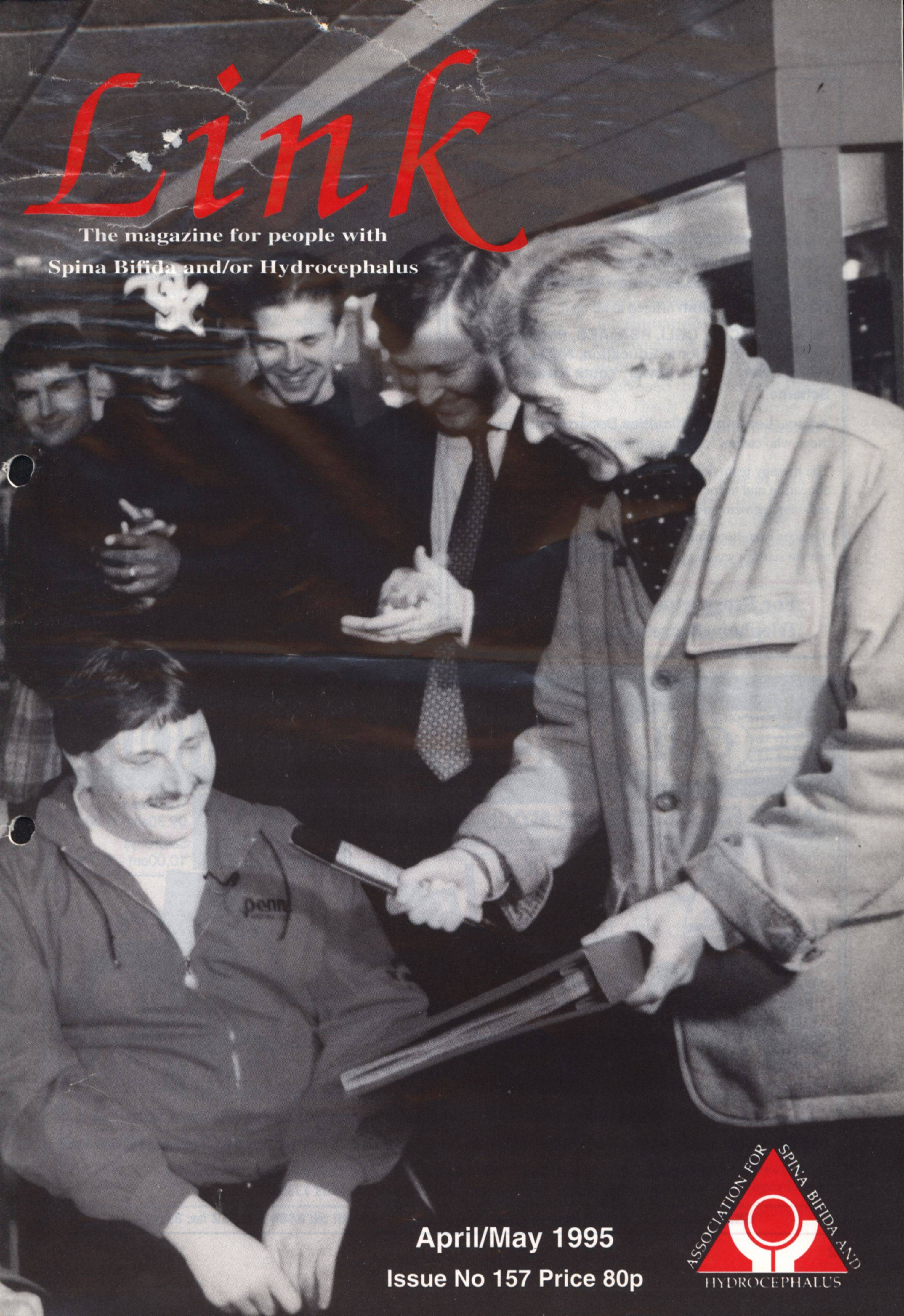
Link

The magazine for people with
Spina Bifida and/or Hydrocephalus



April/May 1995
Issue No 157 Price 80p

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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Comment

AT LAST the Government has put its money where its mouth is on the issue of spreading awareness about folic acid by pledging to spend £2.3 million over three years on an information campaign.

This cash commitment by the Department of Health formally recognises how important it is that all women know that folic acid can help to prevent spina bifida in unborn babies.

This awareness campaign is likely to be launched in the autumn. ASBAH will use every opportunity offered by it - and by collaboration with firms like Larkhall Natural Health - to widen public awareness of the importance of our role in society.

See page four of this issue of *Link* for more details.

THE GOVERNMENT'S decision to mount a three-year folic acid campaign could make 1995 a very good year to start the final drive towards the eventual eradication of spina bifida, at least in the UK - well, let's hope so!

This year has already seen the setting up of the Folic Acid Helpline which received more than 260 calls in its first eight days of operation.

The helpline - 0181-994 9874 - has been so successful that its sponsors English Grains Healthcare and operators the Medical Advisory Service have decided to extend the service for another seven months, until December.

This issue of *Link* carries a full report on page seven.

PREVENTION of spina bifida in births is, of course, paramount. But for those who have spina bifida (and/or hydrocephalus) life can be pretty good. Take a look at the achievements of Ray Gainer, featured on the front cover and on pages 12-14 of this issue of *Link*.

In spite of setbacks due to his spina bifida, he has done things which some able-bodied people would be reluctant to try. His determination, courage and enthusiasm to achieve against all odds, and to help others, impressed the makers of BBC TV's *This Is Your Life* programme, and are an inspiration to us all.

IN FACT, this issue of *Link* is full of achievers. Turn to page eight for a report on three children who have earned the McDonald's Child of Achievement Award this year.

And in *HN News* we feature three young people in their twenties, who through determination and positive thinking, together with support from family and friends, are getting much more out of life.

Liz Cawthorne
Editor

Contents

ASBAH is a registered charity

Cover: That Magic Moment! Ray Gainer is caught unawares by This Is Your Life presenter Michael Aspel. See pages 12-14

Battle of the Bills

THE REVIVED Civil Rights (Disabled Persons) Bill, sponsored by Labour MP Harry Barnes, passed its second reading on 10 February.

However, it is not expected the Private Member's Bill will be given the necessary parliamentary time to become law.

Meanwhile, the Government's own Disability Discrimination Bill has a head start on the Barnes Bill, having almost completed its Committee Stage.

Membership

INDIVIDUAL ASBAH membership - receive publications and voting rights at Council meetings. £17.50 a year (waived if you are on benefit). Application form: The Company Secretary, ASBAH, 42 Park Road, Peterborough, PE1 2UQ.

£2.3m folic acid campaign on the cards this year

THE DEPARTMENT of Health is expected to launch its long-awaited, major health information campaign on folic acid later this year.

Sources in the Department of Health have indicated that a three-year folic acid information programme, costing a total of £2.3 million, will start this autumn.

No details have yet been confirmed as to how the Government will ensure that all women will hear about and remember the important part that folic acid plays in helping to prevent spina bifida in pregnancy.

ASBAH hopes the Department will not repeat its mistake of November 1993 - when the first attempt at a campaign was confined to a few leaflets and posters issued to doctors' surgeries.

"This campaign will be a very real opportunity to dramatically cut the number of spina bifida pregnancies. The opportunity will be lost if the Department of Health follows the same route again," said ASBAH executive director Andrew Russell, who has been involved in meetings at both ministerial and official level at the Department of Health. ASBAH is working on the issue with Prof Nicholas Wald, of the Wolfson Institute of Preventive Medicine, and has agreed a policy statement with theWolfson.

"The campaign must be aimed beyond the doctor's surgery, where women still tend to go to have their pregnancies confirmed. The Department of Health should also seriously consider ways of increasing women's perceptions of the level of risk to their unborn babies from spina bifida, within the framework of a general decline in incidence.

"Spina bifida can still affect pregnancies anywhere, at any time, and in any place. Women must be infomed about the best means of helping to protect their babies."

The Department of Health is planning to launch its revamped campaign this spring but it has been delayed by moves within the Department to put the project out to tender.

"We have a sinking feeling that the Department are less concerned with the content and delivery of the message than privatising it. Let's hope we are wrong," added Mr Russell.

■ ASBAH has joined with the Wolfson Institute of Preventive Medicine at St Bartholomew's Hospital, London, to seek the compulsory fortification of flour with folic acid in order to help eradicate neural tube defects.

This measure, which would require Government action, would ensure higher folic acid consumption by the general population and help provide protection for women who have unplanned pregnancies.

Leadership change for *Your Voice*

EXPERIENCED local association member Terry Denyer has taken over the reins of *Your Voice In ASBAH (YVIA)*.

He replaces Jonathon Burke, who stepped down due to pressures of work after being the chairman of the *Your Voice* group since its formation three years ago.

Terry, who over the years has been active in Surrey, South Wales and Kent, is keen to see more people with spina bifida and/or hydrocephalus get involved in their local association.

This way, he says, there will be more people taking an interest in local issues which in turn could develop into an interest in the national ASBAH scene.

Terry, from Rochester in Kent, said: "We want to get people involved locally so they can start thinking nationally."

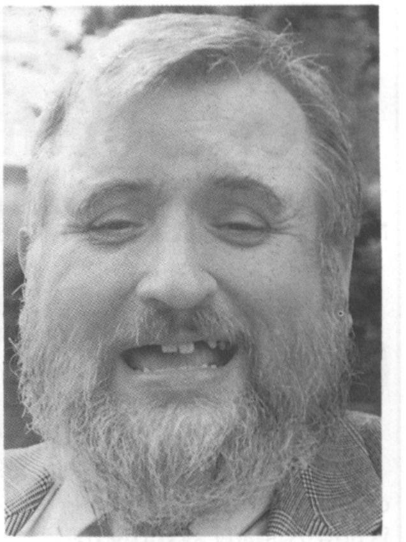
This will be helped by a £5,000 Government grant to be spent over three years on developing regional forums for people with disabilities.

Decisions are still to be made on how the money will be spent but one option will be training.

Terry, aged 50, said: "We've got some ideas for training and are looking into possibilities of dates, subjects and costings - so that other people with spina bifida and hydrocephalus become more confident and assertive, and take part in national and local activities."

Although now retired, Terry has been a housing officer, social worker and personnel officer.

Being a union shop steward in local government, a member of ASBAH national executive and winning medals for Latin American and ballroom dancing in the days when he could walk, are ranked among hiss other varied past achievements.



Terry Denyer, the new chairman of Your Voice in ASBAH.

Jonathon Burke, from Huddersfield, will continue to take an active role in *YVIA*, but working on specific projects rather than the day-to-day running of the group.

He said: "I think the activities of *YVIA* have grown in importance as far as the association as a whole is concerned.

"There has been an increase in the number of our members on the National Executive and much of the groundwork has been done.

I'm happy to be handing over to Terry Denyer (chairman) and Alan Twyford (vice chairman)."

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Two new fieldworkers for Northern Ireland

TWO fieldwork vacancies in Northern Ireland have been filled.

Rosemary Whalley, (*pictured left*), has 170 clients in Belfast, North Down and Ards Peninsula - an area previously covered by Margaret Young who is now ASBAH's Northern Ireland regional co-ordinator.

For eight years Mrs Whalley, 42, worked for UK charity, The Buttle Trust, as its regional secretary in Northern Ireland. The trust gives grants to individual children in certain categories of need.

She has also worked as information officer for Disability Action - previously the Northern Ireland Council for the Handicapped.

Of her new full-time appointment at ASBAH, Mrs Whalley said: "It brings together old interests and the previous work I was doing was quite administrative. I am interested in working with families again."

Marian Doherty, (*pictured left*), takes on 70 clients in North Antrim on a part-time basis.

Mrs Doherty, 40, had previously worked for four years with terminally ill people as a staff nurse for Marie Curie Community Nursing.

She has also been a marriage guidance counsellor for 12 years.

During her training in Belfast's Royal Victoria Hospital's neurosurgical unit, she worked with people with spina bifida and hydrocephalus.

Being able to combine her nursing and counselling skills was the main attraction of the ASBAH fieldwork job.

She said: "I have been spending time with dying people and I now want to help people to live rather than die.

"I haye experience of working with people with difficulties and feel I have something to offer them."

Fi dwork eplacements

ASBAH fieldwork vacancies in Sussex and in Leicestershire/Northamptonshire are being filled.

The Sussex post, formerly held by Val Hardy, is 25% funded by Sussex ASBAH.

The Leics/Northants post - formerly Pat Waller's - is funded with a contribution from Leicestershire ASBAH and by money raised by a local donor, who was sponsored to climb Mount Kilimunjaro in East Africa.

Disaffiliation

BY DECISION of the Executive Committee of ASBAH on 17 January 1995, Essex ASBAH will be disaffiliated as from 1 April 1995.

ASBAH's fieldworker Barbara Dawes will no longer be employed in Essex.

Thanks were recorded to Mrs Dawes at the meeting, recognising her excellent work, and members were pleased that she had agreed to become fieldworker in neighbouring Suffolk, where her knowledge and expertise will continue to serve the Association and all those with spina bifida and/or hydrocephalus.

Wendy Rattray to retire

ALTHOUGH Wendy Rattray enjoys good wine, she won't be raising her glass when she retires as fieldworker for Devon.

At 62, she says she will miss her part-time job with ASBAH even though she will have more time to pursue the hobbies she has never had much time for - such as spinning, dyeing her own wool and designing children's knitwear.

One of her most humorous memories came right at the start of her ASBAH career during a trip to London for training with Cornwall fieldworker Lynne Young.

The pair had never met before but soon discovered a common interest - they both enjoyed a glass of wine.

When they reached the capital, they went off to buy a bottle and took it back to the hotel where they were staying during the course.

But, once in their room, they discovered they lacked a cork-screw, so went down to reception to ask to borrow one.

Wendy finished the story: "We were given funny looks as it turned out the hotel happened to be teetotal! They didn't have a cork-screw so we had to go out and buy one."

All in all, Wendy has enjoyed her seven years at ASBAH with about 120 clients on her list - most of them living in Plymouth, Exeter and Torbay.

She said: "I've got a lot of pleasure from my job as fieldworker. It's quite a unique job."

House of Commons launch for START

PETER THURNHAM MP has agreed to host a reception at the House of Commons on 15 May to launch ASBAH's new service - the Service Team for Assessment, Rehabilitation and Training (START).

The launch will coincide with a mailing aimed at service purchasers and care managers in the social services and health services areas - giving them the information they need about our unique package of services for people with spina bifida and/or hydrocephalus.

Education leaflet updated

OUR GUIDE to Educational Statementing (Information Sheet No 7) has been revised to take into account changes in the law and the new Code of Practice. The new sheet is available free from our national centre but please enclose SAE.

Folic Acid Helpline continues until December

A NATIONAL folic acid telephone answering service has been extended until the end of the year - once its initial period of operation runs out in April.

Callers to the Folic Acid Helpline on 0181-994 9874 can talk confidentially to nurses about folic acid, spina bifida and other neural tube defects.

The service is available from 2pm to 10pm until the end of April and then from 5pm to 10pm until December.

The line is sponsored by English Grains Healthcare, makers of Folic Plus tablets, and run by the Medical Advisory Service, a registered charity.

The helpline received 264 calls in its first eight days of operation - following its launch by ASBAH vice-president Claire Rayner at the House of Commons in January.

The important gateway for pre-conceptual care was still being missed by many callers: 62 thought they might be pregnant or had had their pregnancy confirmed. Of the others, 75 were thinking of having a baby; 71 already had children, 13 had miscarried in pregnancy and four had babies who were either still born or died shortly after birth.

Forty of the callers were either parents or grandparents wanting information for their own children, or professionals of one kind or another.

Three of the callers were referred to ASBAH for further support. Other points of referral were GPs, midwives, pharmacists, a consultant, an infertility clinic and the Brook Advisory Service. Most of the callers discovered about the service through editorial coverage in newspapers and on the radio.

Help & Advice

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

London, Surrey, Kent, Sussex

South East Region Office, ASBAH, 123 East Barnet Road, New Barnet, Herts EN4 8RF. Tel: (0181) 449 0475
Regional Co-ordinator: Gina Broughton, BA (Hons).

Lincs, Cambs, Leics, Notts, Northants, Norfolk, Suffolk, Essex, Herts, Beds *Eastern Region Office, ASBAH House, 42 Park Road, Peterborough PE1 2UQ. Tel (01733) 555988. Regional Co-ordinator: Mary Malcolm*

Northern Ireland

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

Northumberland, Durham,Cleveland, N Yorks, S Yorks, W Yorks, Tyne & Wear, Humberside

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

Rest of England and Wales

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 details. Prescriptions for drugs or medicines should not be sent to AlphaMed.*

Young achievers

TWO outstanding young people with spina bifida and hydrocephalus, plus another who has raised £200 for his disabled cousin, were recognised in this year's McDonald's Child of Achievement Awards.

★ Eight-year-old Jake Elstone, who goes to Hawksmoor Grant Maintained School in south-east London, has been described as an inspiration to other children. The head teacher who nominated him said Jake was an example of how a child with disabilities can be integrated into mainstream school.

★ Ten-year-old Sabrina London, from Great Yarmouth in Norfolk, was nominated by her head teacher because of her determination to go with her friends to mainstream school - despite having to undergo extensive surgery when her feet became deformed.

★ Ten-year-old Callum Dunn, from South Shields, was put forward by his head teacher after organising a sponsored run to buy a special bike for his four-year-old cousin, who has spina bifida and hydrocephalus.

Jake, Sabrina and Callum were among 150 youngsters, nominated from up and down the country, to receive awards from a star-studded panel of presenters, including Bill Oddie, Brian May, Bob Holness, Anita Dobson and Carmen Ejogo.

The presentation ceremony and a party lunch was held, on 8 February, at the Queen Elizabeth II Conference Centre, opposite Westminster Abbey.

The awards co-founder Julie Fisher said of those receiving the awards: "The inspiration that you show to others, the care you demonstrate for family and friends and those in far off lands, all make us realise how very fortunate we are that the future is in your very capable hands."

Main picture: Sabrina London receives her award from Krypton Factor presenter Gordon Burns and singer Beverley Craven. Inset: Jake Elstone and Callum Dunn.

Try out a vehicle at the roadshow

THE MOBILITY Roadshow on 14 July will be opened by Her Majesty the Queen.

On the same day she will also present the 500th Motability vehicle to a disabled person.

The show provides an opportunity to see a wide range of vehicles, vehicle adaptions and mobility equipment currently available throughout Europe.

Disabled motorists can also try out vehicles for themselves. At the last roadshow, in 1993, more than 5,000 test drives were conducted on the site's private roads.

The Mobility Roadshow is held at The Transport Research Laboratory, Crowthorne, Berkshire, from 14-16 July. For details call 01344-770463.

Sport for all

LONDON'S first umbrella body to represent sports organisations for disabled people in the capital was headed into action on 30 March at Arsenal's football ground.

Top disabled sports personalities, including international powerlifting champion Gary Jelen MBE, were invited to the launch of the London Sports Forum (LSF).

And there were demonstrations by disabled athletes of sitting volleyball, fencing, goalball, cricket, football, table tennis, short tennis, powerlifting and boccia.

The forum, initiated by the Sports Council, the Greater London Sports Association and British Association of Disabled People, has so far attracted interest from 30 organisations across the London boroughs.

■ ***LSF welcomes new members. There are four working parties - events, marketing and publicity, training and sport development. For further details of becoming a member of LSF, contact Angus Robertson on 0171-354 8666.***

ASBAH NATIONAL COUNCIL MEETING REPORT

Make it a visiting scheme - not befriending

PLANS for a befriending scheme, but with a different name and a slight change in emphasis, were approved by National Council in March.

After expressing reservations, many of those present said they would prefer to be involved with a well thought-out VISITING scheme - with National helping to set standards and provide training, and local associations providing supervision and probably meeting their own expenses. They unanimously called for a consultation paper before the idea goes ahead.

Derek Riseborough, chairman of Herts & South Beds ASBAH, reflected on how his active membership had declined in the last 30 years. To survive and continue offering service, local associations must adapt to changed circumstances. The use of trained volunteers, giving a sympathetic ear to families, would give fieldworkers more time for difficult casework.

Jo Baxter, from Leeds & Bradford ASBAH, spoke of a similar scheme operated by her local association before it had a fieldworker. It was known as visiting rather than befriending - and this was generally agreed to be a better title.

Alison Twomlow, Leicestershire, said: "We don't have a befriending scheme but there are certain times when a volunteer can help. We find it is a personality thing - you have to send in the right person rather than just send anyone in."

Brenda Sharp, South Wales ASBAH and National Executive, pointed out that families living in isolated areas might need visiting every week and transport costs would mount up. She also asked who would pay volunteer expenses if the local association did not have any money.

Michael Flynn, of Derby & District, was concerned the scheme would lead to a dilution of the fieldworker's role.

He said: "If a fieldworker leaves an area, are we going to recruit or continue with befriending?"

ASBAH executive director Andrew Russell replied: "There is no intention to run down our fieldwork cover. In fact, we want to increase it. The idea is to divide their caseload into non-urgent visits, and urgent casework for a fieldworker where advocacy and knowledge of the way services are offered is needed."

John Lewis, South Wales ASBAH, thought something far more fundamental had been overlooked: "There is a large amount of distrust, probably misconceived, that National is just waiting to get hold of local association funds. Any suggestion that befriending will be funded by local associations will put a lot of people's backs up.

"It is a very dangerous road to go down - to make suggestions to local associations which are proud of their independence because they were there first. Before you do anything like this you need to win their trust."

Zem Rodaway, National Executive and YVIA, thought the visiting scheme sounded interesting, but asked: "What about areas where there isn't a local association or active local association? It seems to involve a partnership - does that mean they will miss out on the scheme?"

Mr Russell replied: "Yes, some areas would miss out but that doesn't mean we couldn't include them in another way."

Mrs Twomlow, Leicestershire, wondered how recruitment and training of the befrienders would be done.

Mr Russell replied: "We would look at whether we could introduce a tailor-made syllabus in some further education colleges. The volunteers could be people in local associations, if not we would advertise. The interviewing would be done by someone from here and the local association."

Janet Waugh, Leeds & Bradford ASBAH and YVIA, said: "I think it would be a good idea. I'd like to think that we are the future. First there were the parents, we were the babies, and I'd like to think we can put something into it. This scheme could do this. It could take us into the future."

Vice-chairman Austin Crowther said: "What we are trying to do is provide a better service for our client group."

Eric Prentice, North West London and National Executive, agreed, saying: "Our fieldworker was glad to have someone to visit the lower end of his caseload."

Acquiring some more money to

By Liz Cawthorne

A LIVELY yet friendly atmosphere pervaded at ASBAH's National Council Meeting, with 10% of local associations represented.

After the main business of the meeting, there were questions from local association members on the Carers' Bill; new figures on numbers of babies born with neural tube defects; social services charging for services; failure of health and education departments to work together on child assessments; and parents having to fight for appropriate respite care.

Executive director Andrew Russell reported that ASBAH would remain a 'hands-on' national organisation providing services - but the level of services depended on finances.

"We're striving always to improve our performance, address ourselves to priorities and have a bit more money to spend."

Currently, ASBAH has more than 40 fieldworkers, 10 disabled living advisers, four regional co-ordinators, an information department, and publicity and PR to raise its profile.

Services is 80% of what ASBAH does. It is also an influential, lobbying group and a lot of work is going on at Government level. In future this is also going to include Europe which will act as a further source of money.

Education

The difficulties facing parents with disabled children following the introduction of the Education Act and Code of Practice was also mentioned.

Local associations were urged to put forward to National ASBAH any parents facing difficulties in choice of school, access, etc.

Social services funding

Approaches were being made to many social services departments for financial help in providing fieldworkers and disabled living advisers, as well as study days and training.

Mr Russell said: "We try to liaise with local associations before approaching social services departments in their area. We wouldn't want to tread on your toes. But, if any local associations feel we should be doing more in your area, we would be very keen to hear about that."

National ASBAH, he said, would also be very keen to find out from local associations about whether their local social services departments were charging clients for services.

Child assessments

At national Government level,. ASBAH was pressing for increased co-operation between health authorities and others with local education authorities when making individual child assessments.

Civil Rights Bill

ASBAH was also watching closely the progress of the new Civil Rights Bill which Mr Russell described as a "watered down" version of the previous Bill.

START launch date

A House of Commons launch for START on 15 May was announced. After the launch, marketing and promotion will go on for the rest of the year to build up the level of activity and reputation of START.

Greater participation

Attempts to encourage more people with disabilities involved with ASBAH is progressing through *Your Voice in ASBAH*.

The group had increased the representation of disabled people on Executive Committee and efforts to attract more interest from disabled members in the regions would be helped by money from the Department of Health.

Educational research

ASBAH now considers bids to support educational research, and is making bids to educational trusts for help with this potentially-important part of its work.

Folic acid campaign

Mr Russell said that one of the most important pieces of research had been the breakthrough in folic acid.

"We have pressed the Government to inform the public about folic acid and it has agreed to implement a campaign which will cost £2.3 million over three years.

"In the long term, this could very much reduce spina bifida in births."

One of the things ASBAH has been

allow us to do more

pressing for is the fortification of flour in order to get folic acid into the diet of those who do not take sufficient care of their health, but the Government has so far refused to do this.

Decline in babies born with neural tube defects

ASBAH's own research has shown that the number of babies with neural tube defects has dropped from 2,000 to 1,000 a year - based on latest available OPCS figures (for 1992), and other relevant data.

Mr Russell said: "This means fieldworkers will be concentrating more on hydrocephalus. An increasing number of babies with just hydrocephalus are surviving."

Shunt campaign

ASBAH's hydrocephalus shunt alert cards, developed to improve the general awareness of hydrocephalus and shunts, have been sent out to hundreds of people with hydrocephalus.

Where requested, ASBAH had also arranged for a specially-prepared information leaflet to be sent to their GPs.

Awareness of spina bifida will be increased with a repeat of Spina Bifida Week later this year.

Mr Russell said: "Last year, it led to quite a number of referrals and put pressure on ASBAH last August - this can only be good."

Regional development

Finally, he reported that ASBAH's regions were developing well, though neither the Eastern nor the Northern regions were fully staffed yet.

Northern Ireland Region was reported to be very vibrant with local branches in good touch with the regional office.

This region had been recognised by the Northern Ireland Department of Social Security in the form of a grant.

Plans are afoot to create a Welsh Region in order to attract similar funds from the Welsh Office.

Incontinence video welcomed

PETER'S Story - a moving account of the devastating effects of double incontinence - was given a warm reception from members when it was shown during the council meeting.

The video is the true history of Peter's birth, diagnosis, health care and education. It was written by ASBAH disabled living adviser Mary White and adapted for presentation by Maddie Blackburn, Brian Walsh and Penny Tyler. It has been sponsored by the Gulbenkian Foundation and the Johnson Foundation.

The video was also shown at a special conference on 21 March at the Royal College of Nursing to mark this year's National Continence Day. A report on this conference is planned to appear in the June issue of *Link*.

For copies of the video, send a cheque or postal order for £25.00 (payable to Derby & District ASBAH) to: Anthea Hewitt, Secretary, Derby & District ASBAH, St Merryn, 20 Burley Hill, Allestree, Derby, DE22 2ET.

Stepping out for ASBAH

SIX men and women from North Wales raised more than £500 for ASBAH by striding out in fancy dress along 25 miles of coastline after a mum lost her baby because of spina bifida and hydrocephalus.

The walk was masterminded by Lynne Speed whose 20-year-old daughter Ann-Marie delivered the baby at 22 weeks.

Mrs Speed, from Connah's Quay, wished the family had heard about ASBAH earlier in her daughter's pregnancy and is now keen that its work is more widely known.

Mrs Speed, 43, said: "We wanted to do something for ASBAH because of what we went through with Ann-Marie.

"A lot of girls who become pregnant could have babies with spina bifida and hydrocephalus and not enough is being done to raise awareness about the problem."

The good news is that Ann-Marie is now pregnant again and has been taking a folic acid supplement - which has been shown to reduce the risk of babies having neural tube defects.

Those who took part in the 25-mile sponsored walk from Rhyl to Connah's Quay on 26 February included Mrs Speed and Ann-Marie's boyfriend Dean Wallace, along with family and friends.

If you are planning a fund raising event for ASBAH, contact our appeals department on 01733-555988, for official sponsor forms.

'It was a real shock. I nearly said something rude. I was gobsmacked!' – Ray Gainer, about a little surprise party sprung on him in March.

RAY Gainer, wheelchair tennis champion and chairman of Manchester United Disabled Sports Association, turned up for what he thought was filming for a TV documentary on the famous football club - only to find he was the subject of a *This Is Your Life* programme!

The 34-year-old had started spouting from a script he had spent two hours rehearsing for the fake documentary being filmed in the Manchester United FC museum.

As the camera rolled into action, the club's first team crept up to stand behind him, and *This Is Your Life* presenter (and ASBAH vice-president) Michael Aspel popped out from behind a presentation case with his famous red book.

Ray, who lost a leg 18 months ago, interrupting a bid to become the first person with spina bifida in Europe to gain a commercial pilot's licence, said: "I was in front of the camera for what I thought was filming for the documentary and everything seemed to be going wrong.

"Even when Michael Aspel appeared from around the corner, I didn't twig. I thought he was something to do with the documentary. Then when he came up to me and said, 'This is your life!', I still didn't believe it. But everyone around me was nodding their heads.

"It was a real shock. I nearly said something rude, but I was gobsmacked."

Ray, who is current British National Divisional Tennis Champion as well as chasing titles in table tennis, basketball and ice hockey, was then whisked away to a posh hotel to change before being taken to Granada TV's Manchester studios.

He had no idea what was in store for him as his family, sporting colleagues and Manchester United had all kept tight-lipped about the programme.

But he now realises that a string of unusual happenings in the months leading up to the red letter day were preparations for the big surprise.

He said: "There were lots of funny things happening - like the phone ringing and me picking it up and no-one being there. Whoever it was obviously wanted to speak to someone else.

"Then there were members of the family telling me they were going on little holidays when in fact they were having meetings with the production company to talk about my life."

His doubles tennis partner, John Lambert, resorted to stalling tactics when receiving calls from a *This Is Your Life* researcher and Ray was within earshot.

Ray, from Crosby, near Liverpool, said: "Even the football ground didn't let on what was happening."

And so Michael Aspel was able to tell Ray's story - broadcast on BBC1 at the beginning of March - with the usual scattering of surprise guest appearances from family, friends and celebrities.

Among those giving congratulations on video link-ups was TV personality Sir Jimmy Savile, who knows Ray as a competitor and trainer in the National Wheelchair and Disabled Games at Stoke Mandeville Hospital in Aylesbury.

Sir Jimmy said: "What Ray does with his sporting activities is such a light at the end of the tunnel for my guys and gals down here who have been recently injured. They think life is going to be hard, then see Ray and say life might be hard but it's not over."

Alex Ferguson, manager at Manchester United, added: "We've seen today the determination of the man; it's determination that great people need.

"Everyone at Manchester United is proud to have him at Manchester United."

The production team threw a big party for Ray, his family and friends after the show. "It was an evening full of surprises," added Ray.

OUR REPORTER LIZ CAWTHORNE WRITES ABOUT THA

IT WAS Meg Horsley, a long-standing [illegible]dmire
persuaded Granada TV to select the wheelcha
champion as a subject for *This Is Your Life*.

Meg, 76, who has a rare blood disease and us
wheelchair to get around, is a close friend of
Jim and sister-in-law Sandra.

She rang up the TV company and insisted the
the show.

Meg, of Worsley, Manchester, said: "I suggest
because I thought he was such a fantastic per
staggered at his courage.

"I had never met him but I had heard of him -
suffered in operations and had bounced back
done things for things for other people, partic
children.

The pair met for the first time during the maki
programme. "I was staggered to meet him. He

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example to us all," she said. Meg's persistence finally set the ball rolling and the production company got in touch with Ray's wife Gill.

Gill, 32, said: "I was really shocked when I found out Ray was going to be featured on *This Is Your Life*. It was a great idea, but something I'd never thought of."

Gill had to keep the secret from her husband for nearly three months.

"I had people ringing up all the time and they were frightened to talk to Ray in case they gave something away and we were trying to organise things," she said.

When the big day finally arrived, all the hard work paid off.

ASBAH fieldworker Angela Lansley, who has known Ray for seven years, voices these sentiments: "Ray is tremendous. He's had lots of setbacks, but just keeps going and tries something different. Each time one door closes, he manages to open another one."

Star-studded support cast for Ray's big night out!

CELEBRITIES and friends who made surprise appearances on Ray Gainer's *This Is Your Life* programme included:

☆ Sir Jimmy Savile, who knows Ray through his involvement in the National Wheelchair and Disabled Games at Stoke Mandeville Hospital in Aylesbury.

☆ Manchester United manager Alex Ferguson, assistant manager Brian Kidd, and first team players Brian McClair and Lee Sharp.

☆ RAF flying team Red Arrows representatives who had donated money to Ray for his bid to gain a commercial pilot's licence.

☆ Phil Downes, secretary of Manchester United Disabled Supporters Association (MUDSA).

☆ Ray's tennis doubles partner John Lambert, and coach Vince Rudolph.

☆ Wheelchair racer Mike Pyke who joined Ray in the "Twin Towers" race from Blackpool to Paris - raising £5,000 for Mere Oaks Special School in Wigan, where they were once both pupils.

☆ Mere Oaks' deputy head Helen Corish and sports teacher Steve Owens.

☆ ASBAH fieldworker Angela Lansley was among the invited audience.

Continued foot of next page

Disability on film by Paul Darke

WHY would anybody be interested in my mother's favourite film?

Well, hopefully it will become clear as we go along. My mother's favourite film is *The Raging Moon* (known in the USA as *Long Ago Tomorrow*), made in 1970 in Hertfordshire.

Its plot, beautifully summarised in Halliwell's film guide as "a love affair between two inmates of a home for the physically handicapped", is simplistic in the extreme.

Not that my mother is simple; but why does she like it so much - and why do we all tend to like the films that we do?

Simply put, my mother always admired the film because it supported her beliefs and actions - and that is not a criticism, more an observation.

The film, directed by the esteemed British director, Bryan Forbes - who has himself since been diagnosed as having MS - reinforces certain ideas about disability that have long since been challenged.

It endorses segregation, and implies that disabled people will only ever get to marry their "own kind" and even that is probably doomed (the female lead in the film dies).

The year the film came out, I was eight years old and sent to a "special boarding school" for people with spina bifida where I could be given the care and attention I needed. (The validity of such places is another article in another time!)

My parents felt bad about this - and along comes *The Raging Moon* which supported institutionalisation for our own good.

It even implied that some semblance of happiness could only be achieved by letting disabled people ("the handicapped") perhaps, however tragically, love one another.

The film reinforced my parents' actions, it made them feel better about themselves and it supported them in actions they had been insecure about carrying out.

If we try to examine why we like a film, more often than not, it will tell us something about ourselves - some things good and some things bad.

I hate *The Raging Moon* because I disliked being sent away to a "special boarding school". So, in many respects, the film - any film - is irrelevant. The reason for our liking or disliking a film is rooted in our lives and attitudes and not in the film itself.

And as our lives are determined so much by the world we live in, to term it complex seems like a rather simplistic turn of phrase.

We cannot blame our parents for the wrong decisions they made in the past about our own lives.

It's not my mother's fault she likes *The Raging Moon*, just as it isn't mine that I don't.

As for my favourite film, you'll just have to read the next issue of *Link*.

❒ ***Paul Darke has spina bifida and hydrocephalus and is currently taking a PhD on the way disabled people are portrayed on film.***

Why Ray became famous for 30 minutes

From page 11

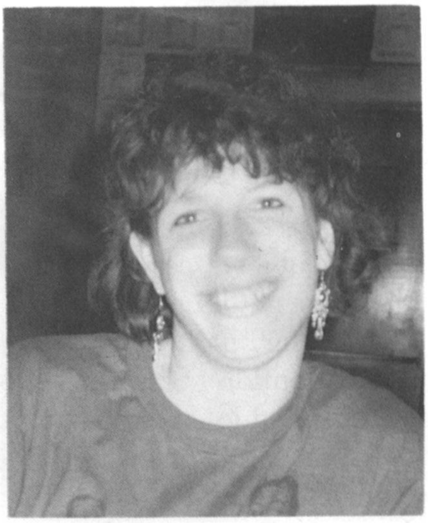
HERE are some of Ray Gainer's achievements which so impressed the *This Is Your Life* team:

- **First person with spina bifida to gain an "unrestricted" private pilot's licence.**
- **First person with spina bifida in Europe to complete commercial pilot training.**
- **Current British National Divisional Champion in Wheelchair Tennis.**
- **Current British Open 'A' Division Tennis Doubles Champion 1994.**
- **Member of the National Great Britain 'B' Squad for Wheelchair Tennis.**
- **French Open Divisional Champion Singles/Doubles 1993.**
- **In 1993, took part in a wheelchair run from Blackpool Tower to the Eiffel Tower - covering about 28 miles a day for 18 days. The charity effort earned Ray and Mike Pyke a place in *The Guinness Book of Records*.**
- **Holder of *The Guinness Book of Records'* World Record in Flying by completing 213 non-stop take-off/landings in 17 hours.**
- **Still trying for a commercial pilot's licence, despite losing a leg in October 1993.**
- **Hoping to take part in the European Wheelchair Tennis, if he can find another £800 support.**
- **Chairman of the 200-strong Manchester United Disabled Supporters Association.**
- **Volunteer at Mere Oaks Special School, Wigan, where he gives wheelchair training.**
- **Represents Southport Paraplegic Sports and Social Club every year in the National Wheelchair & Disabled Games.**

Hydrocephalus Network
News

SPRING 1995

ASBAH, 42 Park Road, Peterborough PE1 2UQ
Telephone: 01733 555988
Reg Charity Number 249338
Co-ordinator: Rosemary Batchelor



Penny Sternberg

Never say never

HN member* Penny Sternberg *says positive thinking, with a little bit of help from family and friends, can do wonders for getting more out of life. Here she describes how her disability has helped her in her work as a teacher and has given her special insight in her travels abroad.

PROBABLY every person with a disability grows up used to the pity of others, whether it is sympathetic clucks from strangers or the over-protectiveness of their family. However, in my case, the older I become the more I realise how lucky I am - in spite of, or even because of, my disability.

I was born in North London in 1966 and developed hydrocephalus at eight months. At 11 months, I had a Spitz Holter valve fitted at Great Ormond Street Hospital: so from the beginning, I had the very best care, not forgetting that of my mum, who is a nurse.

I first walked at 19 months and, apart from problems with balance and lack of co-ordination, there were not many problems until the age of seven when the shunt became blocked and had to be operated on.

Since then, I have had a limp and a left-sided weakness, which, more than anything, have caused me embarrassment as I don't really "look disabled", just unco-ordinated and clumsy, falling over frequently and unable to do certain quite simple things for no obvious reason.

So far, though, I'm lucky enough to have had no further problems with the shunt.

When I was eight, we moved out of London, especially so my sister and I could go to St Christopher School in Letchworth, Herts - a small private, progressive school where my parents thought I might benefit from the high staff ratio and support. I was fortunate enough to have 10 years there - thanks partly to the county council's assistance with fees on account of my disability.

Being able to attend St Christopher's has made an enormous difference to my life because of the respect and consideration which staff give to individual children. I was

more on page ii

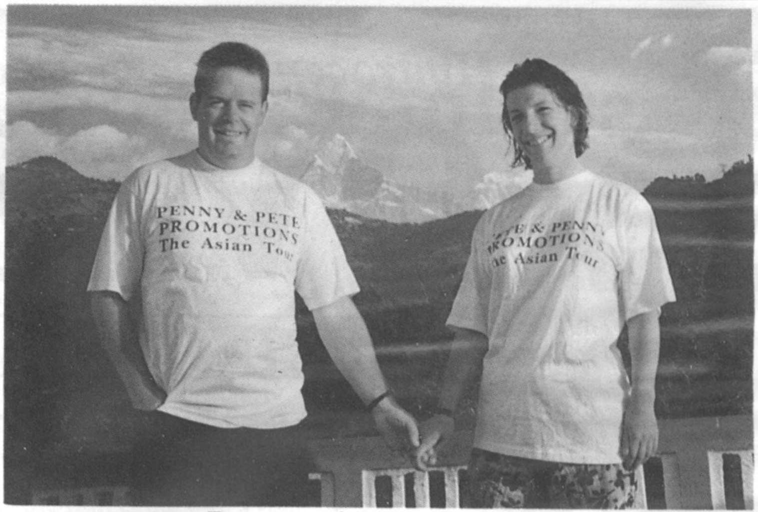
News from the Network **. . . Over 1,000 people from around Britain are now carrying our shunt alert cards wherever they go, and the idea is being copied abroad . . . Dr Roger Bayston, ASBAH's honorary adviser on hydrocephalus, launches a new getting back to basics series in the next issue of *HN News* . . . a Hydrocephalus Study Day for parents and interested professionals is being organised in Peterborough on Saturday 11 November *(for details, tel Becky Sewell, 01733-555988)* . . .**

Never say never, from page i

helped on my weak points, such as being given separate PE tuition so as not to make my disability stand out.

I was also encouraged in my strong subjects, especially languages. I did get my share of bullying but, because of the close attention I was paid, this never lasted long. I went on to get nine 'O' levels and three 'A' levels, and to take a degree in German at the University of East Anglia, and a certificate in Teaching English as a Foreign Language. This led me to live and work, both as a nanny and a teacher, in Germany, Austria and Spain.

I found I was particularly good and patient with children, and put this down to the patience I have had with myself over the years in learning to do anything - from tying my shoelaces to swimming to walking downstairs without clinging to the wall! As my skills and confidence have grown, the less I have found people taking much notice of my disability or regarding me as an object for sympathy, and I rarely bring it up in conversation or, say, application forms.



Penny and Pete in Nepal

In 1991, when I was between jobs, I spotted an advert in the local paper for residential workers in a new housing project for adults with learning disabilities, who were being resettled from an institution. Because I felt I already had a good understanding of disability and of the feelings it can induce in the disabled person (embarrassment, inferiority, frustration) and also because of my reserves of patience, I was confident I would be able to do the job.

And, sure enough, it must be the best move I ever made. Three years on, I'm still loving the work and the hunches I had about why I might be good at it proved quite right.

Eventually, I would like to train as a teacher for primary-aged children with learning disabilities.

Apart from discovering an enjoyable and fulfilling field of work, perhaps most importantly this job led me to meet my boyfriend Pete, who was also doing the work for the first time.

After two and a half years in the job, we took a seven-month break (planned and saved for from day one) and flew off to Asia for an incredible adventure through India, Nepal, Thailand, Malaysia and Indonesia. I achieved things I would never have believed possible a few years ago, such as walking in the Himalayan foothills, climbing a volcano, snorkelling and riding on an elephant through the jungle!

On a more serious note, after seeing the suffering and poverty of disabled and able-bodied people in every country we visited, I hope I have learned never to feel sorry for myself again.

Little by little, I am building up a list of achievements which might seem small to many but mean an awful lot

Continued at foot of page iii

Penny on her Pashley Premier trike in the Hertfordshire countryside

Learning to live with a shunt

22-year-old Donna Draper *tells her story*

IN NOVEMBER 1993, when I was 20 years old, I was diagnosed as having a condition known as "Benign Intracranial Hypertension" which is similar to hydrocephalus.

The raised intracranial pressure was pushing on the back of my eyes and caused the discs to become swollen.

I began to have black-outs occasionally and suffered from terrible headaches and sickness. After two years of being told I was suffering from migraines, depression and stress, I was eventually treated by a neurological hospital and diagnosed correctly.

I was told after undergoing CSF pressure studies that I would benefit from having a shunt fitted.

My first shunt was a lumbar peritoneal shunt which was fixed in my back. Unfortunately, this blocked three times in a very short period and I was fitted with my next shunt – number four!

This shunt worked, but worked too well and caused over-drainage which made me feel very ill. I suffered dizzy spells, headaches and severe neck pain. After returning to Addenbrookes, it was decided to take out the lumbar shunt and insert a ventricular shunt but this did not drain due to my ventricles becoming slit.

My VP shunt was removed and I was fitted with a cisternal shunt which is working well although I still experience some problems. My fluid levels affect how well I feel and on bad days I try to drink plenty which seems to help.

I am also in full-time employment as an administrator in a pharmaceutical company. My job involves a lot of documentation and computer work.

I found it difficult to cope at first but gradually I am learning to live with a shunt!

I use little Post-It notes and make lots of lists to remind me. I try to pace myself and ask for help when I need it and gradually people are beginning to understand.

Donna with her dog Ika

With their help and the love of my family and friends, I am able to lead a normal life but it takes time and a lot of patience and understanding.

I become frustrated and ask the question "Why me?" but that doesn't achieve anything apart from depression and tears!

I try to be optimistic and not afraid to ask for help, and I try to accept that it is a condition you are living with and not an illness.

After 12 operations I have finally begun to live again, without a headache! And at 22 years of age, it is not a day too soon.

Penny looks on the positive side

Never say never, from page ii

to me. Most of these, I think, have been a matter of gaining confidence, thanks particularly to Pete, to my parents and to finding a job that I do well. I still can't drive a car or ride a bike (instead I'm the proud owner of a 12-speed Pashley trike), but one day I'm confident that I will.

It is hard sometimes, but I try to keep cheerful about my disability and am able to laugh at myself, which I think is important, especially as I don't like other people to feel embarrassed on my behalf.

Although little problems crop up daily, I try to look on the positive side and the "gifts" I feel I have because of it. I honestly think I have been very lucky.

We're so proud of you, Sam

A personal success story by Sam's mother Valerie Hawkins

HAVING already miscarried twins, Sam was such a longed for baby. Our joyful shout of "It's a boy" was heard at the far side of Newton Abbot Hospital!

Then the doctor came and told us there was something wrong with his spine and he would have to go to the Special Care Baby Unit in Exeter. It was only when I had to complete an operation consent form, several hours later, that I first heard the words "spina bifida."

I still treasure the black and white Polaroid photographs the ward sister gave us, as it was to be two months before Sam came home. He went from Exeter to Plymouth at 10 days to have his hydrocephalus shunt fitted - and then our troubles really started.

Over the next dozen or so years, the valve became blocked or infected with monotonous regularity.

Only once during his growing years did it actually have to be lengthened as we were in and out of hospital so often.

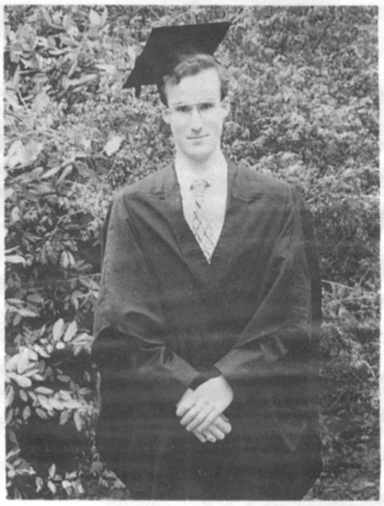
Twice whilst staying with my parents in Cheshire, Sam had to have emergency operations at the Royal Manchester Children's Hospital, involving weeks away from home. At one, never to be forgotten, agonising time, he had to have a blood clot removed from his brain.

Sam also proved to be doubly incontinent but by the time he was three, he could walk unaided, even if, like Royalty, his shoes are handmade (although his by the orthopaedic hospital!)

The big plus was that he was always otherwise healthy. Even bigger pluses were the wonderful medical staff who cared for him and the many long-standing friendships we have made - people we would never have met if Sam had been born "normal".

Our village school refused to take him and he had to attend a special school for physically handicapped children. What a bonus that turned out to be - he could not have had a better start educationally anywhere and with their help at 11 years old, he passed to go Torquay Boys' Grammar School.

There he just had time to catch up with his studies when he missed months of term time because this was the period of his many orthopaedic operations. The teachers were always supportive, however, and Sam gained eight 'O' levels and two 'A' levels, with extra time being granted for his mathematics examinations because of his hydrocephalus.



Sam at his graduation ceremony

Life was not all work and hospital. Sam was a keen cub and because he could not join the usual rough and tumble sports, he joined a bowling club where he was made most welcome. He was confirmed and was a server at our local parish church and he joined the St John Ambulance Brigade at 10 years old and is still an active member, having gained his Grand Prior and represented Devon at a special event at Buckingham Palace where he met the Princess Royal.

It was when he got a weekend job as an auxiliary in a local residential home at 17, to pay for his driving lessons, that he decided that nursing was the career for him and now, at 21, he has just qualified from the Royal Berkshire School of Nursing as an RN (M) and has obtained a post as psychiatric nurse in Ascot - and yes, he did pass his driving test at the fifth attempt!

Looking back, all I can say is that I am glad I did not know in 1973 what was going to be in store for us all, but in 1994, we were the proudest parents at that graduation ceremony.

PRODUCT NEWS ... PRODUCT NEWS ... PRODUCT NEWS ... PRODUCT NEWS .... PRODUCT

This information is given as a service to readers. It is not intended as an endorsement of any product or service.

The goodness of cranberries in a tablet

CRANBERRIES, which have been used for years in the treatment and prevention of urinary tract infections, are now available in convenient tablet form.

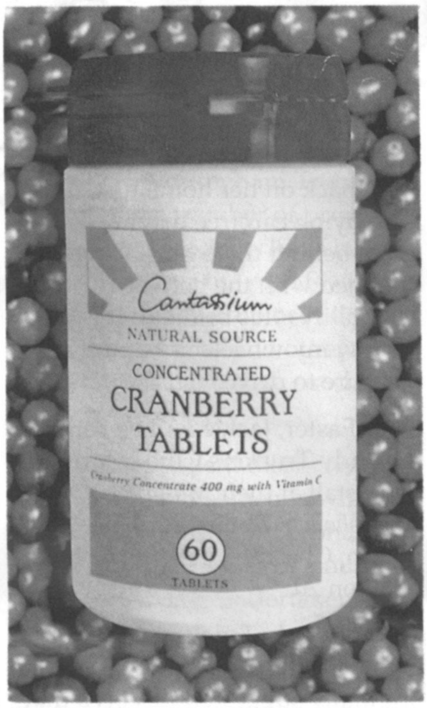
Grown mainly in the USA, cranberries are recommended in drink and powder form to women and men suffering from cystitis and to those prone to urinary tract infections such as sufferers of kidney stones and prostrate enlargement.

Now vitamin makers Cantassium have produced Concentrated Cranberry Tablets which provide 400 mg cranberry extract per tablet and contain only naturally occurring sugars.

Cranberry Vitamin C is also added to the tablets to help the body's defensive and protective immune system.

With less than half a calorie per tablet, they are much lower in calories than a cranberry drink which contains around 49 calories per tiny glass.

Recent research has confirmed the antibacterial properties of cranberries. The latest study was a case of a controlled clinically-based trial published in the *Journal of the American Medical Association* (9 March 1994).



The study involved 153 women, and those drinking a cranberry juice drink (sweetened with saccharin) every day were 58% less likely to develop a urinary tract infection than women who took a drink not containing cranberry juice.

Infections which were already present were only a quarter as likely to continue. The researchers concluded that, after taking cranberry for 4-8 weeks, it did indeed reduce the occurrence of bacterial infections in the urinary tract.

They thought the reason cranberry seemed to be so effective was due to its ability to stop bacteria from sticking to the bladder wall.

The study leader indicated that there was nothing to stop people trying cranberries now, but it was too early to suggest cranberries could completely replace antibiotics for urinary tract infections.

Further studies were called for - especially on younger women with symptomatic cystitis, as well as other patient groups with recurrent urinary tract infections.

❍ ***Cantassium Concentrated Cranberry Tablets are available in pots of 60, retailing at £6.95. They are available from most health food shops and chemists, and via post free mail order from Larkhall Green Farm, 225 Putney Bridge Road, London, SW15 2PY. Tel: 0181-874 1130.***

Tone up in a spa - in your own home!

THE ANCIENT healing art of hydrotherapy has been given a technological facelift in the *Vitalizer Hydrobath* - a spa system which exercises and tones muscle tissue as well as blowing streams of ozone-enriched air bubbles over the skin.

The system, with levels of bubble-blow varying from a gentle soothe to a vigorous blast capable it is said of trimming cellulite, is available in Britain through ***Ultraspa, 1 Belsize Road, Norwich NR1 4BR.***

The product comes in the form of a folding mattress which is placed in the bath, a control unit and connections. It costs £499.00, and this issue of *Link* carries a pre-paid postcard for readers who would like more information.

The bubbles are ozone or 'active oxygen'-rich. Ultraspa director Dean Cartwright told *Link* that scientific research has shown that ozone - absorbed in the blood through pores in the skin - removed viruses and bacteria, literally freshening up the bloodstream.

"Our product is not a cure but it promotes resistance to illness, and certainly promotes health and offers relief from pains and discomfort."

The *Vitalizer* comes with full safety instructions and its literature contains testimonials from people suffering from spinal problems, arthritis, rheumatism, stress and poor circulation, who all praise its benefits.

The *Link* diary

This and That!

DOWN to earth with a thump after cruising in the stratosphere as the first person with spina bifida to pass the driving test for a 38-tonnes articulated lorry - that's Jackie Doughton *(see last Link)*. In March, we caught up with again behind the wheel of her Renault Clio car *(pictured below)*.

"I made the local television news and then travelled to Scotland to take part in the BBC2 *Top Gear* programme, but I never had any time to drive it by myself. A Central TV crew also came along for the ride", said Jackie, of Bilston, West Midlands.

Jackie became the focus of media attention after Volvo Trucks lent her a 38-tonne cab and low loader after hearing that she had dreamt of becoming a heavy lorry driver ever since her dad used to take her out in his own HGV. Volvo fitted hand controls, provided a wheelchair ramp and paid for Jackie's tuition and test fee. Jackie passed what is now called the large goods vehicle test in Birmingham at the end of last year - a great result all round.

"I went up to Scotland to do the piece on *Top Gear* but it was a nightmare weekend," said Jackie.

"Nobody told me the way to the racetrack where they were doing the filming, so I was driving this enormous truck round the ring road in Edinburgh not knowing where I was going. When I got there, I found that there were a lot of other disabled drivers waiting to be filmed.

"Someone complained that my truck cut up their turf, I was left waiting to be interviewed on my own in the truck all day, and - to cap a truly great day - I ended up with a ruddy great dent in the side of the lorry!"

Now back on her home turf, Jackie is enjoying carefree driving once again behind the wheel of her Clio, obtained with the help of Motability. "It's brilliant. It is easy to stow my wheelchair and a pleasure to drive."

Over Easter, Jackie will be running the Lady Truckers Club information stall at their *Motorvation Truckshow* at Poplar 2000 Services, Lymm, Cheshire, just off the M6 at junction 20.

She and Lady Truckers Club president Ilona Richards, who originally suggested to Volvo that they make it possible for Jackie to pass her LGV test, will be happy to chat to anybody who pops in.

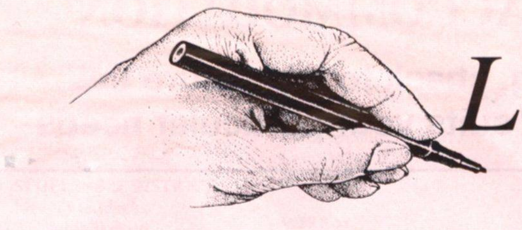
***PLEASED** to hear that the Dandy Walker Support Group founded last year is starting to flourish. Mothers Julie Rattue and Heather Jury received 25 inquiries after a spate of publicity, including a national newspaper feature written by Heather's own family doctor at the time - Dr Hilary Jones, well known as the medical man in The Sun newspaper. They have had no meetings yet because members are scattered as widely as Sunderland, South Wales and County Antrim. But the group is gathering facts from members, and busy putting families with similar experiences in touch with one another - in the hope that members will feel less isolated.*

Link recently carried a very useful information article on Dandy Walker cysts by paediatric neurosurgeon Miss Carys Bannister, copies obtainable from our information department. Readers who want to join the new support group can contact Julie Rattue at 21 Stag Hill, South Ham, Basingstoke RG22 6JF, tel 01256-59964.

STAFF at the BBC TV disability programmes unit were left fuming when their flagship magazine programme *From the Edge* was moved for its current series from the its early evening slot on Thursdays to 2.35 in the afternoon - losing about 800,000 viewers in the process."We had built up an audience of almost a million - not bad for a disability programme", said one insider.

The show has been relegated from a fairly mainstream slot which competed with *Neighbours* to a sleepy afternoon ghetto. What a lousy signal about the importance the BBC give to the interests of disabled people in their programming.

TB



Letters

IF PEOPLE want to see smutty, sexist trash, they can buy a soft porn magazine from a newsagent and not expect to find it in the covers of a respected, well-informed disability magazine. I am, of course, referring to recent *LIFT* cartoons of a disabled man learing down the blouse of a woman and making suggestive comments.

Perhaps I am over-reacting and *LIFT* was trying to make a point - disabled men can be equally as sexist and humiliating to women as non-disabled men. Now that is equality to strive for!

Tracey Proudlock
London, N10

Editor's note: LIFT, our magazine for disabled members, has an excellent cartoonist who contributes material from his viewpoint on a variety of subjects. Our future selection will reflect his wide range of interests.

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

IN THE science departments at Nottingham Trent University, a number of projects for disabled students have been sponsored over the past few years. Under the leadership of Professor Alan Jones, books and other publications have been produced with these projects.

As an independent disability consultant, and someone with spina bifida and hydrocephalus, I assist Professor Jones in a number of projects being undertaken.

We would like to encourage disabled children or students to take up science or technology careers, and are planning a series of biographies from disabled scientists or technicians so they can act as positive role models for disabled young people.

We are looking for a cross section of people in a wide variety of jobs that are broadly science or technology based. We would also be pleased to hear from students who are still following science or technology based courses, or who have recently completed such courses.

Ideally, the profiles should be between 750 and 1,000 words long and include experiences which will motivate disabled young people.

We are sure that reading these profiles will improve the confidence and self-esteem of many - even though they may not be able to enter high level technical posts.

If you have any queries about this project or what to write about, please get in touch with me at the address or telephone numbers below.

Christopher Hopkins, 36 West End, Long Whatton, Loughborough, Leicestershire, LE12 5DW. Tel: 01509-843354, or 0374 -672094 (mobile).

FORTHCOMING ASBAH EVENTS

2 - 4 June

Family Weekend, a residential course for families with a child aged five or under with hydrocephalus and/or spina bifida, brothers and sisters, Meldreth Manor School, Royston, Herts. *Details: Lynn Thomas, ASBAH, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988.*

Wednesday, 21 June

Eastern Region study day, Understanding Hydrocephalus, Peterborough Central Library, 1 - 8pm. Speakers include: Roger Bayston, ASBAH's hon consultant in hydrocephalus; Jonathon Punt, consultant neurosurgeon, Nottingham City Hospital; Mrs Leonie Holgate, ASBAH disabled living adviser. Students £5, professionals £15. *Details: Becky Sewell, ASBAH, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988.*

28 - 30 July

Weekend parenting course, 'Parents with disabilities and their families', Hereward College, Tile Hill, Coventry. Designed to give families a break, time to explore and learn, and to make new friends. £25 each adult, children free. *Booking forms, returnable by 14 April, from Joan Pheasant, tel: 01943-609468.*

SMALL ADS (cont'd) - ITEMS FOR SALE

EVEREST and Jennings Elite Whisper electric wheelchair, excellent condition, £699. *Tel: 01253-761283.*

RACING wheelchair, Bromakin Arrow Racer, four years old, fit 14" hip, £250. Bromakin Training Roller four years old, £100. Or sell both together £300. Tel: 01705-582499.

SNUG Seat Junior, supplied with two covers, foot rest, mobiliser pads, pommel, car-fixing kit, buggy wheels and rain cover. Good condition. £300 ono. 01952-407669.

HOLIDAY ACCOMMODATION

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

MID-WALES

Nicely furnished self-catering bungalow, sleeps five. Wheelchair accessibility Grade 2, in beautiful valley. Maximum £220 pw. B & B and 6-8 berth caravan available. Ideal touring area - mountains, waterfalls, lakes, dams, steam trains, castles, fishing nearby. Astronomy holidays, 16" telescope - beginners welcome. *Details: Ann Reed, 01938-810446.*

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.*

STAFFORDSHIRE, ALTON

Wheelchair-accessible holiday accommodation in country cottage, B-B or H-B. *Details: Jean Ditchfield, tel: 01538-702189.*

NAISH HOLIDAY VILLAGE, NEW MILTON, HAMPSHIRE

Fully equipped, completely wheelchair-accessible, two-bedroom bungalow. Sleeps six. Site near sea with access to New Forest, Bournemouth. Excellent site facilities 100 yards from chalet. *Details: Mr P Cash, tel: 01425-672055.*

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SELSEY, SUSSEX (SASBAH)

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ALGARVE, PORTUGAL

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Sue Abbott, 123 Coppermill Road,
Wraysbury, Staines, Middx TW19 5NX, tel: 1753-685718

HOLIDAYS (Contd)

ROMNEY SANDS, KENT

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Parents with disabilities and their families

A weekend course designed for people with spina bifida and/or hydrocephalus to give you a break, time to explore and learn, and to meet new friends. £25 each adult, children attend free.

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Joan Pheasant, START
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West Yorkshire LS29 8BD.
Tel: 01943-609468.

28th - 30th July 1995

Venue:
Hereward College,
Tile Hill, Coventry

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS
