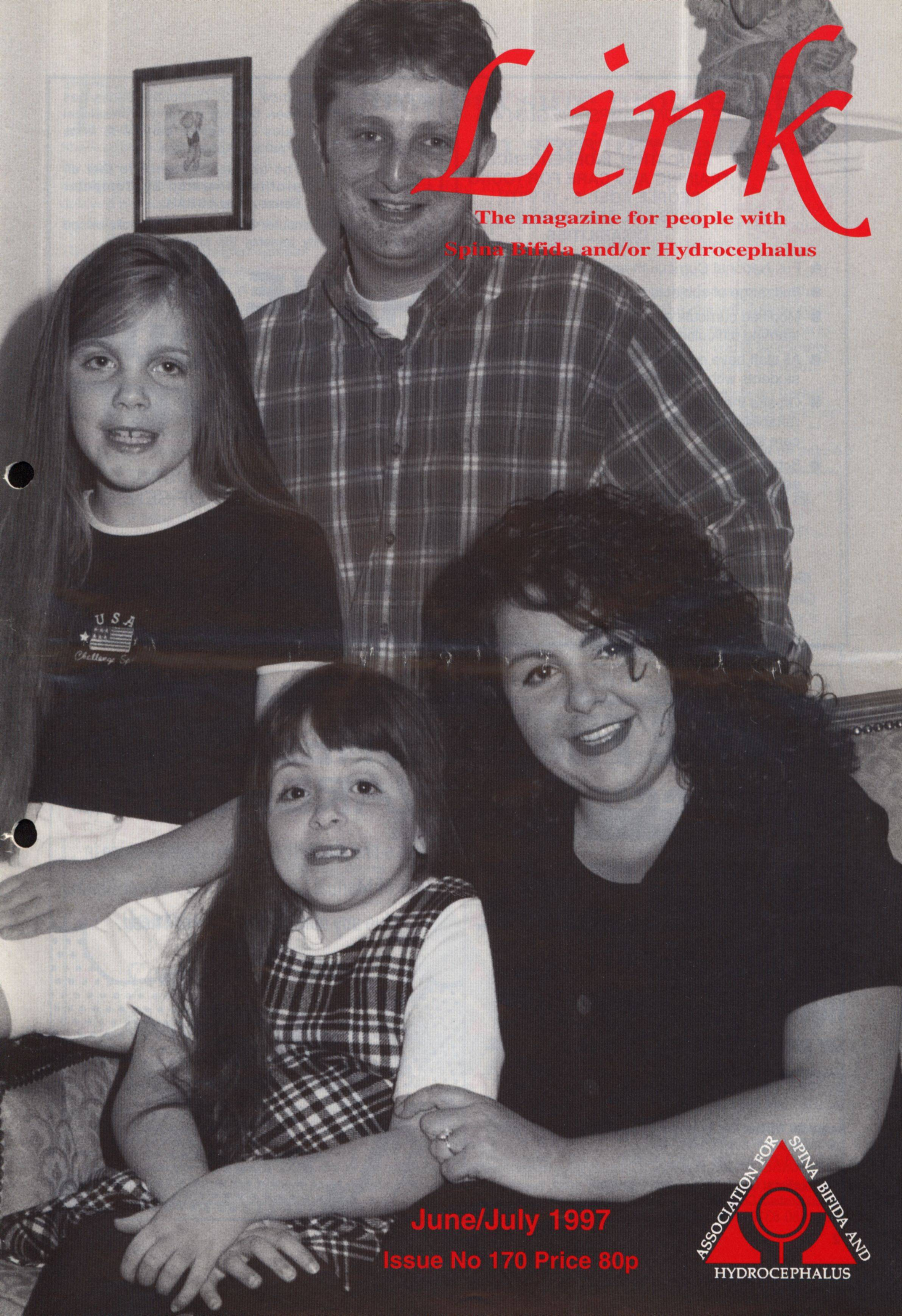
Link

The magazine for people with
Spina Bifida and/or Hydrocephalus



June/July 1997
Issue No 170 Price 80p

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Slow but sure progress for actions on sodium valproate

THE FIRST of a series of actions against health authorities alleging mis-leading advice about taking the anti-convulsant drug Epilim during pregnancy has been delayed because an expert is waiting for some more information.

The writ is due to be issued against Wirral Health Authority for failing to warn Diane Walker of Wallasey in Merseyside that, by taking Epilim – made of sodium valproate and tegretol – during pregnancy, she was risking the health of her unborn child.

Ms Walker's son, now six, has spina bifida. Hers is one of more than 80 cases being dealt with by Cheshire-based solicitor Nina Roland.

Another of Miss Roland's clients – featured on the front cover of this *Link* – is Michelle Wise, whose younger daughter Amber, aged eight, has spina bifida and arrested hydrocephlaus. Mrs Wise became convinced Amber's spina bifida was due to taking Epilim during the pregnancy after reading a magazine article six years ago.

Mrs Wise, from Whyteleafe in Surrey, said: "I'd been taking Epilim since I was 13. When I was having my first child, Rochelle, I was a bit worried about taking the tablets, but was told to put my worries to one side. Then, the day before Rochelle was born, the midwife said: 'Of course, you know the baby could have cleft palate and hare lip?' I told her, I didn't."

Luckily, Rochelle, now 10, was born without any problems.

Mrs Wise continued: "So when I was expecting Amber, my second daughter, I was a bit reluctant to take the tablets but the doctor told me not to worry, it was like taking Aspirin. Later on, I asked the doctor again and he told me I could come off the tablets.

"Now my solictor is Nina Roland and, once the doors are open for one case, the rest will follow suit. But there are so many procedures to go through, it could be another two years before there's a result."

● Since our last article on Epilim in the April/May issue of *Link*, we

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Folic acid 'flash' on foods

NEW research from the Health Education Authority (HEA) has found that two-thirds of pregnant and recently pregnant women would like to be able to identify foods with added folic acid.

To help them and women planning pregnancy, the HEA has launched a new folic acid labelling initiative. From May, foods fortified with the B vitamin can carry a 'flash' – a distinctive blue circle around the letter 'F' – on product packaging.

The scheme has the support of major food retailers and manufacturers, including Sainsbury's, Tesco, Asda, Co-op, Kelloggs, Safeway, Allied Bakeries and British Bakeries.

The HEA-approved flash does not mention that folic acid helps

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ASBAH is a registered charity

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

Cover: Michelle and Terry Wise are one of scores of couples taking legal action against health authorities for failing to warn of the alleged risks in taking an anti-convulsant drug during pregnancy. Story, this page.

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

TWO new posts have been filled in Northern Ireland – for a specialist adviser (hydrocephalus) and a user group forum project worker. Both part-time posts won funding for three years from the National Lottery Charities Board.

● HELEN Quinn – the new user-group forum project worker for Northern Ireland – is getting married, moving and beginning a new career within a few months.

Helen, who has spina bifida, looks forward to a new challenge and a new direction after working for 17 years in a bank, followed by a spell in computerised book-keeping in a solicitor's office.

Very independent and mobile herself, Helen says she has always concentrated on the positive and encourages this in others.

"With the new job, I will still be in contact with people and because of my awareness of spina bifida, I can share and help."

It was through her interest in socialising and going out with friends that she met her future husband, Anthony Clarke, a farm worker and gardener.

"I met Anthony over four years ago through a social worker friend when we were in a bar in Dunpatrick. My friend met her husband at the same time and we will be living within a few miles of each other."

Helen, aged 36, sold her home in County Tyrone in April, moving 65 miles to Anthony's semi-detached bungalow in Co Down.

The couple marry on 26 July and will spend the first few days of their honeymoon in 'the romantic hotel of Ireland' in Connemara.

● LORNA Johnston is the new specialist adviser (hydrocephalus) and continues her existing job as part-time specialist adviser (education) for Northern Ireland.

Over the last year and five months, she has discovered much about the learning difficulties of children with hydrocephalus.

Although she had more than 20 years experience in special needs education before she joined ASBAH, Lorna's knowledge in this area has increased since she has been working with families on an individual basis.

"I did know a lot about learning difficulties – both from my own past experience, and from what I learned about hydrocephalus from Leonie Holgate when I joined ASBAH," she said.

"I understand it more now. Children have taught me how 'physical' maths is: if a child is not 'seeing' the environment in the same way we do, how can they be expected to have picked up important ideas about, for example, sizes and angles?

"The trouble is that ideas of number are really picked up from physical activity and, if no-one realises there is a problem with that, then the kids are 'at sea without a paddle'.

"They need to use practical materials for much longer than many schools realise – and not just for counting."

Lorna has introduced some parents to 'Multilink' – plastic cubes that can be joined together on all six faces. With these, the children can at least get some practical mathematical work at home. Some of these children (4-10 year-olds) also had a very weak grip and she has been told that, since they started to use Multilink, their handwriting or colouring has improved. Acquiring skills like this boost the child's self-confidence.

Multilink can also be used for teaching more advanced ideas in maths to teenagers.

As specialist adviser (hydrocephalus), Lorna will also be working with adults in training and employment situations – areas which are new to her.

"I look forward to the challenges this new role brings and being able to build on the work I have already achieved," she said.

Lorna will continue to be based from her home in Portavogie, County Down, tel: 012477-72191.

● GERALDINE Potuszynskyj, part-time adviser for North Yorkshire and Cleveland and medical adviser for the Northern Region, got married in April.

Her new name is Geraldine Binstead. She and her husband Kim spent their honeymoon in the Highlands.

Joan's 20 years

A WOMAN who worked her way up from nursery nurse to manager celebrates 20 years with ASBAH.

Our longest-serving staff member, Joan Pheasant started out working in residential care for Liverpool City Council and Barnardo's. She then spent some time working in a Barnardo's children's home and three months with Liverpool Spina Bifida Association before joining ASBAH in 1977.

Joan was recruited as a care assistant at Five Oaks at a time when a number of strategic and staffing changes were taking place. Five months later she was third in charge and in 1978 became deputy. In 1983 she was appointed head of care and in 1985 manager of Five Oaks – a post which she held until centre closed in 1994.

"Initially, we were dealing with children from 0-20 who were there for respite care. Then we took on a small group of long-stay residents which were children because they were being cared for in hospital and we felt they had a right to a life outside hospital.

"They lived with us and were integrated into the community and went to local schools. One went into mainstream schooling, which was unusual in those days."

Five Oaks continued to offer respite care. During this time, there were 'family' summer holidays for the children living at Five Oaks and local association holiday facilities were used. These were happy times, enabling the children to develop into individuals.

In 1977/8 ASBAH started to run independence training courses for the 16-20 year olds. "This was a new venture in which we were able to develop the ser-vice and widen the age-group over the following years. In 1981, ASBAH was awarded first prize in an International Year of Disabled People competition for this work," Joan recalls.

Another new step was to take older long-stay residents. Many of these were students with hydrocephalus who were not coping at college. Around this time, pioneering studies by Leonie Holgate and Hazel Benner were highlighting the problem of delayed maturity and the specific learning difficulties of people with hydrocephalus.

While Joan was head of care at Five Oaks, former project officer Jim Stanton developed activity holidays. This change reflected a shift in age-range – from 0-20 to 8-25.

At this time, it was decided that children who had been cared for at Five Oaks should move on, and they were successfully found foster families or returned to parents.

Joan said: "One of the joys of working for ASBAH is that it has been able to respond quickly as needs and demands change.

"The independence training courses continued and Five Oaks became a centre for activity holiday, independence training and respite care."

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Joan's 20 years
cont'd from page 5

In the late 1980s work began on the flat complexes Denton View and Wharfedale – to provide extended independence training programmes for youngsters of 18+. This project received a Helios award – presented to Joan and former ASBAH executive director Moyna Gilbertson in Brussels in 1991.

One of the saddest moments in Joan's career came in August 1994 when Five Oaks closed. But this sad event also spawned one of the happiest moments in the shape of the farewell party.

"It was a happy day because a lot of ex-residents and staff came and I was able to catch up with a lot of people," she says.

"We also had weddings, 21st and 18th birthdays and engagements at Five Oaks which were all enjoyable, fun times."

Five Oaks closing hailed the biggest career change for Joan – from managing a care/training centre to the dual role of Northern Region co-ordinator and manager of START – the Service Team for Assessment, Rehabilitation and Training.

"I have been lucky to have been able to develop my own job and provide services to members, which has been a great challenge," she says.

Joan now leads a professional team of four advisers, three specialist advisers and a secretary at temporary offices in Ilkley.

With some staff dividing their time between START and Northern Region, they are working under considerable pressure. Joan's estimate of the number of START assessments which could be completed was more than doubled in the second year. "Last year, we did 11 assessments, many of them requiring in-depth reports for the commissioning authorities."

For START and Northern Region, Joan is also organising courses, including the ground-breaking *Relationships, Sex and You.*

In her spare time, she is doing a diploma course in management studies, which is helping her to make the most of her current dual role. Other interests include her home computer, swimming, entertaining, driving and gardening.

Was there really a ghost at Five Oaks?

Joan says: "I never saw the ghost but I strongly believed it was there. It was a little girl. At one point I had to ban people from talking about it because staff were leaving.

"Things would go missing for a few days or a couple of weeks and then re-appear back in place.

"One of the first signs for me was when a young resident was packing up to go to a foster home. Could we find her favourite doll? Two weeks later I went up to the treatment room to see someone and there the doll was, sitting on the bed.

"Clothes would go missing on the Friday when we were packing cases, and re-appear on the Sunday.

"OK, all these things can be explained – someone could have put them there. What really convinced me was when daughters of two members of staff, who had never met, both told us the same name the ghost had given them.

"There were several years between the sightings and both daughters saw it in the staff quarters. We couldn't remember the name the first daughter had told us, so we had to ring her to find out – it was Anastasia."

Sodium valproate actions, *from page 3*

have been contacted by the Fetal Anti Convulsant Syndrome (FACS) support group. FACS is used to describe a range of 'minor' abnormalities, including wide-bridge nose, low ears, closely packed teeth, high palate, learning difficulties and behavioral problems.

Affiliated to Contact a Family, the support group has about 30 members.

Linda Hamilton, who is the contact for the FACS support group, has a seven-year-old son, Adam, who is affected. She said: "From what I have found out, it seems that women who have been on anti-convulsants for a long time have low levels of Vitamin D and calcium in their bodies which lead to many of these so-called 'minor anomalies.'

"The aim of our group is to give women all the information that is available and then get them to go to their GP. Taking folic acid while trying to conceive can be a big help."

Mrs Hamilton's contact details are: Newton of Brux, Glenkindie, Aberdeenshire AB33 8RX. Tel: 019755-71340.

❍ Another anti-convulsant drug called Lamictal, made by Glaxo Wellcome, has, so far, not been linked to birth malformations.

Glaxo Wellcome has set up a voluntary pregnancy register to find out if Lamictal is having any effect on the babies of women who take it while they are pregnant. The signs, so far, are that the drug has no effect on babies, but more cases are needed before conclusions can be reached .

● ***We will have more on Glaxo Wellcome's pregnancy register for Lamictal in the next issue of Link.***

Continence pad cuts loom on the horizon

ASBAH's campaign to win better continence supplies, treatment and advice for people with severe disabilities is vital – as signs of service cuts appear on the horizon.

Parents of children with spina bifida and hydrocephalus, who generally receive free continence pads from their third birthday, may find in future that they have to wait until their child's fourth or even fifth birthday to benefit from the service.

The number of free pads issued each day may also be held down, even if the actual number required to keep a child clean and dry may be double that issued free.

In a snapshot survey of the continence supplies policies of 31 NHS Trusts, ASBAH has discovered that the minimum age for the supply of free pads was three for most trusts.

But two trusts questioned – Leicester General, and Rockingham Forest and Northants Community – say they already operate a minimum age of four. East Wiltshire Healthcare say they issue pads to children from three and four. South Lincs Healthcare and Lincoln District have gone further down the road. Their continence service does not issue pads until the child's fifth birthday.

Julie Llewelyn, an ASBAH specialist adviser (medical), said: "Most trusts reported a present minimum age for supply of three years but warned that they will have to raise the lower limit to five years of age in time, when it becomes harder for them to balance rising demand against financial restrictions.

"This has worrying implications for our service users, whose neurological condition frequently makes them heavily reliant on continence supplies until – if they have access to a good service – satisfactory continence management can be worked out."

Julie, who with colleague Paula Thompson phoned NHS Trust continence advisers, added: "There's no national set of standards to brandish at trusts who do little to help people with spina bifida and hydrocephalus. Where health authorities or trusts issue supplies, the guidelines say these should be free."

Where pads are issued every day, a limit of four or five being typical. But, when up to10 a day are required (as they can be), the extra must be bought privately.

The policy on re-usable continence supplies (things like bedsheets and absorpent pants) is more confusing. NHS Trusts like Calderdale in Yorkshire, Barking, Havering and Brentwood in Essex and St George's, London, say they issue none. Tyneside, Fosse in Leicestershire and Norwich Community Health Partnership say individual assessment decides

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Help & Advice

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

London, Surrey, Kent, West and East Sussex

ASBAH South East, 123 East Barnet Road, New Barnet, Herts EN4 8RF.
Tel: (0181) 449 0475. Regional Co-ordinator: Jo Francis.

Lincolnshire, Cambridgeshire, Leicestershire, Nottinghamshire, Northamptonshire, Norfolk, Suffolk, Essex, Hertfordshire, Bedfordshire

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

Northern Ireland

ASBAH Northern Ireland, 73 New Row, Coleraine, Northern Ireland
BT52 1EJ. Tel: (01265) 51522 Regional Co-ordinator: Margaret Young.

Northumberland, Durham, Cleveland, North Yorkshire, South Yorkshire, West Yorkshire, Tyne & Wear, Humberside

ASBAH North, Five Oaks, Ben Rhydding Drive, Ilkley, W Yorks LS29 8BD.
Tel (01943) 609468. Regional Co-ordinator: Joan Pheasant NNC.

Rest of England and Wales

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

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.*

Catheterising needs more pads, not less

MY son Simon has spina bifida and hydrocephalus and is doubly incontinent. He uses at least five pads a day. This was cut last year to two pads a day by Southmead Health Authority. Clearly this was totally insufficient as we were trying to regularly catheterise, which meant we were using more, not less pads.

The amount that is being supplied now has been increased to 3.7 per day but again this falls short of what we actually use. We got the increase after I went to see a urology consultant and explained the situation. I had previously spoken with a continence adviser who was unhelpful and said two pads were the maximum number issued per day.

I have had no alternative but to buy our own supplies and, as Simon is 10 years old, I cannot buy any in the shops. I am buying extra pads from Paul Hartmann Ltd and have spent more than £150 on pads to date.

Mrs P Panton
Horfield
Bristol

Continence Supplies

Yes, I want to tell you about my problems in this area.

Name ______________________________

Address ______________________________

____

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Postcode ____________________

Phone number (day-time) ____________________

Best day of the week to contact me ____________________

When completed, please cut out or photocopy this form and send it to:

Mrs Julie Llewelyn,
Services Dept, ASBAH House,
42 Park Road,
Peterborough PE1 2UQ.

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Continence pad cuts, from page 7

who gets what. East Wiltshire Healthcare allow two sheets a year, one free pair of pants and then more at a cut-price; but they say they have a flexible approach, sometimes giving them away free.

ASBAH executive director Andrew Russell commented: "We want parents of children with spina bifida, and adults with the disability, to feel they have a right to the best continence service – and to use ASBAH to advocate that right, if they don't get what they want.

"Keeping as clean and dry as possible is important for health, so we regard continence supplies as an important health service. If 'market forces' in the NHS means forcing people to buy their own supplies, we stand by the principle of free health services for disabled people."

"There is a coupon for readers to fill and and return on this page, if they want to take up particular problems with one of our specialist advisers. Please involve us."

ASBAH is campaigning to secure better continence supplies and treatments for our service users. We aim:

- **▲ To find out what service-users can expect as a 'right' or at least an accepted quality standard of service, equipment and supplies;**
- **▲ To find out more about what's happening to our service-users;**
- **▲ To provide an action guide for users/members, informing people of their reasonable rights and expectations and how to press to have their needs met;**
- **▲ To increase advocacy for service-users in cases of poor service;**
- **▲ To issue ASBAH guidance/information to professionals in order to emphasise good practice;**
- **▲ To lobby government and the NHS to improve consistency and demands.**

Avoiding discord between parents and children over those mobility benefits

THE FRICTION which can arise between parents and children, when the parents are confronted with the situation of losing a good quality family car as the adult child prepares to leave home, was a matter of concern raised at ASBAH's services committee.

The discussion referred to the mobility component of Disability Living Allowance which is given to the young disabled person and is therefore taken with them when they move into their own accommodation.

ASBAH's services committee chairman Austin Crowther knows that discord does arise between parents and their grown-up children. Sometimes the situation escalates into a crisis and is a bar to the young person achieving independence.

Mr Crowther explained: "A lot of our disabled youngsters have their allowances drawn by their parents and the parents have come to rely on that as part of the family income.

"These allowances become tied up in the family budget and that causes friction when the child leaves home.

"Parents must be aware that the monies, which are there when the child is being cared for, are not part of the family income, but part of the care component.

"They must not come to rely on the money as a main part of the family budget. The mobility component is there for the benefit of the disabled young person."

He added: "As parents we must encourage youngsters to take responsibility for their own lives.

"In a lot of instances parents have given up their right to work and come to depend on the child's allowances.

"It is essential that everyone is aware of the situation which could develop and should take early opportunity to discuss this and plan ahead for the time when and if the young person wishes to move to independent accommodation, or to have their own vehicle."

Austin Crowther

TEENAGERS should be vigilant and parents should use their common sense in order to avoid problems over mobility payments, says 26-year-old Tina Gibson from Leicester.

Tina's parents signed the mobility component of Disability Living Allowance over to her as soon as she became 16.

The change from Tina's parents using the money on her behalf, to Tina taking driving lessons and getting her own specially adapted car, was successful because there was give and take on both sides.

Tina says: "I had to have a car when I was 16 to get my driving lessons going. Before that my parents had used the mobility component to help run their own car and pay for taxis to hospital."

Tina added: "Youngsters have got to be very careful about lending out their car. I do lend mine out to my dad occasionally but he doesn't abuse the system. My mum doesn't drive."

"You have also got to bear in mind that your family has done a lot for you and you'll want to repay that, but you've also got to stand your ground and be vigilant."

STAFF NEWS EXTRA ..... STAFF NEWS EXTRA

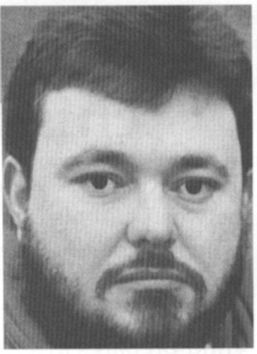
● WE welcome Paul Wootton's return to ASBAH's fundraising team. He now works part-time to support appeals manager Donna Treanor, concentrating on fresh initiatives and seeking to develop and establish further worthwhile links with the corporate sector.

Paul's original career spanned 25 years as a manager with various leasing and corporate finance subsidiaries of the Midland Bank group. Following his retirement, he joined us as business liaison manager when he negotiated and secured the contract with vitamin supplement manufacturer Larkhall which has generated income in excess of £65,000 to date.

He left us at the end of 1994 to undertake a two-year contract as operations director and subsequently chairman of a Peterborough-based publishing group.

Paul, who remained in close touch with us, commented: "I'm delighted to have been invited to help again. The general team spirit, dedication and professionalism throughout ASBAH has always impressed me tremendously and I look forward to doing my best to find some more pound notes, preferable in large bundles, buried among stones we've not yet had the time to explore or look under."

Darke looks at the media



Disability specific television is, by and large, awful. *Link*, the Sunday morning slot on ITV and the BBC's *From* and *Over The Edge* have as much originality and life to them as a dead sheep. At least dead sheep have some use.

I remember Nabil Shaban telling me that he refused to be on the 21st birthday edition of *Link* because, as he saw it, if the programme was still on after 21 years, it had obviously failed to make any significant in-roads in challenging the ghettoisation of disability on television.

I agree with Nabil, but feel the situation to be worse. By having a programme such as *Link*, ITV (and the BBC's Disability Programmes Unit (DPU)) are excused from making inclusive television in any real sense. Why should they make anything different from what they already produce, as they put so much money into disability specific programmes?

I feel not only that disability specific television is detrimental to disability empowerment, but in the manner in which it is facilitated by both the BBC and ITV and, sadly, by Channel 4 (though it is the least guilty of all).

The disability movement needs the blood of democratisation and decentralisation of power if it is to achieve anything of any great significance in the near or long term future.

Yet the DPU is the embodiment of a centralised hierarchy churning out the same, or already used, disability imagery. It is even sadder considering that its three key members were the first people to identify the dangers and errors of creating a disability culture elite. Though I am sure being on £30-40,000 a year would encourage me to remain with the elite. At least *Link* has the excuse that age has made it tired, weary, dull and repetitive.

Equally, if you make 52 programmes a year, repetition is, to some extent, excusable. But, as in the DPU, to let an individual producer(s) make the same fatuous programme repeatedly every season is a tragedy bordering on the farcical.

What is needed – remembering that the DPU has now gone so far down the road of institutionalisation within the BBC to be of any future social use – is a long term commitment to a regular series of differing independent productions, commissioned by the BBC from disabled filmmakers (old and new).

This will not only reduce the burden of the DPU from the licence fee payer, but give a greater opportunity for the creation of a diversity of imagery that covers the entire nation; a diversity that is not Londoncentric.

A commitment to disability made by independents in mainstream series such as *Arena, Omnibus* and *Horizon* (to name but three) would not go amiss. But that's hoping for too much.

Folic acid 'flash' on foods *from page 3*

prevent spina bifida – because the labelling of food products with specific health claims is outlawed in the UK.

The Co-op agreed to carry the flash on relevant brand product, including some bread and breakfast cereals but said the initiative did not go far enough. In a surprise move, it has pledged to continue to state the positive link between folic acid and spina bifida on the packaging, even though this is illegal.

Their spokeswoman said: "The law was designed to prevent people making misleading claims about the supposed health properties of products, but we strongly believe an exception should be made when a health benefit has been proved. The Department of Health has recognised the potential health benefits of folic acid for some time.

She added: "The American Food and Drug Administration has similar legislation governing on-pack medicinal claims, but allows products containing folic acid to state that this can help prevent spina bifida and neural tube defects in unborn babies and we call on the UK Government to adopt the same stance."

ASBAH executive director Andrew Russell commented: "Bureaucratic regulations are preventing the food industry from informing consumers, on the packet, about the benefits of folic acid. The UK should follow the US in adding clear information on packaging. The folic acid research was organised and controlled here in the UK, proving the preventive value, but now other governments show they are more interested in public health than ours and have less obstructive bureaucracies."

HEA research last year found that only three per cent of women aged 16-45 knew that some bread and breakfast cereals carried extra folic acid.

'I'm an addict!' says mum

I HAVE to make a confession. I have become an addict, but I don't want to be cured. I have also made my 12-year-old daughter into a semi addict.

Joanna *(pictured right)* has spina bifida and hydrocephalus so we decided she needed a computer for educational reasons, of course. The problem now is that we decided to subscribe to the Internet and I'm hooked. So any one out there thinking about joining the super highway, what are you waiting for – get out there.

I now have the electronic mailing system E-mail, and have looked at some of the spina bifida links – there are over two million of them.

I subscribed to a parents' mailing list. It's been fantastic. It is parents, mainly in the USA, but also some European, discussing and sharing information.

We access a chat page based in an American hospital where we arrange to chat – all for the price of a local call. I have made new friends and we have a common starting point – our children.

Joanna writes to two girls of her age from the USA with spina bifida and hydrocephalus, not about disability but general girl talk.

There are lots of babies being born in the USA with spina bifida and/or hydrocephalus, and many parents know before the birth and actually use the Internet to find out information to prepare themselves for their child.

I receive about 30-60 letters a day from the parents' mailing list and I may chat a couple of nights a week. Joanna is chatting at weekends to her pen friends.

If you are already on line, why not E-mail me. If you are still not sure, you can contact me through the Bolton and Bury Association – my husband is secretary.

I am sure I can turn you into an addict too.

Eve Clyne
E-mail address:
dclyne@netcomuk.co.uk

Racing chair built to beat the best

AN EX-WHEELCHAIR racer, who now runs a wheelchair supply company, has developed a racing model which he says will compete with the best from the USA.

Barry Norman, who runs GBL Eastern at Papworth Everard in Cambridgeshire, has taken several orders for his chair, *Draft Mistral.*

Mistral is the result of 12 months' research and has been designed by his business partner, Don Chambers, a cycle-frame builder.

Retailing at £1,450, it is nearly £400 cheaper than *Top End* – its USA rival described by Barry as "the Rolls Royce of racing wheelchairs."

Computers and special educational needs

ANY aids which will assist pupils in their learning are to be welcomed. In recent years the development of technological aids has been astounding and none more than the personal and lap-top computer.

The fascination of almost everyone with computers and video games has reached the point of addiction. For pupils with learning difficulties, this can be harnessed to provide stimuli and motivate them, as well as act as an 'aide memoir.'

Many children with spina bifida and/or hydrocephalus experience difficulties in some areas such as reading, spelling, handwriting, sequencing, visual discrimination, memory, motivation and organisational skills. Computers with appropriate programmes can greatly assist learners who are struggling to make progress and provide them with a sense of achievement. Computers can be used to:

- allow each student to work at their own speed on an individualised programme.
- increase the interest of the material to be taught by the use of colour and sound.
- present material in the format of an interactive game.
- provide immediate feedback.
- allow a student to be continuously tested and backtrack if mistakes are made.
- allow material to be repeated over and over again.
- allow material to be personalised by using the student's name.

With good teaching methods, added to the addictive effect that a computer seems to produce, use of computers has the potential to be a very powerful teaching tool. Even for pupils with considerable physical disabilities, computers are adaptable. There are many and various keyboards available.

For further information, contact: Gill Winfield, Information Officer, ASBAH, 42 Park Road, Peterborough PE1 2UQ. Tel: 01733-555988.

SportsTalk

by Marshall Thomas

editor of *Challenge*, the UK's national disability sports paper

David Holding winning the London Wheelchair Marathon

DAVID Holding, Paralympic champion and world record holder at 100m, gave a scintillating display of his awesome power to earn himself an unprecedented fourth Flora/Disability Sport England London Wheelchair Marathon title in mid-April.

The 28-year-old Kettering accountant's victory was something of a repeat performance of his record-breaking triumph in Atlanta last year, as Sweden's Haken Ericsson, the Paralympic 100m silver medalist, was again the man who followed Holding over the finish line.

Holding and Ericsson were part of a group of four athletes with victory in their sights approaching the final turn into The Mall, but Holding's superior sprint finish was the telling factor as he came home in a time of 1hr 42min 15sec, just one second ahead of Ericsson. His time was a new personal best and the second fastest time recorded in the race's 15-year history.

"This is probably the most satisfying of my four wins, because of the way I won it," said Holding, who first wrote his name in the London Wheelchair Marathon history books in 1989 when he became the youngest winner of the race – a distinction he still holds.

"It was a very tactical race, but after Atlanta I knew I had the beating of Hakan in a sprint finish, and that's how it worked out," he added.

Britain and Sweden also dominated the women's race, with Sweden's Monica Wetterstrom denying Tanni Grey her fourth London Marathon victory. Grey finished just over 10 minutes behind the Swede, but despite having to make three short stops during the race for mechanical adjustments, still came home four seconds inside the course record she had set last year.

WHILE David Holding made history in the 1997 London Wheelchair Marathon, Murray Cran has made history north of the border by becoming the first recipient of the Aberdeen Male Disabled Sports Personality of the Year for 1996.

The award, initiated by the Scottish Sports Council, has come in recognition of Murray's achievements in bowls and table tennis, both at which he represents his country. Last year, the 30-year-old from Bucksburn helped secure the Scottish wheelchair doubles table tennis title for Aberdeen and also finished runner-up in the singles.

He has also represented Scotland at the British Sports Association for the Disabled (now Disability Sport England) National Bowls Championships in Scarborough and has ambition to emulate Scottish team mate David Heddle and go on to Paralympic success.

Murray, a purchaser for a furniture company, took up bowls and table tennis at the age of 16 after an injury prevented him from carrying on doing archery, and does not confine his talents to competitions for disabled people. As a member of local table tennis squad Triangle Swifts, Murray recently helped his team to third place in the third division of the 1996/7 Aberdeen and District Table Tennis League.

"I like table tennis because it is a fast game, but with bowls you have to think all the time, although it's much slower," he says. "The thing I like about sport, whether it's bowls or table tennis, is that I get to meet people from all over Scotland and Britain who have the same kind of determination as me."

Britain's No 1 men's wheelchair tennis player Jayant Mistry has risen to his highest ever world ranking of 12 after winning the US Clay Court Championships at Delray Beach, Florida, in April.

To pay, or not to pay?

by Tim Leech
ASBAH specialist adviser (mobility)

LET'S look at the three options available under the new wheelchair voucher scheme.

1. **The standard option** is the same as is being offered at the moment where a person will be assessed and supplied with a wheelchair and maintenance.

2. **The 'partnership' option.** If you would like a different wheelchair, you can choose from a limited NHS range and you pay the difference between the NHS chair, which you have been assessed for, and the chair you want, as long as it meets your clinical needs. This means you are paying for the right to get another chair. As with the standard option, you will have the maintenance and insurance of the chair covered by the NHS, but you will not receive the chair until you have paid the balance. You will not own the chair, so at the end of the contract, the chair is handed back.

3. Under the **'independent option,'** the chair represents the value of the voucher and you are allowed to choose any chair as long as it meets your clinical needs but you have to pay the difference. Again, you may pay up to 90-50% of the price of a chair. Also included in this package is some money to cover the maintenance but that could be as little as £15 a year – not enough to cover a call-out fee, never mind the repair. At the end of the contract time, which could be five years, you own the chair.

It is important to remember that the amount of money you get is represented by the chair you are assessed for. That amount is the price of your chair to the NHS, which could be as little as £150.

With lightweight chairs ranging from £400-£2,000, it could mean that you are paying for the right to have a lightweight, active-user chair which should be part of your clinical needs on the NHS. You do have a choice under the new scheme, but it's the same choice as you've always had. You can buy your own chair if you want to. The only difference is that you can get the value of the chair for which you are assessed plus maintenance by the NHS, or a little money towards maintenance.

Under the partnership option you don't get to keep the chair. Under the independent option you can keep the chair and possibly sell it, but wheelchairs depreciate in price, even more than cars, so you could be left with something for which you paid £1,000+ only being worth £200. To find £1,500 every five years to buy and main-tain a chair is a heavy price.

The moral of this is if you can pay you can get. Unfortunately, people with disabilities tend to be on low incomes and will not be able to pay so they will not be able to get.

ASBAH is launching a campaign to try and improve the quality of service to wheelchair users and to try to ensure that your needs are adequately met.

The first stage of our campaign is to gather information through a questionnaire which I have compiled on the Wheelchair Voucher Scheme. If you would like to air your views about the scheme by completing a questionaire, please write to me, *Tim Leech, Mobility Adviser, ASBAH, 42 Park Road, Peterborough PE1 2UQ.*

One-stop shop for leisure information

INFORMATION on a range of leisure pursuits – from hang-gliding to gardening – is available at centre for people with disabilities near Birmingham.

The Leisure Resource Centre, at Shapland House, Clews Road, Oakenshaw, Redditch, is run by Scope to encourage and advise all disabled children and adults who want to increase their leisure opportunities.

There is information and advice on play opportunities and equipment; sports, games and outdoor activities; creative arts, days out and holidays.

The centre is open Monday to Friday but to attract new visitors, it is having a series of open days:

Thursday 10 July
Tuesday 16 September
Saturday 11 October
Wednesday 12 November
Tuesday 2 December.

Contact Nick Lesley or Lesley Butcher, tel: 01527-550808.

NEW car stickers are on sale which will ask other motorists to give disabled drivers more room in car parks. The stickers cost £2.99 with 25% of the selling price being donated to the Cancer Research Campaign. Send cheques to KAR-Stickers!, 68 Grange Close, Horam, Sussex TN21 0EF.

"Terry was a serious person with a sense of humour and great resilience. He had done a lot in his life, and was keen to give other disabled people a chance to develop their own talents. In spite of considerable disabilities, he had a purposeful energy about him and would speak calmly and with authority, often with a humorous twinkle which meant he'd seen a lot of this before!

"He will be remembered with respect and love by many, many people amongst the members and staff of ASBAH. I know I will miss his support and friendship."

Andrew Russell, executive director, ASBAH.

"Terry brought a wealth of experience not only from his work with people like ASBAH but from his personnel officer days.

"He was always smiling and always pleasant to see when he came into the office. He was someone you could rely on.

"He was always keen on independent living and had been involved in the Disabled Persons Accommodation Agency since it started nearly three year ago."

Leon Jenkins, chief executive of the Disabled Persons Accommodation Agency in Kent.

"He made a valuable contribution to the steering group of aware. He brought personnel skills and support for the worker, which I appreciated.

"Having a disabled man involved on the steering group kept us on track to be a user-led organisation and his influence enabled the organisation to go on from strength to strength. He will be greatly missed."

Lynn Purcell, former development worker for aware.

"Terry was so knowledgeable and sensible and had real vision about what disabled people could do and become.

"He had real insight into how young people could get involved by giving them encouragement, training and confidence, and was committed to carrying forward those ideas. He was a lovely man."

Sue Rickell, freelance disability consultant and trainer, and now chair of aware.

Tributes

Your Voice in ASBAH chairman Terry Den
devoted to improving the lives of others th
range of organisations. Much of his ener
enthusiasm went into giving a voice to ou
users by developing _Your Voice In ASBAH_.
tributes from some of the people who knew,
worked with him.

TERRY Denyer, one of the driving forces behind *Your Voice in ASBAH* and a former executive committee member of ASBAH, died in April.

His premature passing ironically coincides with *YVIA* beginning to achieve the very aims towards which he had been working for many years.

Terry, aged 52, had been unwell for 12 months, but was hoping to attend the next meeting of *YVIA* of which he was chairman. During his absence he had remained very involved from his home in Strood, Kent.

Margaret Twyford first met Terry 29 years ago when they were both taking part in a lecture at Hammersmith Hospital about adults with spina bifida. Margaret is married to Alan Twyford, Terry's newly-appointed successor on *YVIA*.

Margaret was struck by Terry's charm, warmth and generosity of spirit. She and Alan became great friends with Terry.

In an address at Terry's funeral service, Alan said Terry had a no-nonsense determination to get by, which stemmed from his parents. His father, in particular, had encouraged him to be independent.

This resulted in Terry being able to take risks and gain from new experiences, such as leaving home to move into lodgings near a job he had found himself. In the days when he could walk, Terry excelled at Latin American and ballroom dancing, winning bronze medals.

Before retiring four years ago as personnel officer for Camden Borough Council due to ill health, Terry's career spanned eight years as a housing officer
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conferences, are involved in publications and involved in ASBAH executive committee."

Terry supported meetings in the North of England to enlist support for further *Your Voice* groups. These meant him giving up time to prepare talks and to travel to Manchester and beyond.

Two years ago, he led a delegation of *Your Voice* members to a meeting in Belgium of the International Federation for Hydrocephalus and Spina Bifida, and spoke on a topic of mutual interest and importance.

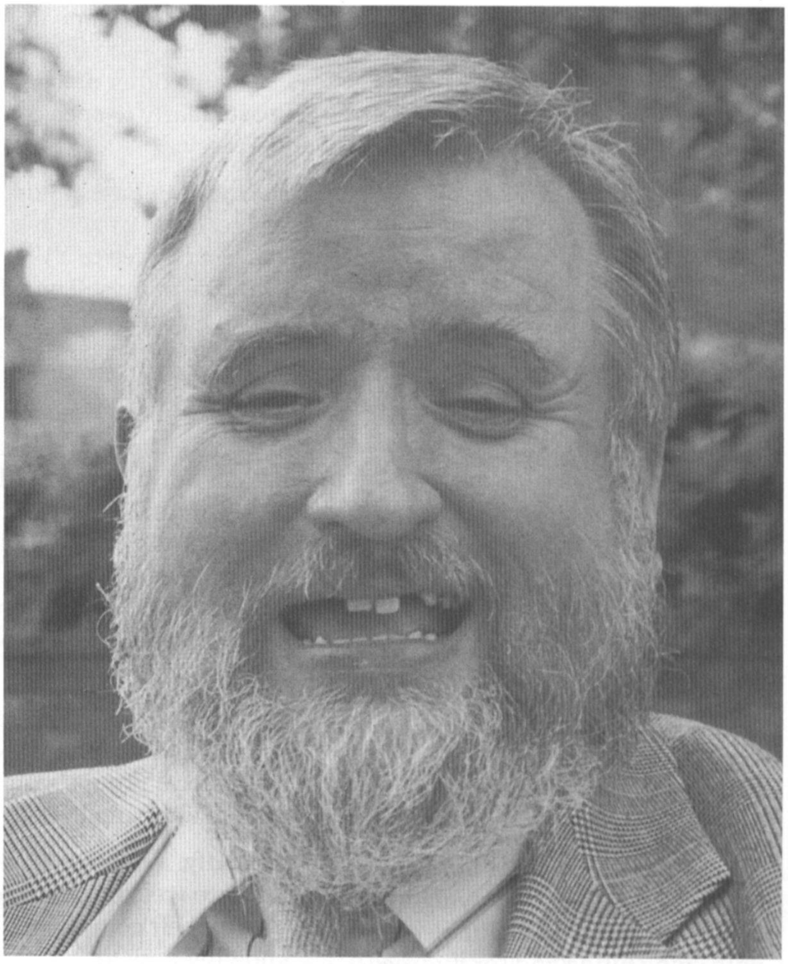
Last year, Terry introduced *YVIA* to trainer Sue Rickell and they invited her to run the *YVIA* training weekends.

He was also involved in a number of other organisations including aware (formerly the National Association of Clothing Workshops), which seeks out manufacturers who make or adapt inexpensive clothing and footwear to give disabled people more choice of better fitting clothes and shoes. He was also vice-chair of Kent's Disabled Persons Accommodation Agency and part of a forum on disability access to hospitals in Kent.

He and his wife Gwen were a great support to each other. Gwen, a former nurse and midwife from South Wales, has had severe kidney problems.

Husband and wife developed an interest in jewellery and model-making. Terry had a passionate interest in the ballet and, if the chance arose, would travel to see live ballet. Before becoming ill, he had started an Open University course and began violin lessons. He also enjoyed driving and reading.

At his funeral, on 14 April, Gwen kindly asked that those wanting to pay tribute to Terry should send donations to ASBAH for use in *YVIA*.



"Terry worked tirelessly in so many different spheres to build on the work of improving the quality of life of disabled people.

"It was a privilege to have known him and counted him among my friends. I hope it is a comfort to Gwen to know that so many people will remember him with great affection.""

Teresa Cole, senior services manager and YVIA liaison officer, ASBAH

"Terry was involved in the very early stages of YVIA and got on with everyone.

"He was very level-headed and took a realistic view of things. He was a very good communicator – very good at putting across his point of view even if he knew not everybody would agree.

"He was good at getting people to talk to each other who wouldn't normally have done, so when I stepped down from being chair of YVIA he was the obvious person to take over."

Jon Burke, former chair of YVIA

Your Voice in ASBAH – building on Terry's success

by Alan Twyford, the new chair of *YVIA*

Regional YVIA meetings

Terry was heavily involved with some regional meetings in Manchester and Leicester, following up contacts ASBAH had with people with spina bifida and/or hydrocephalus who could be involved in *YVIA*. Terry then kept in touch with a small group keen to develop *YVIA* in these areas.

International Federation for Hydrocephalus and Spina Bifida (IFHSB) Conference

In September 1995, Terry led a small delegation from *YVIA* to Belgium and spoke on user empowerment and discussed the problems we encounter in the UK with regard to continence supplies. This attracted international Federation delegates.

Long-Term Medical Condition Alliance (LTMCA)

ASBAH was invited to address the LTMCA annual meeting on 'user involvement' in May 1995, with other speakers. Terry led a quartet which also included Teresa Cole, ASBAH senior services manager, Tracey Proudlock from *YVIA* and myself. We each spoke and it was clear that those present were impressed how much we had achieved. It was some time after the meeting closed that we got away as the other delegates wanted particularly to speak to Terry and Tracey.

Since then, an East London University research project has agreed to pay a small fee to *YVIA* for the attendance of myself and Teresa to speak to a conference on user empowerment – planned in May.

Training

Terry and our previous chair, Jonathan Burke, addressed an ASBAH annual meeting about three years ago on the subject of more disabled people being involved in ASBAH nationally and locally. It was clear there were two distinct situations:

> Firstly, people with spina bifida and/or hydrocephalus wanting to join local groups' committees but not knowing how to;
>
> Secondly, a number of groups ready to welcome disabled members to their committees but not knowing how to.

It was clear that training in committee skills and disability equality were required. Terry, Jonathan and I contacted people or organisations we knew and gradually came up with two disabled disability-equality trainers and a designer of training packs.

A pilot course was held with *YVIA* steering group members in April 1995 in Coventry. From this evolved training courses in Blackpool and Cornwall. The courses have been attended by steering group members and people new to *YVIA*. They have educated us in the disability move-ment, provided discussion on disability issues, and have started us thinking on how *YVIA* should develop best to be of maximum benefit to those with spina bifida and/or hydrocephalus.

The age-group of those trained has extended from 16+ (the minimum practical age for delegates) to over 50 years of age. So you can see the training appeals to all ages.

Terry introduced us to the trainer who has led two of the courses – Sue Rickell – who was born with cerebral palsy and who is chair of the executive committee of awear, formerly the National Association of Clothing Workshops, on which Terry represented *YVIA* for some time.

Terry very much wanted Sue to help us start to do some serious work on forward planning, something she had helped awear to achieve when she was a paid project worker for them first.

Teresa and Terry were able to discuss the idea last year and, following the Cornwall training weekend on 4-6 April 1997, it was agreed that Sue, Teresa and I should meet at our house and start this work. We will eventually have a 3-5 year strategy which will see *YVIA* develop appropriately.

Those trained in the three courses have included individuals from the steering group and others who have referred themselves after seeing articles in *Link* and *Lift*, or whose ASBAH advisers have encouraged them to attend.

Guide to special schools

SPECIAL Schools in Britain is a nationwide guide to special needs schools from primary education through to further education.

The book gives comprehensive details on independent and state special schools. It has a reference section divided into geographical and special needs categories.

Special Schools in Britain 1997/98 is available from June 1997 and costs £8.99. ***To order a copy, telephone 0171-292 3738, or write to Special Schools in Britain, Freepost 39, London W1E 6JZ. Please mark your letter 'ASBAH' and we will receive a donation of £3 from the publishers.***

HYDROCEPHALUS NETWORK NEWS

ASBAH, 42 Park Road, Peterborough PE1 2UQ
Tel: 01733 555988 Fax: 01733 555985
Internet Web Site: http://www.asbah.demon.co.uk/
Registered Charity Number 249338

Summer '97

Incapacity Benefit – an unfair test for fitness for work?

MANY people are having difficulty applying for Incapacity Benefit because the questions on the 20-page application form ask about physical disabilities and not problems which are commonly associated with hydrocephalus.

ASBAH executive committee member Jane Franklin knows of at least two people who worried over their applications because no questions on the form related to their disability.

Questions on the form for Incapacity Benefit ask if the applicant has any difficulties sitting comfortably in a chair, getting up from a chair, standing, walking, bending and kneeling, lifting and carrying, using their hands, seeing, hearing, speaking etc.

Nowhere does it ask if the person has learning difficulties, memory or concentration problems, all of which mean they would find it hard to hold down a full time job.

Some people, like Jane herself, need an afternoon nap or a good rest the day before to be able to perform well.

All these problems affect the employment possibilities for people with hydrocephalus.

Jane, who herself receives Incapacity Benefit but is concerned that it may be withdrawn, said: "It is a worry. A lot of the time I can present myself really well and people think what an earth is wrong with me? It makes our problems difficult for other people to understand."

Even if you go on to have your application backed up by the 'All Work Test' for mental disabilities, it can still be extremely difficult to score enough points to gain Incapacity Benefit if you have hydrocephalus alone.

For example – you only score two points if you cannot answer the telephone and reliably take a message and you only score one point if you cannot concentrate to read a magazine article or follow a radio programme.

Clive Michel, a spokesman for the Benefits Agency, commented: "Incapacity Benefit was brought in for people incapable of work and

continued on page 2

HIGH DEMAND FOR NEW 'ALERT' CARD

HIGH demand for our revised shunt 'alert' card has resulted in almost 1,700 requests for it so far being received. They are being sent out as soon as possible.

The card – which people with hydrocephalus shunts should carry at all times – asks for more details about the type, manufacture and serial number of the shunt, and which surgeon did the operation.

For a new card, send your name, address, phone number and your GP's name and address, together with a SAE, to: Lyn Rylance, ASBAH, 42 Park Road, Peterborough PE1 2UQ. Mark the top left-hand corner of the envelope 'H'.

HYDROCEPHALUS NETWORK NEWS

Contacts

Network Co-ordinator: Rosemary Batchelor 01733-555988.

Education (National): Peter Walker 01733-555988.

Medical (National): Paula Thompson 01733-555988.

Medical/Continence, (National and Eastern Region): Julie Llewelyn 01733-555988.

Medical/Continence (South East Region): Caroline Berkley 0181-449 0475.

Education (North): Mike Dodd 01484-510202.

Occupational Therapist, (Northern Region and START): Rose Hinchliffe 01943-609468.

Medical (North and North West): Geraldine Binstead 01943-609468

Education (Northern Ireland): Lorna Johnston 012477-72191

Medical/Continence, (Northern Ireland): Marie McGonnell 016487-64748.

Hydrocephalus (Northern Ireland): Lorna Johnston 012477-72191

User-group forum project worker (Northern Ireland): Helen Quinn 01265-51522

ASBAH's Honorary Consultant on Hydrocephalus: Dr Roger Bayston M Med Sci MRC Path, contact through ASBAH's Services Dept at ASBAH House.

INTRODUCING NETWORK CO-ORDINATOR ...

Rosemary Batchelor, who rates walking, eating out and going to France for the wine as her main leisure interests.

She started working for ASBAH seven years ago as a counsellor, moving on to become a specialist adviser in hydrocephalus and then, three years ago, co-ordinator of ASBAH's specialist advisers.

Her spare time is centred around socialising with her four grown-up sons (two of them doctors, two of them psychologists) and her partner's grandchildren.

She also helps raise money for her local Grantham & District General Hospital and Rotary charities.

One busy weekend was recently spent helping a friend entertain four young visitors – three of them sisters with severe physical disabilities – from an orphanage in Romania.

Rosemary has a nursing and teaching background. She has taught students with special needs in a college, health and first aid at a grammar school and health education in a prison.

Incapacity Benefit, continued from page 1

the form is a start in giving us information to work out an applicant's entitlement. The form is backed up by the All Work Test. Both are designed to pick out the information we need."

● *A report by the National Association of Citizens Advice Bureaux has found that thousands of sick and disabled people are being refused* **Incapacity Benefit** *because they are failing the All Work Test.*

The report, 'An Unfit Test,' was based on evidence from over 200 Citizens Advice Bureaux across the country and details the problems people face at every stage of making a claim.

Many people told how they found the 20-page questionnaire daunting and difficult. Others related the pain, distress and humiliation caused by the Benefits Agency medical, many of them facing a six month wait for an appeal hearing on reduced benefit.

● RADAR – the Royal Association for Disability and Rehabilitation – is conducting a survey of people who have disagreed with and appealed against a decision that they are capable of work. Further information and copies of a questionnaire are available from Margaret Lavery at RADAR on 0171-250 322.

THE UK SHUNT REGISTRY

By Collette O'Kane
Research Sister/
Project Co-ordinator

THE MOST commonly established treatment for hydrocephalus is the insertion of a cerebrospinal fluid shunt. For the majority of people, a shunt is for life. Unfortunately, most shunts rarely last a lifetime and at one time or another, all or part of their shunt might need replacing; a process known as shunt revision.

There are numerous reasons why a shunt might be revised. No shunt can mimic perfectly what the body does so well under normal circumstances; that is keeping just the right amount of cerebrospinal fluid circulating round the brain at just the right pressure. Shunts can overdrain, underdrain, block, become infected, disconnect or break.

There are many different causes of hydrocephalus, affecting tiny babies to people of advancing years. There are many different types of shunt and many different questions to answer as to why shunts need revising.

If an individual hospital decided to monitor their own shunt operations, with a view to a better understanding of what goes on once a shunt is in place, it would take years and years to accumulate enough information to be meaningful.

However, there are at least 3000 shunt operations performed in the UK per year and it was decided that if some kind of surveillance mechanism could be established on a national basis, then a clearer picture could be built up sooner.

In response, the United Kingdom Shunt Registry was initiated in Cambridge by Professor John Pickard in December 1995 following a short pilot study.

The project has gained the support of the Society of British Neurosurgeons, The British Association of Paediatric Surgeons, The UK Hydrocephalus Group and ASBAH. The Department of Health Medical Devices Agency, has provided the funding and is keen to see all shunt operations registered nationally.

All paediatric and neurosurgical centres performing shunt surgery have been identified and contacted. At the beginning of 1996, the complex process began of visiting every centre to discuss our objectives.

The Registry is gradually beginning to accumulate more and more information about what happens to shunts following insertion.

Every centre has been asked to complete a form giving details of each operation. These details include patient identification, diagnosis, reason for revision and shunt type.

Patient identification is important as we need to keep track of people over the years to see how long their shunts last. Young children and adults in the course of their lifetime, are quite likely to move around the UK, be treated at different hospitals, or move from paediatric to adult care services. All personal information is treated as strictly confidential and is protected by the UK Database Protection Act.

There are now over 4000 operations documented in the Registry, with about 59 centres participating to a greater or lesser degree. Some centres are further on than others in making a contribution. In a recent audit, reporting rates varied between 25 to 100%,

continued on page 4

What's in the June / July Link

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

Relaunch of Disability, Pregnancy and Parenthood magazine

THE magazine *DPPI (Disability, Pregnancy and Parenthood International)* is to be relaunched – after being awarded £180,000 over three years by the National Lottery Charities Board in order to establish a national information service.

Since it was set up four years ago, DPPI has won many plaudits for the information, innovation and inspiration it provides.

On several occasions, it has featured women with spina bifida and hydrocephalus. In issue 158 (mid-1995), ASBAH's *Link* magazine reprinted a major article about childbirth involving mothers who have spina bifida.

Until now, *DPPI* has been run entirely by a small group of home-based parent volunteers. Their new national information service should start by the end of the year. It will employ an information officer and a project administrator, and be based at the headquarters of The Maternity Alliance.

The information service will give *DPPI* the power to respond to enquiries from parents, prospective parents, professionals and disability organisations. It will be a resource centre and have a library of books, articles, audio-visual resources, relevant organisations, equipment designs and have its own Web site on the Internet.

DPPI editor Mukti Jain Campion said: "We cannot do this alone. It is essential to work closely with other information-providing organisations, maternity and social service professionals, and with individuals who have expertise to share.

"Since the Maternity Alliance Disability Working Group (of which ASBAH is a long-standing member) provides an existing forum for networking on these issues and has already played an advisory role to *DPPI* over the past few years, we would like to continue and build on this relationship as well as attracting new members with a commitment to our common aims."

DPPI, 1 Chiswick Staithe,
London W4 3TP.

New national directory of self-help groups

THE G-Text Directory of Self Help Groups contains up-to-date details of more than 400 national self-help and support organisations.

In addition to groups covering medical conditions, such as ASBAH, there are groups who help with mental problems, phobias, financial problems, adoption, victims of accidents, crime, gifted children, children with special needs, etc. The directory is not just a reference source for health care professionals but for every single household.

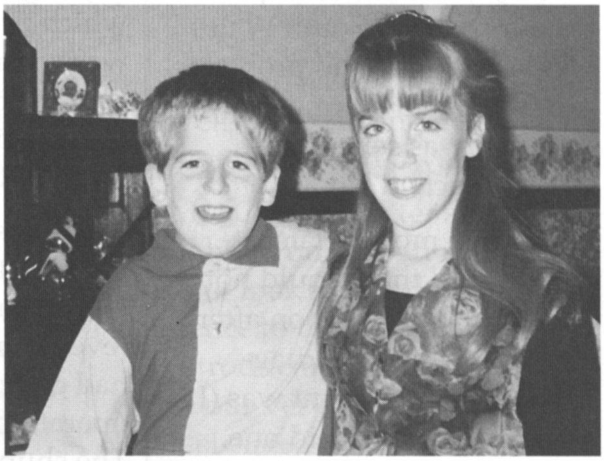
To order, send £5 to: G-Text, PO Box 33, South Shore, Blackpool, FY4 3GB.

THE UK SHUNT REGISTRY *from page 3*

which we hope to improve upon.

We are now in the process of preparing our second annual report to the Department of Health. We feel that in time the Registry has the potential to make a real contribution to the field of shunt technology and that the information that we shall provide will help in the treatment of hydrocephalus. We are most grateful for the encouragement that ASBAH has given us and we would welcome your support too. It is important that as many operations as possible are recorded to ensure that the Registry fulfills its promise. If you or your relative needs a shunt revision in the future, please ask your surgeon to make sure that the operation details are sent to the UK Shunt Registry!

True story



Twins Glenn and Katie Sloane, now 14 years old

by Carol Sloane
Haverhill, West Suffolk

WHEN my twins were around six months old, I began to notice our son was not meeting any of his baby milestones like his twin sister.

Our GP told me not to worry because often girls developed sooner than boys.

When my son's eyes began to turn, our GP said not to worry, he had a narrow bridge above his nose, but his eyes were fine.

When our son's head became a lot bigger than his twin sister's, we were told boys are often smaller than girls till their teens. Again we were told not to worry.

When Glenn failed to walk with Katie, we were told it could be because his twin sister did everything for him. So when our son failed to talk, we felt it was because he was lazy.

When at 18 months he began to walk often falling over and hitting his heavy head, our GP stitched him up.

We lost count of the times we took him to our GP, often upset, always worried. We were told to go home and enjoy him – he was the perfect little boy we had wanted for years. (Our twins were the result of the clomid fertility drug).

At two and a half years he fell out of his bed at around midnight. He was out cold.

We rang our GP, who told us to take him to his surgery. After an examination, he wrote a quick letter and told us to get him to hospital.

On handing the letter to the nurse, we were shown to a cubicle where we were asked many questions.We were treated very nastily.

X-rays were carried out. I asked to see them, but was refused. However, after the x-rays had been looked at by loads of doctors and nurses, we were offered tea, coffee, toast, even a bed for the night.

A few hours later a neurosurgeon and other doctors came to speak to me. They did not confuse me with medical words like hydrocephalus. I was told my son had water on the brain, and was an extremely sick child.

My son was in a coma by this time and needed to be operated on if he was to stand a chance.

This was 12 years ago. Today our son is 14 and a half years old. We never took legal action against our old GP. However, I did write to him, explaining our disappointment in his lack of ability to listen to us.

Even if he felt our son was a healthy child, he should have sent us to a paediatric doctor for a second opinion.

To this day our son is slow to learn. However, he is happy, friendly, caring and loving.

Four shunt operations on, we regret not asking for another doctor's advice. Our son was diagnosed as suffering from gross congenital hydrocephalus at the age of 2 and a half years.

So parents, don't be afraid to ask or question, and ask again if you fail to agree or understand.

If you have a true story you would like to tell other members of the Hydrocephalus Network, send it to:
Rosemary Batchelor, Co-ordinator, Specialist Advisers, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

Letter from 'down under'

WHEN I was born on 2 October 1956 at Camden Hospital in country New South Wales I was seen to have no problems except being a bit underweight. I was sent home when I reached 6lb.

About five months later it was noticed that I could not hold my head up. Soon after, hydrocephalus was diagnosed. The first shunt was (I think) a subarachnoid one, although a 'flare up' in 1980 resulted in me having two VP shunt in just over two years.

This flare up was a mystery to all concerned. A social worker with the then NSW Society for Crippled Children tried to convince me to get an opinion. Apart from three very heavy colds as well as a lot of behaviour disorders and joint pains, I felt OK.

In May 1980 I had been under a rheumatologist for several months because arthritis had been suspected the year before. Fortunately, he found no trace of this condition but sent me for blood tests and skull X-rays. These found my prolactin level to be abnormally high. My pituitary gland which produces prolactin, was slightly overactive. He said the reason for this was that the original shunt was right on this gland.

I told this doctor during the May visit that I had been feeling unwell for some time (even though other doctors had convinced us that a shunt operation is a one-off thing). The shunt seemed to be making noises, like I could feel the CSF circulating. This problem worsened when I got upset, overloaded or hungry, the third situation remaining today.

At my request, the doctor (who practised in Macquarie Street, the 'medical street' in Sydney) sent me to a neurosurgeon, at Royal Prince Alfred Hospital, where I still go. I was monitored eventually by a third neurosurgeon who is my current doctor, and a week later had the first VP shunt.

In 1983 after much discussion I had a new shunt. To be honest, I am amazed it lasted so well. A lot of illness followed including glandular fever and chronic bowel inflammation. Because of the bowel situation I may eventually be given a VA shunt. I am not worried about this because the neurosurgeon has explained things well to me.

If I hadn't (for some reason) become more assertive about things, I am sure I would have been a lot sicker. I have the chronic form of hydrocephalus which can take up to two years to develop in me.

I am interested in education and at last was able to continue with the Certificate in General Education, which so far has been quite easy.

Both doctors I saw in 1980 have since died but without them I may not even be here, or at least been as well as I have been. It is due to their support that I set up a group here in Australia for people with hydrocephalus. A lot of new people attended our recent AGM (we are spread throughout Australia and New Zealand).

If people wish to contact me (or join) they can. The group is for people who have hydrocephalus (with or without spina bifida).

I hope to hear from people, if possible.

Penelope Wilkinson
13 Hosking Crescent
Glenfield
New South Wales 2167
Australia

PS If anyone has absolute pitch (like I do) I would also like to hear from you.

WE always like to hear of people's success stories.

Perhaps you have done well in school sports or exams, or been on an adventure holiday.

If you have done something you thought you'd never do, why don't you let us know about it?

Write to: Mrs Rosemary Batchelor, Co-ordinator, Specialist Advisers, ASBAH, 42 Park Road, Peterborough, PE1 2UQ.

HN NEWS letters

I FELT compelled to write after reading the letter from Baljeet Ghavri published in the Spring *HN News*.

Four years ago, two weeks after the birth of my son Harry, I had severe headaches which became dramatically worse and I was eventually admitted into hospital.

On the first scan they could find no signs of a tumour but when I had the final scan, at another hospital, it was discovered there was a narrowing at the back of my neck (the aqueduct) which is believed to be congenital.

I had had headaches all my life, but the extra fluid in my body during pregnancy and labour had exacerbated the problem, and the fluid in my brain was not able to drain away quickly enough.

I have had my shunt replaced once, due to blockage. Although I feel much better for having a shunt, I have suffered certain 'side effects' from the original operation and follow up in July 1996. My short-term memory has been affected and I have become absent-minded. Consequently, I have been unable to go back to my job.

Due to the anxiety and uncertainty that I have been left with, and the family pressures, my husband and I agreed it would be safer, for all our sakes, for us ***not*** to have any more children – not knowing how pregnancy could affect my health and well-being during the nine months and afterwards.

Mrs Ghavri's letter shed new light on our situation. We now look forward with confidence to the possibility of introducing a brother or sister to our very precious son and feel elated by this new turn of events.

Thank you *Link* and *HN News* for always being there with vital advice and information.

Tracey Bourne
Brighton

Mum's poem for her little 'miracle'

A MOTHER in Wales was moved to write a poem after her little girl survived a fall two years ago.

Jan Highton's daughter was born with a Dandy Walker cyst. Doctors told Jan that they did not expect Michelle to be able to see, walk or talk. Michelle proved them wrong on all counts, learning to walk when she was five years old.

In 1995, Michelle fell down some stairs, stopped breathing and turned blue. She was rushed to hospital and put in intensive care as she was having breathing difficulties and fits.

Miraculously, Michelle got better and is fine now except occasionally when she turns round quickly and goes wobbly. She is now eight years old.

Her mum Jan, of Llandudno Junction, Gwynedd, said: "I don't know where the poem came from. I wrote it the day Michelle came home from hospital. I sat there and it all came out. It had been a very frightening time for us – we didn't think she'd recover."

ASBAH adviser Elin Richards added: "I think the poem expresses some of the discrimination disabled people feel."

Extracts from:
Michelle, My Special Girl

Your reactions are normal,
They're what I expect,
What I can't understand,
Is the lack of respect.

A head such as hers,
Is unusual, God knows,
But must your reaction be
So deliberate it shows.

Her will is so strong,
But you'll never know
All the suffering she's been through,
She'll never show.

Please, no more suffering,
Please, no more pain.
I don't understand,
What does it gain?

Please give her a life now,
We'd all like to live,
A life full of love,
For she has so much to give.

True story

by Sarah Williams, from Billingford, Diss, Norfolk

I HAD a positive pregnancy test in April 1996. Rob, my partner, and I were really happy.

A few weeks after my results, I started to get headaches and vomiting. I put this down to 'morning sickness' and was told it would subside by the time I was 12 weeks pregnant.

At 12 weeks, I was still being sick and the headaches were just as bad. The doctor told me the headaches were 'vascular' and would be over by the time I was 16 weeks. At 16 weeks the headaches had become so bad that getting out of bed was agony, making me vomit with pain. The doctors assured me the headaches were due to my pregnancy and were 'vascular.'

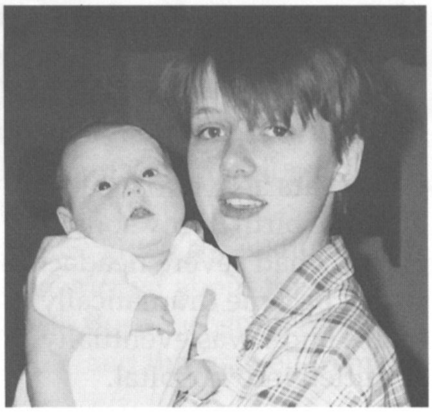
At 20 weeks I was referred to a neurologist and I thought I was finally being taken seriously. After various tests, the neurologist told me the headaches were 'vascular.'

By now, I was very disheartened as I knew in myself that there was something amiss.

The headaches and vomiting got worse. By now, I was taking up to eight Paracetamol a day (under doctor's orders!).

At 28 weeks of pregnancy, the headaches became so bad that I started to black out and I couldn't bear the light. Rob called the doctor who referred me to the same neurologist. He still insisted it was 'vascular' and advised that Codine might be more effective than Paracetamol. I was offered a scan, although it was felt not to be necessary.

I said I would like a scan if only to put my mind at rest. I had a scan the next day, but felt so ill I could only bear it for 10-15 minutes.



Sarah (aged 25) and Rosie

I was admitted for 24 hour observation and went to the ward. After 30 minutes the neurologist appeared and what he told me completely changed my life.

The 'vascular' headaches were, in fact, a brain tumour which was stopping the fluid circulating in my head. I was taken to Addenbrookes and the next day had a shunt fitted. The change was dramatic. For the first time in six months I was headache-free and it felt really good.

Five days later I had the tumour removed and five days after that, I was home. Finally, after all that, I was able to enjoy my pregnancy.

I cannot say enough for the neurosurgeons and staff at Addenbrookes. They show so much care and offer the support which is much needed.

On 14 January 1997, I had a beautiful little girl who we named Rosie. She went through two major ops and really was born against all odds.

I feel very bitter that doctors dismiss the symptoms of hydrocephalus so readily, and people are left to suffer for so long before receiving the treatment which they both deserve and need.

I WOULD like to take out an annual subscription – four issues a year – of 'HN News.' Annual subscription rates: £2 (UK); £5 European and overseas surface mail; £10 by airmail.

Service user's name ______________________

Parent's name (IF APPLICABLE) ______________________

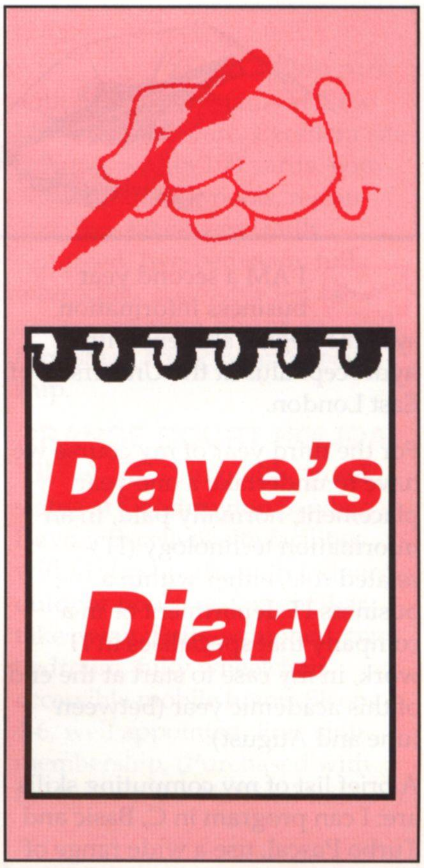
Address ______________________

____

Postcode ______________ **Tel:** ______________

I enclose a cheque/postal order payable to 'ASBAH.'
All payments should be made in Sterling.

Please cut out or photocopy completed forms and send to:
Lynn Thomas, ASBAH, 42 Park Road, Peterborough PE1 2UQ.



Dave's Diary

IN previous 'diaries' I have tried to promote new activities for readers, such as my suggest-ion to abandon sports in favour of a variety of hobbies.

Recently, my conscience/family (same thing really) has been pricking. "What," it asks me, "is *your* hobby, big mouth?" I splutter things like writing, reading, going to the cinema and watching telly.

"Not good enough fat boy," my conscience replies. "The first is a job and the others don't produce anything. Get a life – get a hobby!"

In my defence I must say I've had hobbies before. For a time I was seriously into wine making. But, as everyone eventually discovers, it is a heck of a long wait to produce something you'd rather clean a drain with than drink at a party! I suspect my new hobby will take just as long to bear fruit.

Inspired by the move into a new home and the late Geoff Hamilton, I have decided to take up gardening. I initially saw gardening as an activity for old fogies, or as something disabled people are expected to do for the good of their health, souls, and to make them closer to nature. Why anyone expects me to be 'as one' with nature I don't know. My existence is the result of technological achievements. If it had been left to good old Mother Nature, the only gardening I'd be doing is pushing up the daisies!

It isn't daisies I'll be growing. My interest in gardening is more basic – food! Growing my own fruit and veg should (I hope) save me a bundle on what I pay down the local supermarket, especially for exotic stuff like melons, though I'm told you need all sorts of equipment for serious gardening. It starts off with knee-supports for long kneeling sessions talking to the spuds. Eventually you advance to a range of wonderfully ferocious and lethal devices including strimmers, hedge trimmers and the like. The sight of me staggering around with an active chainsaw would unnerve the hardiest soul!

There is one device which I particularly want to get my hands on, as I am developing a certain need for it. It's a huge tub-thing into which you can put small trees. With a considerable amount of noise, this device turns said item into a mound of shavings. The next person who makes me rush out of the shower to answer the door, only to hear about the glories of spiritual salvation, is going to be introduced to the business end of that tree chopper! I am sure such people act from the goodness of their heart and I have a great respect for their relationship with their god. I just wish they had the same respect for my relationship (and my privacy)!

I am tired of being preyed upon by people who feel that being disabled I am in need of their pity, salvation or redemption. I remember one woman followed me down the street demanding I kneel and pray for forgiveness of my sins. As I was just nipping out from work to buy a chicken sandwich, I thought I was on fairly safe ground sin-wise! Good thing she didn't catch me when I was having some *fun*!

David Fulford-Brown

Practical gardening guide

A PRACTICAL guide to garden tools, equipment and design for older people and people with disabilities has been published by the Disabled Living Foundation.

A Garden For You provides well researched information for people who are interested in gardening but who may find well designed tools or special techniques helpful.

In addition to outlining traditional tools and methods, the illustrated guide describes the alternatives that can make activities such as planting, weeding and pruning easier and more enjoyable.

Addresses of suppliers and useful organisations that can provide further information and advice are also listed.

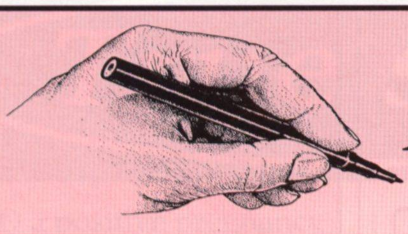
A Garden For You is available from DLF, 380-384 Harrow Road, London W9 2HU and costs £5.95 including p&p.

A cool summer holiday!

TOURS around the cold but very beautiful country which spawned pop singer Bjork are available this summer.

Iceland tourism company Ferdafelagar specialises in sightseeing holidays for disabled people. You can book individually or as a group and prices are £1,519 per person.

Leaflets and booking forms from: Sveinn Gustavsson, general manager, Ferdafelagar, Reynigrund 65, 200 Kopavogur, Iceland. Tel: (354) 564-4091. Fax: (0354) 564-4092.



Letters

I AM a second year business information systems degree student with hydrocephalus at the University of East London.

For the third year of my course we have to undertake a one-year placement, normally paid, in an information technology (IT)-related role, either within a business IT department or in a company that specialises in IT work, in my case to start at the end of this academic year (between June and August).

A brief list of my computing skills are: I can program in C, Basic and Turbo Pascal, use a wide range of applications including Microsoft Office, Lotus SmartSuite and Borland Paradox for Windows. I can use MS-DOX, Windows 3.1x, Windows 95, Windows NT Workstation 4, Macintosh System 7.1 and UNIX (SunOS and Linux).

I have a thorough knowledge of PC hardware including knowledge of how to install, remove and configure peripherals and other components such as RAM, hard disks, expansion cards, CD-ROM drives and printers.

If anybody can help, please contact me at the address below, E-mail on bar4994n@uel.ac.uk or by phone or fax on 01708-224634.

John Barnett
20 Lime Avenue
Upminster
Essex RM14 2HY

Send your letters to:
Link Editor, ASBAH,
42 Park Road, Peterborough
PE1 2UQ.

I WONDER how many people have always wanted to visit Areas of Outstanding National Beauty but have always found it impossible due to access problems?

A new easy-going trail has opened at the Charterhouse Centre on the Mendip Hills near Cheddar in Somerset. It has been designed so that everybody can enjoy the peacefulness and the scenery of the hills. There is a powered chair and a scooter which can be hired from the centre manager on 01761-462267 (prior notice is needed to ensure a wheelchair is available).

The Charterehouse Centrte also has 'owl prowls' which I found very enjoyable. There are bird boxes close to the trail, so you can see the birds flying in and out. Not only is the trail accessible to people in wheelchairs and parents with pushchairs, but it is accessible to the hard of hearing and people with sight impairments.

I thoroughly recommend a visit. For more information, ring the above phone number.

Ian McArdle
Rooksbridge, Somerset.

DATES FOR YOUR DIARY

27-29 June

ASBAH North Wales residential training weekend, for young people aged 14 -18 with spina bifida and / or hydrocephalus, Plas Menai, The National Watersports Centre, Caernarfon, Gwynedd. *Inquiries to START (Joan, Rose or Anna), tel: 01943-609468.*

2-5 July

Annual Scientific Meeting, Research Society for Hydrocephalus and Spina Bifida, Manchester.

11-13 July

1997 Mobility Roadshow, organised by the Dept of Transport at the Transport Research Laboratory at Crowthorne, Berkshire. *Tel: 0171-271 5252.*

Monday 14 July

ASBAH support group, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. *Valerie Bottoms, tel: 01582-605749.*

Monday 14 July

Disability Equality Training Course, advanced course led by Barbara Lisicki, Greater London Association of Disabled People, 9.30am-5pm, at 336 Brixton Road, London SW9 7AA. *Brenda Ellis, tel: 0171 346 5805.*

26 July - 2 August

'Share Music' courses at two venues: Crabhill House, Redhill, Surrey and Calvert Trust Centre, Keswick. Encouraging young disabled people to take part in musical activities, in company with other musicians and guided by tutors skilled at working with people with special needs. Other dates and venues arranged. *Brochure from: Dr M Swallow, 15 Deramore Drive, Belfast BT9 5JQ, tel/fax: 01232-669042.*

FOR SALE

SYMMETRIKIT chair with tray, suitable for child between 2 and 7. Good condition, washable blue dralon covers and spare arm covers. £400 ono. Wakefield 01924-374936.

QUICKIE HP2 folding, quick-release wheels, 14-inch frame. Metallic purple. VG condition. £500. Tel: 01630-655709.

BOOSTER town and country Tetra scooter, in excellent condition. Complete with all-over cover to protect from rain, wing mirror, spanners and shopping basket. £1,100 ono. Mrs M Conroy, tel: 01643-377460 (Gillingham, Kent).

HOLIDAY ACCOMMODATION

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

DERBYSHIRE DALES – Large family en-suite room with wheelchair access throughout. TV and tea/coffee making facilities. Sleeps 5/6 comfortably. Full English breakfast to set you up for the day. Friendly, personal attention. Peaceful country surroundings. Fantastic views. Ideal base for touring. Carriage driving instruction available for disabled drivers with specially adapted vehicles to take a wheelchair. Or just relax and indulge in the atmosphere of a busy working stables. *Red House Stables, Darley Dale, Matlock, Derbyshire DE4 2ER. Tel: 01629-733583.*

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 entertainmernt, heated swimming pool, free site bus service. Nature reserves and places of interest nearby. *Details from Mrs B Nunn, tel: 01903-763473.*

ISLE OF WIGHT ASBAH – Fully-equipped two-bedroom holiday bungalow, sleeps six plus cot. Clubhouse, indoor heated pool, shop etc. Site overlooks sea. Own transport advisable. *Details: Mrs P Burden, 36 Sherbourne Avenue, Binstead, Ryde, IOW, PO33 3PX, tel: 01983-564604.*

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: Margaret Humphreys, tel: 01494-714270 (Bucks & E Berks ASBAH).*

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: 01621-785899.*

ROMNEY SANDS, KENT – Two-bedroom holiday chalet, sleeps six, fully equipped, wheelchair accessible. Full club facilities, heated pool etc. Across road from sandy beach. *For details, contact Fran Chapman, tel: 01797-367342.*

NAISH HOLIDAY VILLAGE, NEW MILTON – Clifftop park with "excellent" status at New Milton, Hampshire. Excellent site facilities within 100 yards, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible log cabin accommodation. Sleeps six, well-furnished. Free club membership.

GRANGE COURT HOLIDAY VILLAGE – Park with "good" status at Goodrington Sands, Devon. Excellent site facilities within short walk, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible mobile home. Sleeps 4-6, well appointed. Free club membership. (Purchased with funds from the National Lottery).

MILLENDREATH HOLIDAY VILLAGE – Excellent seaside site with good facilities, just outside Looe in Cornwall. Restaurant, clubhouse, indoor pool. Fully-equipped, and fully wheelchair accessible, two-bedroom chalet accommodation. Sleeps six – well-furnished and comfortable. Free club membership.

Details: Mr P Cash, tel: 01425-672055 – Bournemouth Spina Bifida Association, registered charity number 261914.

LINK Rates

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

Small adverts for the next issue of *LINK* (August) should be submitted by Friday, 30 June. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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