Stuart thinks the baby's limb was about three inches long – moving just under my urostomy bag.

Monday 7 September

Week 31. Appointment at St Thomas' about my back pain. It

continued on page 24

The twins' tale

Part Two of Ann Wright's pregnancy diary

– continued from p 23

seems my pelvis is loosening up which is a good sign, I'm told, and is common for women who have been pregnant before.

I'm delighted to get this far into the pregnancy – I'm told it's quite an achievement for someone expecting twins.

Tuesday 8 September

See health visitor at our flat. I'm angry at her attitude – she has labelled me 'disabled full stop.' She seems to be saying: *You can't have two babies stuck in this flat all the time and you can't be stuck in the flat either.* Yes, I have had problems with my right foot but I'm keeping my weight off it as much as possible so I don't get an ulcer and I've got a scooter to get about. I've also got a loving husband and daughter who are very supportive. Everyone else is so pleased with me.

When I see myself in the mirror, it's quite a shock to see how big I am! It's a *nice* shock, though, as you know, at the end of it, there are going to be two lives. The twins haven't stopped kicking. I talk to them and tell them what's happening.

Friday 18 September

Week 33. See physiotherapist at St Thomas' to have an elasticated support fitted to push my pelvis together and help me carry the extra weight. The physiotherapist massages my pelvis and back. I feel so relaxed: she seems to find all the sore points. She will see me again before the twins are born. See midwives.

Saturday 19 September

I slept like a log after the massage and I feel good today. I even eat my dinner and keep it down!

Up to now, the twins have been 'living off my fat' and I have lost weight through the pregnancy but, during the last couple of weeks, I have put on weight which is reassuring. I'm still suffering badly with heartburn as the twins are taking up so much space and my stomach is being shoved out of the way.

Monday 21 September

Another scan at St Thomas'. One of the twins is 'engaged' and is very low down – practically between my legs! The other twin is on top of the first twin's feet, so hopefully it will follow suit. I'm feeling a lot of pressure 'bearing down' and I feel uncomfortable when I walk. The estimated weights are: Baby A – 5lb 3oz; Baby B – 5lb. They couldn't check the size of Baby A's head because it was too uncomfortable for me for them to get the measurements. All Baby B's measurements are fine.

Tuesday 22 September

See obstetrician.

Wednesday 23 September

Week 34. I have really enjoyed the pregnancy. The babies are still kicking which is a lovely feeling. The sense of 'bearing down' is uncomfortable, however, especially when I walk.

Thursday 1 October

Week 35. See physiotherapist about my pelvis so she can exercise it. She sees I am having trouble walking. My left leg is really painful and I have a urine infection as well. The physiotherapist rang the antenatal ward and I was told to go to the day assessment unit.

Here I had a three-hour wait in my scooter and was in agony with my back. I was very concerned about my leg but I can't do anything as I'm afraid of losing my place in the queue. Stuart had to go home to meet our daughter Samantha.

When its my turn, midwife checks my urine and blood pressure etc.

Friday 2 October

A scan on my leg is due to be done today. At 5.30pm, I'm told the scan operators have gone home for the day and I'm asked to stay in overnight. The pain is dreadful. Later I'm told an emergency scan will be done and it's a relief to discover that there are no blood clots.

Sunday 4 October

I'm told to put on tight stockings – these look awful but help bring down the swelling in my leg.

This evening I feel uncomfortable – [illegible] think due to one of the twins being so low down in my pelvis.

Monday 5 October

7–8am: I have some Brackston Hicks' contractions but these disappear by 9.15am. I am put on a monitor and the obstetrician confirms I am having contractions.

I go for another scan to check the babies' sizes. Then, in the scan room, I'm told to take off my stockings. I query this and find the scan operator has been given the wrong forms! They have reused the forms issued about my leg.

Tuesday 6 October

More contractions – these are very slight and soon disappear.

At about 8pm, I go to the day room and chat to the other expectant mums. I ask how they are and wish them luck. All of a sudden, I feel funny and get double vision. I phone my daughter and our conversation feels strange as if something is about to happen.

I go to bed thinking I must be tired.

Wednesday 7 October

Week 36. Wake up at 2.15am with a pain which I confuse with a bowel problem I had a few days ago. I go to the loo but the pain is still there.

I call the midwife and explain there is water on a towel between my legs. She dismisses this, saying my urostomy bag must be leaking but I tell her the damp patch is in the wrong place for that as my bag is on my tummy. She also tells me that I should be getting pains higher up and I try to explain that, because of my spina bifida and the fact that I cannot feel pain in some areas, I am not like other women. Then the midwife asks: 'What shall I do? Shall I get the doctor?'

The doctor comes and tells me I am 8-9cm dilated! I wonder: how on earth did this happen? I then start grabbing things off my bed and my bed is rushed to the labour ward. They ask me if I want to contact Stuart, and I agree.

A doctor, accompanied by a student, does a quick scan and confirms that [illegible]e twin is in the 'engaged' position [illegible]d one is breech. They put me on a drip as a precaution. Stuart arrives and starts rubbing my back with oil, (the scars on my back were quite puffy and tight, he tells me afterwards). I lie on my side and then on my back, but am told to return to lying on my side as the doctors can see the baby's head better. I can't believe it when they say this. I ask for a mirror to see if it's true, but none is available, so I get Stuart to look to confirm what they are saying.

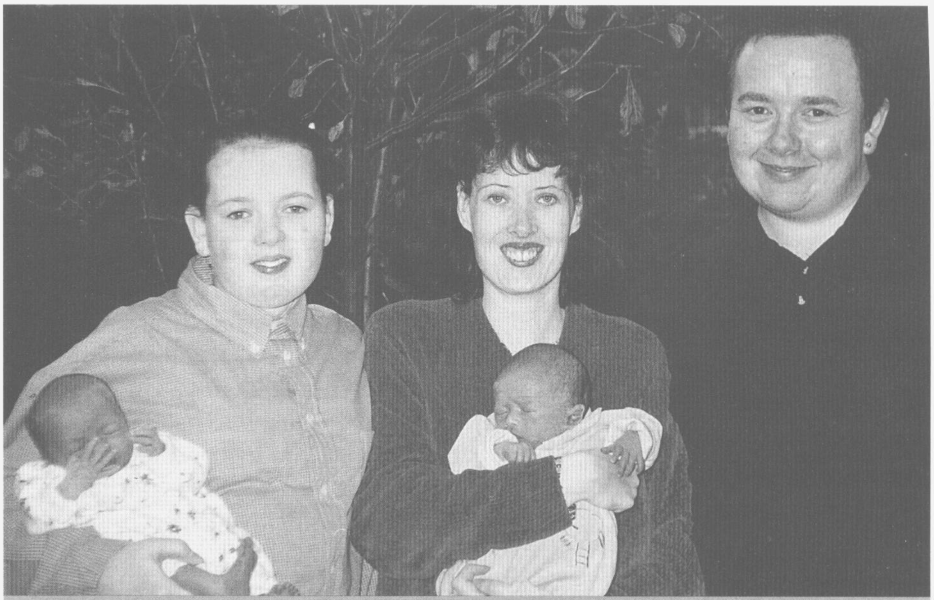
At first, they can't pick up the heartbeat of the first twin, so they put a probe on its head.

After 6am they say I can push. When [illegible]ed if I'm tired, I say I'm not. I try [illegible]ork with the labour.

Robert Peter was born at 6.15am, weighing 5lb 11 and a half oz and Chloe Ann arrived at 6.25am, weighing 4lb 11oz. Chloe's birth was assisted as she arrived bum first and I had to be cut. But her arrival was like the popping of a Champagne bottle cork – if the doctor hadn't been ready for her she would have landed on the floor!

My labour experience was terrific from start to finish. It is something I will never, never forget. I didn't need a Caesarean, I didn't even need gas and air. It lasted four hours and 15 minutes. The midwives, who changed over once during my labour, were so nice.

The twins arrive on exactly the first day of the 36th week of my pregnancy. Both are classed as premature but Chloe needs more attention than Robert, who sleeps after he has been fed. They are absolutely gorgeous.



Ann and Stuart Wright with their eldest daughter Samantha and twins Chloe Ann and Robert Peter

I return to the Grosvenor Ward and tell all the other mums about it. I return to the antenatal ward where I have a side room. The midwives on the ward are very busy and don't have time to help me with breastfeeding for some time and I get very frustrated about this. I have achieved the pregnancy and labour, and now I want to achieve breastfeeding as well but the midwives keep telling me: 'In a minute, in a minute.'

Sunday 11 October

Leave hospital today. I am pleased to be going home but was determined to conquer the breastfeeding while help was available on the ward. At the moment, I am breastfeeding Robert totally and Chloe is getting top-ups with the bottle as she is smaller. Her weight is now going up after dropping initially after the birth. Chloe and Robert are not identical twins and their personalities are totally different but we have arranged for them to sleep in the same cot.

Monday 12 October

Midwife fails to turn up as she went to the wrong flat. In the end, we ring the hospital and plead that someone comes as Chloe doesn't seem too good. As it turns out, the midwife, when she does come, says she is OK. We just needed some reassurance.

Tuesday 13 October

Midwife arrives to weigh the twins, give them their Vitamin K and take a blood sample from their heels.

Friday 16 October

Wait in for the midwife all morning. This one is a bit younger than the others and something clicks between us. She helps me again with breastfeeding and offers to change Chloe.

She says she will come again on Sunday to help with breastfeeding which, I think, is mostly just a matter of building up confidence.

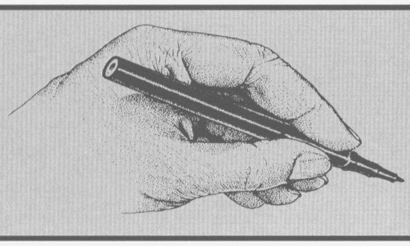
Holiday home swap

A FREE accessible holiday home exchange service might help you to find a place in the sun.

Accessible Vacation Home Exchange is run by the Institute of Independent Living, Stockholm, Sweden.

Prospective exchange partners contact each other by email and share detailed information before reaching an agreement.

The website address is: http:/www.independentliving.org/VacationHomeSwap.html



Letters

MY daughter Susan Jervis, born with spina bifida and hydrocephalus in 1966, had a baby last November.

Although the baby, named Jennifer, was born with a hole in the heart and narrowing of artery to the lung, she made a remarkable recovery from surgery in June.

Baby Jennifer is progressing all the time. Her mum is a swimmer – she won a lot of medals at Stoke Mandeville when she was younger – so she is encouraging Jennifer to go in the water. Every Friday, Susan and her partner, Billy, take Jennifer to a swimming club they belong to. Jennifer loves the water and never wants to come out.

Susan is coping excellently with Jennifer. She feeds and changes her and sees to her in the day, while Billy gets up in the night if she wakes. She is a good baby and, unless not well, is very happy.

I hope this success story helps someone in the future.

Mrs M R Jervis
Maghull, Merseyside

I AM studying Business and Information Technology at Stanmore College. I am 17 years old. My interests are music, TV and going shopping.

If there is anybody like me, with spina bifida and hydrocephalus, who would like to write to me, I'd be delighted to hear from you.

Lydia Blackmore
14 Aylands Close
Preston Road
Wembley
Middlesex HA9 8PJ

THANKS to Paul Darke for his valuable contributions to Link over the last four years. He has decided to quit writing for us in 1999 except on an occasional basis.

MY two and a half-year-old daughter has Chiari malformation (Type 1) and I'd like to hear from anyone with a child under five years who has the same condition. Ciara has problems with balance, co-ordination, is partially deaf and has delayed speech.

Mrs Lorraine Lewington
Flat 3
Block 79
Devonshire Road
London SW19 2EW
Tel: 0181-543 3468

I WOULD like to hear from anyone interested in forming a new disability awareness agency committed to helping disabled people show themselves in positive ways.

I would like the project to be run by disabled people and to specialise in providing support and advice to disabled people engaged or wanting to take part in the arts and education. I am also interested in incorporating a design consultancy for equipment for disabled people.

Lyndon Fishwick
47 Oxford Road
Dawley
Telford
Shropshire TF4 3ED

MY 12-year-old son, Seon, has sacral agenesis and I would like to contact other parents of children who have this condition.

Seon has had surgery to straighten his feet, an artificial sphincter and the ACE procedure.

Please write to me at the address below.

Mrs Shan Williams
3 Bro Pedr Fardd
Garndolbenmaen
Gwyneth
LL51 9NX

We invite letters for publication. Send them please to: *Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ.* The Editor reserves the right to edit letters for publication, so keep them as short as possible.

WE are conducting research on how disabled people can be best supported in their role as parents.

We would like to interview 100 parents with a physical or sensory impairment, or mental health difficulty, who have at least one child aged 7-18 years. We would particularly like to hear from such parents in Nottinghamshire, Northamptonshire, Leicestershire, Derbyshire and Lincolnshire, but would welcome inquiries from other parts of the country also.

We would like to speak to both fathers and mothers, and to people in single- and dual-parent families. We will interview the parent(s) and one child from each family.

Please contact us at the University of Leicester (Nuffield Community Care Studies Unit):

Richard Olsen, 0116-2525429
or Harriet Clarke, 0116-2525434.

ACCOMMODATION

ILKLEY, West Yorkshire – Sanctuary Housing Association wheelchair-accessible flat, sharing with two other persons (female). Emergency warden cover and support services available, if required. Semi-rural location with panoramic views across the Wharfe Valley. Half hour by train from Leeds and Bradford. ***Contact: Mark Best, tel/fax: 01943-603013.***

PRODUCT

HOLIDAY ACCOMMODATION

When booking, check to make sure the accommodation suits your particular needs

ISLE OF WIGHT ASBAH – Fully-equipped, wheelchair-accessible, two-bedroom bungalow. Sleeps six. Clubhouse, indoor heated pool, shop etc. Lovely views, many interesting places to visit. Own transport advisable. ***Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF, tel: 01983-863658.***

WEYMOUTH BAY– Fully equipped, wheelchair-accessible caravan – sleeps five; on Haven Holiday Park, full use of all facilities – heated indoor & outdoor pools, bars, children's club & full entertainment programme. Three miles from Weymouth. ***Details from: Margaret Humphreys, tel: 01494-714270 (Bucks & E Berks ASBAH).***

SELSEY, WEST SUSSEX (SASBAH) – Fully equipped, purpose-designed for wheelchair access, mobile home. Sleeps six, ramp and large veranda, payphone, colour TV, midi stereo etc. Clubhouse entertainment, heated swimming pool, free site bus service. Nature reserves and places of interest nearby. ***Details from Mrs B Nunn, tel: 01903-763473.***

FRANCE – Ile d'Oleron, near La Rochelle – Mobile home for wheelchair-users. Fully adapted (shower etc), sleeps six, near beach, disabled owner. ***Brochure from M Mardle, Fricourt, Filey Road, Old Heath Road, Southminster, Essex CM0 7BS. Tel: 01621-772447.***

HOLIDAY IN NORMANDY – Normandy farm, La Hamberie, offering two accessible, self-catering cottages in the beautiful Calvados countryside. A superb base for gentle touring. The English owners provide evening meals if you want a break from the cooking! ***Brochure and further details, contact Mike McGrother 01706-845041***

ORLANDO, FLORIDA – House with a heart for disabled travellers! Spacious, luxury, adapted bungalow situated on golf course. Three double bedrooms, two bathrooms (Mangar bathlift installed), Cable TV, free local telephone calls, free Country Club membership. 24-hour 'on-call' management company. 15 mins Orlando Airport. 20 mins Disney. Paraplegic owner. ***Sue Fisher, 5 Park Lane, Broughton Park, Salford M7 4HT, tel/fax: 0161-792 3029.***

FOR SALE

44FT CARAVAN with access ramp at Parklands Site, Walls Lane, Ingoldmells, Skegness (opposite Butlins). Wheelchair-accessible. Low light switches, lever taps in kitchen and bathroom, raised toilet with handrails, shower. Kitchen fitted with gas cooker. Microwave, kettle, all crockery, cutlery, fire extinguisher provided. Separate lounge with gas fire, colour TV, settee and 3 chairs (1 high-backed upright). Two bedrooms – enough room to turn wheelchair round (1st bedroom: 2 single beds, cupboards and 2 wall wardrobes in cream; 2nd bedroom: 1 single bed, 1 set bunk beds, double wardrobe and cupboard in cream). Matching duvets and curtains in both bedrooms. Slimline electric heater in passageway. Outside light. £2,000 inc all contents. No offers. ***Phone 01623-654717 (Mrs Haywood).***

ADJUSTABLE 3'2"x 6'6" bed with built-in-therapy remote control massager. Three months old (as new, cost £2,850). Offers. ***Phone 01386-552018.***

FIESTA Auto greg blue 27K stereo. Hand controls for r/hand operation – accelerator, footbrake, indicators. Owner unable to continue driving. £3,199, possible delivery. ***Ring 01844-279701 (d) 01494-563640 (e). High Wycombe.***

NEWTON Regent Powerchair – nine months old, dual controls, and oxygen cylinder cage. £1,795. ***Please phone Rebecca on 0181-877 0170 for further details.***

POWERTEL F40, blue, r/hand drive, seat width 16", three years old, hardly used. Battery and charger included. Kerb climbing and dismounting facility. Offers around £1,000. ***Mrs Clennell, tel: 0191-549 0234 (Sunderland).***

STERLING 4 four-wheeled scooter with battery charger and weather-proof cape. Two years old. Hardly used. Cost: £2,895. Accept: £1,700. ***Tel: 01787-311713 (Suffolk).***

LINK Rates

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£5.25 for 30-45 words;
£6.25 for 45-60 words.

Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of *LINK* (February) should be submitted by Friday, 8 January. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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