

Link

The magazine for people with
Spina Bifida and/or Hydrocephalus



June/July 1996

Issue No 164 Price 80p



**LORD MAYOR TRELOAR
NATIONAL SPECIALIST COLLEGE
OF FURTHER EDUCATION**



HOLYBOURNE ALTON HAMPSHIRE GU34 4LA

exists to provide
**EDUCATION, INDEPENDENCE
TRAINING AND CARE FOR YOUNG
PEOPLE OVER 16 WITH
PHYSICAL AND/OR LEARNING
DISABILITIES**

- Vocational courses leading to NVQ's or GNVQ's at Foundation, Intermediate and Advanced level
- 'A' levels in association with Alton Tertiary College
- ACCESS programme accredited through ASDAN for the Award Scheme for students not ready to follow a full vocational course
- Numberpower, Wordpower and other exams which lead to qualifications accredited by CGLI, Pitman, RSA, NPTC, AEB, and other awarding bodies
- Support from experienced teaching, therapy, rehabilitation engineering and care staff
- Medical and 24-hour nursing care
- College Chaplain, Counselling service and Careers advice
- Supported by The Treloar Trust (Registered Charity 307103) which also supports a school for 5-16 years.

**For further information, please contact:
Admissions Secretary 01420 547425**

**The only computer company to give
ALL its profit to Charity**

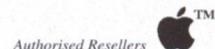
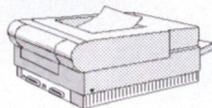
It makes excellent sense to deal with

COMPUTER SENSE

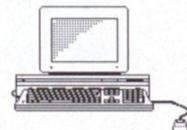
for all your Apple computer service and sales



Authorised Service Providers



Authorised Resellers



A wholly-owned subsidiary of the Association for Spina Bifida and Hydrocephalus, managed by staff who are all highly experienced in the sales, support and maintenance of Apple computers.



- New equipment
- Repairs and maintenance
- Maintenance contracts
- Networking
- Software
- Paper, ribbons etc

Computer Sense Ltd
Unit 7
Grovelands Business Centre
Boundary Way
Hemel Hempstead
Herts HP2 7TE

Tel: 01442-252555
Fax: 01442-219222

..time was running out for Joe, when..



**ADVICE FROM
PROFESSIONAL
DISABLED PEOPLE**

**ONE STOP ONLY ALL YEAR
ROUND EXHIBITION.**

Car parking, Showroom, Toilet all accessible.

GBL Wheelchair Services Ltd,

Units 1 - 4, Shield Drive, Brentford, Middx TW8 9EX
Tel: 0181 569 8955 Fax 0181 560 5380

Regional Office: Unit 3, Minster Court, Courtwick Lane,
Littlehampton, W. Sussex. BN17 7RN

Tel: 01903 733528 Fax: 01903 733530

GBL Eastern: Ermine Street North, Papworth Everard,
Cambridgeshire, CB3 8RG

Tel: 01480 831212 Fax: 01480 831414

**..WHEELCHAIR
WAREHOUSE**

that's the place, It has the largest choice in
ranges of Manual Chairs-Scooters-Power Chairs
plus any other product lines I need.

I'll give them a ring...



The Midlands – we are still in there, batting

HELP is at hand from ASBAH for people with spina bifida and/or hydrocephalus who live in the West Midlands – even though, as reported in our last issue, the independent Midland local ASBAH closed earlier this year.

ASBAH fieldworkers already live in the area and offer personal advice and support to individuals with the disabilities, parents, health professionals, schools, local authorities and other interested organisations.

For people living in Birmingham, Solihull and Sandwell, our fieldworker is Geraldine Long on 01789 763090.

Jenny Green on 01926 511206 provides our fieldwork service in Warwickshire and Coventry.

They continue to be supported by specialist advisers on mobility, continence, education and independence training issues.

Alternatively, people in the West Midlands can make first contact with our national centre in Peterborough, tel 01733-555988.

London

Be part of it!

AN UPBEAT press release about shopping as a disabled visitor in the capital has been issued by the London Tourist Board. It claims that shopping is now easier than ever before, with more stores and shops providing assistance, staff awareness and training.

"It is a friendly environment with wider pavements and parking facilities nearby", says the board, while warning that Orange Badge parking is limited but spaces are available in NCP and Westminster car parks.

For example, John Lewis in Oxford Street has six out of seven entrances suitable for wheelchairs, with eight lifts linking floors. There are toilets for disabled customers on the fourth floor, and access to both Place to Eat and the Coffee Shop. The fashion and menswear departments have larger fitting rooms.

Selfridges, also in Oxford Street, has "ambassadors" available to help disabled shoppers or push wheelchairs. Ask any member of staff.

Both the Pantheon and Marble Arch Marks & Spencer have wide aisles and at least one automatic door. A lift links floors. C&A also has "good access" for disabled people.

In Regent Street, the newly refurbished Dickins & Jones gives wheelchairs level passage through the store. Lack of clutter suits partially-sighted and blind shoppers. The Warner Bros store is "particularly welcoming" to disabled shoppers with wide doors, lift and wide spaces between fixtures.

For travel information, try London Transport's *Access to the Underground* guide, but remember wheelchair access to the Tube is extremely limited.

For those planning an overnight stay, the Copthorne Tara has 10 specially-adapted rooms with wheelchair access and ceiling hoists, and disabled parking spaces. Other recommended hotels are Mount Royal, Berners, Lancaster, Mitre House and the Montague.

The board's Shopping Newslite, updated monthly, is on 0891-505 478.

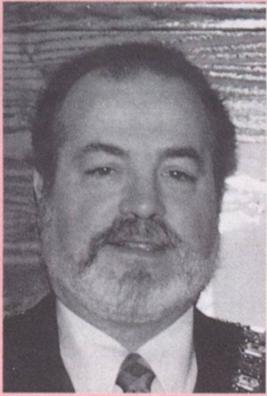
Contents

ASBAH is a registered charity

▲ Research Appeal	6	▲ HN News	ii - iv
▲ Interview - Tanni Grey	8	▲ Your Voice in ASBAH	21
▲ L-driving with BSM	13	▲ Quad Bike Club	23
▲ Monique's home visit	14	▲ Letters/Events	24
▲ Darke at the cinema	16	▲ Dave's Diary	26

Cover: Tanni Grey, wheelchair race ace, winning this year's London Marathon. Read about her in this issue of Link. Picture: Graham Bool.

HAIR TODAY... GONE TOMORROW!



BEFORE – The Lord Mayor's best-known face.

AFTER – his best-kept secret



THE LORD Mayor of Belfast made the ultimate sacrifice for charity – when he agreed to having his neatly-trimmed beard shaved off.

The Rev Eric Smyth, whose distinguished whiskers became famous round the world when he was filmed greeting President Clinton during the American leader's historic peace-making mission to Northern Ireland last year, went under the razor to raise money for spina bifida and hydrocephalus projects in the Province.

A barber shop quartet sang along to make the parting with his 30-year-old beard less painful.

He sat down in a barber's chair in the city's Europa Hotel and, after feeling his smooth chin, he announced that his chin felt cold.

Afterwards, he told the *Belfast Telegraph*: "I think it makes me look 10 years younger. It's a good job, but the wife will say 'get the whiskers back quickly'."

The sponsored shave raised £1,800 towards the Lord Mayor's target of £50,000 for spina bifida and hydrocephalus, which he intends to raise during his year of office.

The £50,000 will be split between specialist urodynamics equipment for a Belfast hospital and lightweight wheelchairs for children.

The Lord Mayor has an adopted four-year-old son, Matthew, who has spina bifida and hydrocephalus.

Chairman of the Lord Mayor's fundraising committee, Vincent McCarthy, told Link: "The Lord Mayor certainly looked younger. It's taking time for the beard to grow back properly."

The Lord Mayor is well on target to raise the £50,000. Mr McCarthy, former chairman of Belfast ASBAH, said typical local generosity meant the appeal did not have far to go. Ten thousand pounds was raised at a civic ball in February.

ASBAH STAFF NEWS

EDUCATION adviser **Mike Dodd** will be ordained a deacon in the Church of England on 30 June.

One of the new breed of unpaid clergy, he will join six ordinands and six deacons being made up to priest at the ordination service in Wakefield Cathedral.

"There will be three men and three women in each group. It should make the retreat afterwards very interesting", mused Mike.

He has been assigned to the parish of St John the Evangelist in Golcar, just west of Huddersfield (and only six miles from home), where he will be assisting the vicar Martin Compton on a part-time basis.

Mike, who has worked part-time

for ASBAH since last September, is based at our northern regional centre at Five Oaks, near Ilkley.

His identical twin brother was ordained 30 years ago.

NEVER mind the professionalism, stamina is the basic job requirement at ASBAH! And our disabled living services co-ordinator **Rosemary Batchelor** showed plenty of staying power when she spoke at a recent neurosurgical theatre nurses conference arranged by Codman, the specialist medical equipment company owned by Johnson & Johnson.

Rosemary was called on to deliver the same talk to small groups of nurses on our experience of working with people with

hydrocephalus not once. . . but five times during the day, for 15 minutes a time, and answer a different stream of questions each time.

"I found out that each talk was a revelation. I hope they were impressed enough to call if they need help in the future", she said afterwards.

FAILURE by the N Ireland Dept of Health and Social Security to buy into the mainland Folic Acid campaign has been tackled head-on by our Northern Ireland co-ordinator **Margaret Young**.

Appalled that the benefits of folic acid were left unexplained in a region with an exceptionally high spina bifida birth-rate, she complained to civil servants. The result? Northern Ireland will get its own campaign shortly!

READ ASBAH'S UPDATED ENTRY ON THE INTERNET: <<http://www.demon.co.uk/citygate/asbah/>>

Hospital parking charges

THERE was a poor response to a recent questionnaire in *Link* about hospitals and NHS Trusts which now impose car parking charges. The lack of information means that ASBAH cannot yet tell the NHS Executive that there is a clearly-defined pattern of locally-imposed charges discriminating against disabled people in hospital and their visitors.

Only seven completed forms were returned - too few for us to be able to build a complete picture of what is happening.

Some interesting views were expressed, however. One reader said a minimum charge of 70p for three hours parking even for cars showing the Orange Badge at Workington Infirmary, Cumbria, was "very unfair".

Visitors to Rotherham District General Hospital, while promised shorter waiting times, had to pay a minimum 50p for four hours. Free parking was available but "at some remote part, furthest away from the main buildings".

One reader said wheel-clamping was in operation at Warrington General Hospital.

And another said a £1 charge at the Princess Royal Hospital, Hull, was "disgusting. . . even low-paid staff are charged. Patients loose out because people visit less often because of the parking fees and I find people less likely to run me to hospital when I attend out-patients."

Horror stories about cars being clamped on the street, even though Orange Badges were displayed, were told to ASBAH's services committee in May. One member, Beverley Holland, said the Road Traffic Regulations 1984 banned the clamping of these cars, although owners could be fined if they parked illegally. Local authorities should at least make sure their clamping companies kept within the law.

Leaflets for young people

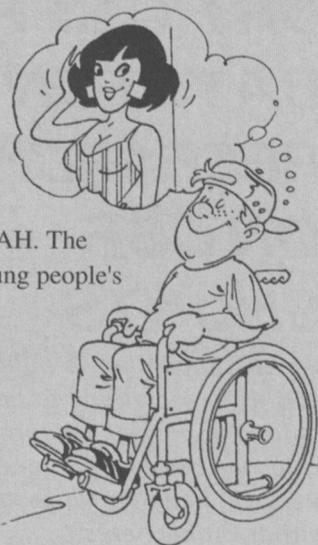
A SET of five leaflets to help young people with spina bifida and/or hydrocephalus understand the growing-up process better have been published by ASBAH. The latest two are about young people's sexual development.

Published so far:

- (1) This is Your Life: 10 tips for a healthier, happier you
- (2) Keep It Clean: top tips for looking good (including a peel-off slip for the bedroom mirror)
- (3) Continenence and You (including ASBAH's dietary fibre sheet)
- (4) Let's Talk About Sex! (preparing for 'going out' with someone, including illustrations of the human body)
- (5) More Talk About Sex! (preparing for a sexual relationship).

The leaflets have been compiled by ASBAH's own disabled living and information staff in co-operation with disabled members, and tackle questions which are regularly raised by young service-users frequently too shy to discuss them with their parents, teachers or friends.

Further copies - free on request from Gill Winfield, our Information Officer (please send SAE). Leaflets on bullying and self-image are in the pipeline.



Officers & Staff

Patron:
HRH The Duchess of Gloucester, GCVO

President: Dr Jeffrey Tate, CBE

Chairman: Mr Godfrey Bowles

Hon Treasurer: Mr Charles Ortnor

Executive Director:
Andrew Russell, MA

Finance Director:
Derek Knightbridge, FCCA

Assistant Director (Personnel):
Paul Dobson, BA (Hons), FIPD

Senior Services Manager:
Teresa Cole, MICA

Senior Appeals Manager:
John Williams

Services Manager: Milly Rollinson CQSW
START Manager/Northern Regional Co-ordinator:
Joan Pheasant, NNC

Disabled Living Services Co-ordinator:
Rosemary Batchelor SRN FETC

Publicity Manager:
Tony Britton

Research and Information Officer:
Gill Winfield Cert Ed

PLEASE SUPPORT DR ROGER BAYSTON'S RESEARCH ON CSF SHUNTS

WE ARE appealing to all local ASBAH Associations to help us fund important research which we believe will lead to practical benefits for those with hydrocephalus.

Dr Bayston's work continues to show up new ways to improve the treatment of people with shunts. But it does need more funds for the results to flow more quickly.

Local Associations are called upon to join forces with national ASBAH to raise the £10,000 needed to continue this work. We have already raised half the amount, and have committed ourselves to raise the balance this year.

If your Association can make a gift, please send it to Andrew Russell, Executive Director at ASBAH, marking your gift quite clearly 'for Dr Bayston's research'.

The cheque should be made payable to ASBAH.



DR ROGER BAYSTON (left), a senior microbiologist at Nottingham University, is ASBAH's Honorary Consultant on Hydrocephalus

For two decades, Dr Bayston's group has been working on infections and other problems in CSF shunts. The four main areas of research are all closely linked.

HOW INFECTIONS ARE CAUSED

Dr Bayston's group first discovered the way in which bacteria, mainly from the patient's skin, gets into the shunt during the operation, and how they are then able to stick to it so that they cannot be removed, even using potent antibiotics. Work is now proceeding on how these adhesive factors are made by the bacteria, with the aim of developing ways of "switching them off".

DIAGNOSIS OF INFECTION

It is often difficult for even a specialist to distinguish between a shunt infection and another problem with similar symptoms, and ordinary lab tests are not much help. Dr Bayston has been studying the antibodies produced in an infection, and a blood test is being developed which we hope will allow rapid, reliable diagnosis.

TREATMENT OF SHUNT INFECTIONS

Dr Bayston's group were responsible for a drug trial which led to a change to a much shorter, more effective treatment for a shunt infection. This method is now gaining wide acceptance, but the shunt still has to be removed.

He has now identified a new group of drugs which can be used safely and which, in early lab tests, appear to "turn off" the factors which prevent effective treatment without shunt removal. Further

work on this is needed to study the way in which the drugs work, with the aim of being able to treat shunt infections without having to remove the shunt.

PREVENTION OF SHUNT INFECTIONS

Dr Bayston's group have carried out exhaustive studies to find antibiotics which can be given at the operation to prevent shunt infection, but the evidence now shows that this approach is not useful. He has therefore invented a process which makes shunts kill bacteria which get into them, and all results so far strongly suggest that this will be safe to use and prevent a large proportion of shunt infections. However, trials are needed to show that the processes actually do prevent infection. Also, more laboratory research needs to be done to explore ways of improving the process.

RESEARCH INTO OTHER SHUNT COMPLICATIONS

Dr Bayston and Mr Howard Brydon have shown that high CSF protein in babies should not delay shunting (unless blood is also present). There is no evidence that high protein levels lead to shunt blockage as was believed. This means that there is no need to wait for the CSF protein to fall before treating hydrocephalus in babies. Work is now needed to show that high CSF protein does not stop the anti-infection process above from working.

Dr Bayston is also attempting to solve a problem common in poorer countries – lots of children dying for lack of shunt because their parents cannot afford to buy one. He has made prototype shunts costing a few pounds and these need to be tried out.

Other projects which aim to diagnose, treat or prevent shunt infections more effectively are in progress.

FOR MORE HYDROCEPHALUS NEWS, READ THIS LINK BETWEEN PAGES 16 AND 21

Vouchers not included

WALES and Northern Ireland have been left out of the Government's plans to provide vouchers towards the purchase of wheel-chairs by severely disabled people.

The Department of Health now says that the scheme will apply to England only, although widening it to Wales and Northern Ireland is being considered.

A RADAR spokesperson said this new information is profoundly disappointing, and should have been made clear at the time of the launch (which was covered in the last issue of *Link*).

Help for lone parents

FREE advice on benefits, tax, holidays and legal rights is available from the National Council for One Parent Families, tel 0171-267 1361, office hours.

Access to Work revived but strings are attached

MORE money has been pumped into the Access to Work scheme which helps severely disabled people find and keep work – but employers will be charged a levy when they use it.

RADAR has welcomed the increase in budget to £19m (against last year's £13m) but warned that the levy will deter some employers from taking on disabled workers, while others will lay off staff rather than pay to be part of the scheme.

Employers will now be expected to pay the first £300, plus 20% of any new claim by a disabled person already on their staff. Access to Work will only pay the full claim if it is for £10,000 or more.

This means employers paying up to £2,300 to keep a disabled person. The change starts on 1 June, so applicants at present in work will not receive support until next month.

ASBAH executive director Andrew Russell commented: "The representations that ASBAH and other disability

organisations have made to the government over the last two years have had considerable effect, but we would still like to see a more whole-hearted approach to the equipment of disabled people. Placing more financial responsibility on employers will inevitably be a disincentive to taking on disabled staff."

Education and Employment Secretary Gillian Shephard told the Commons: "The Government will continue to give top priority to the unemployed, followed by those in work who suffer the onset or worsening of a disability, and then to those whose job circumstances change and those who move to a new employer."

RADAR's Bert Massie commented: "The Government must recognise that some employers will be disgruntled at having to pay a contribution. It could have a great impact on their recruitment of disabled employees."

The scheme was restricted just before Christmas when audit checks revealed an £6m overspend.

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: Gina Broughton, BA (Hons).

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.

WALKING: WHAT'S SO GREAT ABOUT THAT?



John Grooms

TANNI GREY MBE
talked to
HELEN RENSHAW
of the *Daily Mail*
on the occasion
of the publication
of her biography



© Graham Bool 1996

TANNI GREY (pictured above with Minister for the Disabled Alistair Burt) is one of Britain's most outstanding athletes. She has won four gold medals for her country, has won the London Marathon three times and triumphed in countless other International competitions. Tanni, 28, recipient of the MBE, was born with spina bifida and has been unable to walk since the age of eight. She lives in Cardiff with her parents Peter and Sulwen and sister Sian.

People are always asking me if I wish I could walk, but what would be the point? My attitude has been: I can't change the way I am, so I'd better just get on with it.

The funny thing is that I always walk in my dreams. As a kid, I always used to have nightmares that the Daleks were chasing me and I couldn't escape. But since I've been paralysed, I can walk beautifully. I'm never in a wheelchair when I'm dreaming. No doubt psychologists would say that means I've got some deep problem about not being able to walk. But to be honest, what's so great about walking? At least I never have a problem about getting a seat in the pub.

It's hard to remember what it was like to walk - most of my early childhood memories are falling over and having plasters on my

knees. There was never a point when I thought: 'Oh my God I can't walk' It happened gradually and I viewed it more as an irritation than anything.

As a child I never thought of myself as different in any way. Primary school hadn't been a problem and I assumed I'd be going to the high school my sister attended, along with all my friends. It was a bit of a shock when the school authorities turned around and said: 'We don't want you.'

It didn't make any sense to me. When I was told it was because I was in a wheelchair, I thought: 'So what?' The crazy thing is that I was seen as having a problem because of my chair - but plenty of other kids needed far more help than me.

Luckily, my parents fought for my

TANNI - HER INSPIRING BIOGRAPHY BY TED HARRISON, COLLINS WILLOW, 1996. PRICE £14.99

right to stay in mainstream education, but the local authority insisted on 'assessing' me first. They sent a psychologist, who stood in a doorway and stared at me for a while. Then I was taken aside and asked a lot of dumb questions like: 'How many many days in the week are there?'

I experienced very little bullying. All I can remember is one time, when some girl called me Limpy Legs. I mean, wow, that's really cutting. isn't it?

The children I went to primary school with didn't see me as having a disability. To them, I was just Tanni. Problems were more likely to come from outsiders. If you're in a wheelchair, people sometimes give you strange looks - my reaction is to wave and smile.

My teenage years were pretty normal. I wore horrific clothes and spent all my pocket money on records and make-up. I am lucky in that my parent have always allowed me the freedom to make my own mistakes.

Over the years I have been pretty lucky healthwise, too. I've only had three major operations. One kid at school had 29 by the time he was 13. I gradually lost sensation in my legs, and when I couldn't feel them anymore I did stupid things like dragging myself over gravel until my skin was red raw. Once I sat on a radiator until it burnt a chunk out of my leg. That woke me up a bit and reminded me that, although I can't feel my legs, they still need looking after.

When I was seven I had an exploratory operation on the lump on my back. It was a big op and I thought: 'Great, two months off school!' I didn't get away with it though. Mum and Dad brought school work into hospital for me.

Then when I was 13, my back started to twist into a S-shape and I was in quite a lot of pain. I had a metal rod inserted to support my spine. Afterwards I was dosed up on morphine for a while and had

to wear a plaster cast from my neck to my hips for six months.

When it came off, my muscles were so weak I had to hold my head up with my hands for a week, otherwise it just flopped over or wobbled about. My family thought that was hysterical.

Much later, when I was at Loughborough University, one of the bone grafts attaching the rod at the end of my spine came away. I was terribly ill and had to go through another back operation - this time they took the rod out, because they said my spine had stabilised.

I started wheelchair racing when I was about 14 and, by the time I left university, I knew I wanted to be a full-time athlete. Now I train for about twenty miles a day and my next objective is the London Wheelchair Marathon on April 21. I've already won it twice - and this time I'll either win or come nowhere. That's the way I am.

Wheelchair racing is just like any

other sport - there's a certain degree of selfishness involved. A long-term relationship at university came to an end because of my sport - I wasn't ready to give up competing to spend time with him.

The boyfriend I have now is also a wheelchair athlete, and much the same as me - extremely strong willed, competitive and very independent. He wants his own life and so do I.

Hopefully, I'll be able to carry on competing until I'm in my mid-30's. I have no idea what I'll want to do then. As for settling down and getting married - I still think as that as something that grown-ups do. Having kids would be nice one day, but I've got plenty of time for that.

So far, the Paralympic Games in Barcelona in 1992 was the high point - it was the first time I won gold. What an amazing feeling. I

continued on page 10

DIAGNOSIS

JULIE LLEWELYN of the Spina Sifida Association says: *Spina Bifida Cystica is a fault in the spinal column in which one or more vertebrae fail to form properly, leaving a gap through which a sac containing spinal fluid and nerve tissue may protrude. Resulting nerve damage usually causes loss of sensation or paralysis below the damaged vertebrae.*



The severity of the condition varies greatly. Spina Bifida Cystica is more severe and there are two types. Meningocele is where a sac that contains cerebrospinal fluid (CSF) and looks like a large blister protrudes through the gap in the vertebrae. If the nerves are not involved, there is little disability.

Myelomeningocele is more common. In this case the sac contains not only CSF, but nerve tissue and part of the spinal cord, too. There is always some degree of loss of sensation or paralysis below the damaged vertebrae. It's quite common for spina bifida children to be able to walk when they are little. But as they grow the nerves become more damaged and paralysis sets in.

In the past, children with spina bifida rarely made it beyond their teens because bladder problems lead to kidney damage and renal failure. Nowadays this problem is averted early on.

In adulthood, fertility can be affected - more so in males. But people with spina bifida can and do have babies.

Tanni Grey, from page 9

was on an adrenaline high. Sixty-five thousand people had watched me win. That moment was like seeing all my dreams come true - and I count myself very lucky that I am one of the few athletes who have actually experienced that feeling.

Going to collect my MBE in 1993 was pretty nerve-wracking. I'd received a list of instructions about

how to curtsy, but it didn't say anything about what to do if you're in a wheelchair. In the end I just bowed my head when I met the Queen - and worried about my hat falling off.

I'd be lying if I said there were no irritations about being in a wheelchair - like dealing with airlines for example. I spend most of my life travelling round the world to compete, but I have to fill in medical forms every time I fly.

One airline even asked me if my condition was likely to be offensive to the other passengers.

If I was asked to say something to inspire other kids with spina bifida, I'd say I could only think of something that applies to all kids. That is: don't believe in the word can't. Concentrate on what you can do and give it your best shot. As my grandfather used to say 'Aim high - even if you only hit a cabbage.'

Northern Ireland schools take lessons on disability awareness from Stephen Kenny

A MEMBER of ASBAH who has joined the growing ranks of wheelchair-users who go out and about giving talks on disability awareness in schools, is Stephen Kenny.

Stephen (*pictured below with a group of pupils*) lives in Ballymena, Northern Ireland and has taken on a voluntary role as schools information officer for the Northern Ireland Council on Disability (NICOD).

Stephen, who gained a number of qualifications at the NICOD Training Centre, says his main aim is to promote better understanding of disability by speaking to school children about his personal experiences.

"I STARTED giving talks on disability to children about two

and a half years ago, when I began visiting primary schools in my home town of Ballymena", said Stephen.

"Having obtained permission from the appropriate education authority, I contacted each local head teacher personally. The response was excellent and, since those early days, my visits to many schools have been an annual excursion!

"Once I introduce myself to the class, I show a short, animated video aimed at breaking down barriers between able-bodied children and those with physical disabilities. I follow this by talking briefly about my own experiences as a wheelchair user, then finish with a question-and-answer sessions which always proves very popular!

"Since last autumn, I have been expanding my horizons to include primary schools in the neighbouring town of Antrim, plus local secondary schools and youth clubs. My style of presentation for teenagers is similar, although I show slides to highlight local access problems instead of the video.

"I have also launched a 'Design a Badge' competition for primary schools to promote integration between disabled and able-bodied people and to highlight the fact that it is 'okay' to have a disability.

"I have thoroughly enjoyed my work to date and I look forward to the challenges which lie ahead."

If you would like more information about Stephen's work, please contact either Stephen Kenny or Robert Wilson (Job Support Worker, NICOD) at the NICOD Training Centre, Galgorm Industrial Estate, Fenagh Road, Ballymena BT42 1AQ (tel 01266-659111).

Automatics - find out before you buy

A NEW leaflet on two and three-door automatic cars has been published by the Mobility Information Service.

Listing over 160 saloons, hatchbacks, and four-wheel drives, director David Griffiths says knowledge gained before purchase "can sometimes mean the difference between success and failure behind the wheel."

Send SAE to Mobility Information Service, Dept 2 & 3 doors, Unit 2a, Atcham Estate, Shrewsbury SY4 4UG.



30 YEARS AND COUNTING. READ ALL ABOUT OUR ANNIVERSARY CONFERENCE IN THE NEXT LINK

Free information from the government

A NEW 166-page guide for disabled people has been issued by the Department of Health containing information about services from Government departments and agencies, the NHS and voluntary organisations. The guide aims to cover sources of help for everyday needs from money to mobility as well as sections on help for people with particular disabilities and their carers.

A Practical Guide for Disabled People - Where to find information, services and equipment replaces an earlier booklet *Equipment and Services for People with Disabilities*, also known as HB6.

The new guide is available free from: *Department of Health, PO Box 410, Weatherby LS23 7LN. An audio cassette version (HB6A) and a braille version (HB6B) are available from the same address. A version for people with learning disabilities will be ready in the autumn.*

Family Fund becomes a trust

FORMERLY administered by the Joseph Rowntree Foundation, the Family Fund has now become an independent trust and is known as 'The Family Fund Trust for families with severely disabled children'.

The trust helps families in the UK caring, at home, for very severely disabled children under 16 of age. Examples of grants: holidays, help with laundry costs, special play equipment. As well as providing grants for items related to a child's care needs the Trust aims to pass on information to families about other services and benefits.

Further information from: The family Fund Trust, PO Box 50, York, England YO1 2ZX.

Chorister is in peak form for his fortieth birthday!

THOUGH doing nothing to deserve them, Andrew Gilson has now reached that certain age when he has to fend off jibes that 'Phyllosan fortifies the Over-Forties'!

Plans for an enormous 40th birthday party in the Derbyshire Peak village of Penistone had to be called off three weeks before the event earlier this year – when he had to go into hospital for shunt operation.

But, without the aid of any bottle of tonic, Andrew proved he was no party pooper. He bounced back to form after the operation so quickly that he was able to enjoy a lively family dinner laid on by his parents in a nearby restaurant.

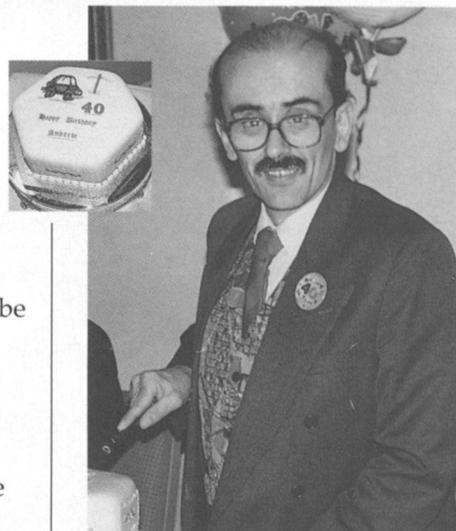
"A couple of dozen relatives and friends turned up and we had a really good time", said Andrew, who had 96 stitches put in his back when his spina bifida was operated upon by neurosurgeon Robert Zachary on the day he was born.

His father Frank, who lives in Chesterfield, commented: "On his 40th birthday, he looked as if he had been on holiday rather than in hospital!"

Andrew, who had his first hydrocephalus shunt inserted seven years ago, has lived life more fully than most.

He is a Methodist Church steward in Penistone, a member of the South Yorkshire Celebration Choir and a Samaritan in Barnsley, where he has been a volunteer for 14 years. Until recently, he was also a Boys Brigade officer – until Brigade nights started clashing with choir practice.

Andrew lives in a housing association bungalow specially adapted for someone in a



Andrew 'looking as if he has been on holiday, not in hospital'.

wheelchair. Andrew does not use a wheelchair but, because he stands just over 5ft high, the low-level fittings suit him just right.

Finding work has never been easy. After training in office skills at Portland College for the Disabled in Mansfield, he took two jobs as a receptionist. Both disappeared when the companies went out of business. Unable to find work since then, the church and his singing have kept him busy.

And the Pennines, those glorious peaks which provide the backdrop to his home, fly by as Andrew drives to appointments in his colourful new Vauxhall Corsa car from Motability.

It's a far cry from his first driving lesson at the age of 16 in Portland College, when he took a corner too fast and turned his 'Noddy' three-wheeler over. No real harm done – just a bruise or two, a dent in his pride and a scratch or two on the car!

"I've fallen in love with the Corsa, which is in this fabulous Atlantic blue colour. Woe betide anybody who puts a dent in this one", said Andrew.



Behind the Wheel

The British School of Motoring has the largest driving instructor training facility in the UK. So why don't they have any disabled driving instructors?

This is one of the questions we raised when Keith Cameron and Martin Arnold from BSM came to tell Link what they can offer disabled learner-drivers.

Q *Are any of your instructors wheelchair users?*

A No - but this is for legal reasons. At present, instructors have to be able to drive a manual car and be able to show someone else how to do so. But the law is likely to change this summer. It has taken six years to get to this point but the Department of Transport now wants those who only drive automatics to be able to become instructors. When the law does change, BSM will certainly be looking to train disabled drivers who wish to become instructors.

Q *How many of your customers are disabled?*

A About five per cent. We have 2,000 cars in the fleet - just over 200 of these are automatics and half the automatics are used by disabled learners.

Q *What kinds of cars do you use and how are they adapted?*

A All the automatics are Vauxhall Corsas. These are adapted to one of three levels:

Level one - basic automatic with power steering, and left and right foot accelerator

Level two - as above, plus push/pull hand controls and steering ball, quick-release handbrake.

Level three - as above, but with infra-red switching for indicators/wipers/horn and lights all located on the steering wheel switch.

Q *Are you able to offer any adaptations specific to an individual learner?*

A We wouldn't like to give the impression that the cars are individually adapted or, conversely, that there is no possible leeway. We can sometimes make small specific adjustments - pedal height for example - but these will depend on cost. We would also expect a customer to have paid for a bank of lessons before adjusting a car for them. Of course, if the person wishes they can be taught in their own car.

Q *What kind of training do your instructors receive to help them teach disabled learner-drivers?*

A Banstead Mobility Centre runs a course specially tailored for BSM. Instructors have usually been with us for three or four years before they go to Banstead, as this is not a course to learn to be an instructor but to learn how various disabilities impact on driving.

Q *Do you teach any other related skills relevant to a disabled driver - how to get their wheelchair in and out of the car, for example?*

A Not usually, because our instructors are there to teach the person to drive and they will use the full hour to do so. If we had a specific request we would try to find someone who could help - at an assessment centre, for instance.

TV PRODUCERS ARE TAKING A FRESH LOOK AT DISABILITY - READ PAUL DARKE ON PAGE 16

Q *Can you provide information on related matters, such as insurance?*

A Every branch has a comprehensive disability information file with lists of adaptation companies, insurers, assessment centres etc. We also have a helpline for disabled drivers on 0181-545 1390.

Q *There's a new theory test coming in on 1 July - are you getting lots of enquiries about that?*

A Yes - we've set up a special number to deal with them and issued some basic facts about the test. The theory test advice line is a free phone number: 0800 700 800.

Q *In your information about the new theory driving test you say that either the practical or theory can be taken first, until January 1997, will this change after that date?*

A After 1 January 1997, you will probably have to take the theory test before you can apply to take the practical test. BSM feels that you should be able to do the test in either order so that you can learn the theory and practical together. So we'll be pressing for this option to remain.

Q *Can candidates have a trial run at the theory test?*

A Yes, BSM is running mock tests in its branches, under exam conditions. We then discuss the results immediately and the results are fed back to your instructor so that he can help you iron out any problems.

Q *Can the new test be taken again if you fail the first time?*

A The theory test can be taken as many times as you like - as with the practical test - though, of course, you have to pay the fee each time you take it. Also, the theory test is valid for two years from the date of passing - so you will need to pass the practical test within this time.

Top 10 facts on the Theory Test

1 - The new theory test is launched on 1 July, 1996.

2 - There will be 35 questions on the test paper, chosen from a total of around 600.

3 - Topics will include the highway code and broader motoring knowledge, such as hazard perception, understanding causes of accidents, night / motorway / bad weather driving, the effects of alcohol and drugs on driving, first aid, basic vehicle maintenance and environmentally-friendly driving techniques.

4 - Questions will vary between text-based, road sign graphics and photos of road and driving scenarios.

5 - The test will last 40 minutes, but with extensions in some cases.

6 - It is expected that the Driving Theory Test will cost between £13 and £15.

7 - The maximum time allowed between taking the theory test and the driving test will be two years

8 - Drivers with a disability will be able to take the new test on reaching their 16th birthday.

9 - You will still be able to take driving lessons with a professional instructor before you take your theory test.

10 - From July to December 1996, you can take either the driving test or the theory test first.

How to get BSM's help with the new theory test

ALL learner drivers who are taking their test after 30 June this year will have to pass a new theory test, as well as the usual practical driving test.

There will be some special provisions for disabled drivers who need them, such as extra time allowed for people with reading difficulties and wheelchair-accessible Theory Test Centres.

You should give details of any special requirements you have on the test application form.

BSM has a 'Theory Test Advice Line' (freephone 0800 700 800) and they are happy to answer any queries you have about the new test.

The brothers with inherited hydrocephalus – how my case notes sprang into life

Monique Jouet was on the team which discovered the gene responsible for X-linked hydrocephalus – the most common form of this inherited condition, usually affecting only boys. She felt she would like to meet one of the families involved, instead of knowing them only by their case number, Family H7. The Towser family agreed to meet Dr Jouet.

Mr and Mrs Towser have two sons with X-linked hydrocephalus: Mark who is now 13 years old and Andrew who is 11 years old. They have an older sister Clare who is 17 years old. Mark and Andrew were not at home on the day of my visit. They were spending the week in a respite home. This arrangement is designed to give their parents a "week's rest" in which they are less busy and able to devote more time to their daughter and themselves.

This account was written on the train during the journey back from Birmingham to Cambridge, so that I would never forget that day.

MR AND MRS Towser and their family live in a quiet, small mining town near Coventry. I informed them of my approximate arrival time and, as the taxi pulled into their close, I saw them waiting on the doorstep.

They invited me in and we talked briefly about my journey to Birmingham and what I was doing there (I went to give a lecture at Birmingham Hospital's Department of Medical Genetics).

Mr Towser said: "Here they are!" On the wall above the mantelpiece, there was a picture of Mark on the left handside, and on the right handside a picture of Andrew. Below, in the middle, there was a picture of their sister.

Mrs Towser commented on how similar they looked and how they could easily be mistaken for twins.

Mr Towser asked me details of our research and if we were going to publish our findings in a book. He



by Monique Jouet PhD
Researcher, Addenbrooke's
Hospital, Cambridge

was stunned to learn that there were no personal lucrative rewards to our research beside our monthly salary. I don't think he believed me! He expressed their desire to receive any publication that would include the study of their sons. He had to go out for a short while and Mrs Towser and I were left to talk to each other.

Mrs Towser told me what a relief it was for them to know what was wrong with their sons. She described her frustrations during Mark's early childhood: he could not drink milk like his sister had done as a baby. He did not talk by the age of two and she knew that was not right. She told her health visitor about it, who told her he was just a late developer and remarked that she was "fussing too much." She remembered feeling stupid bothering them about it, but she knew it was not right.

When Andrew was born, she recalled he was very thin ("a bag of bones") with very thin legs. He was not feeding properly. He developed what originally seemed to be an ear-ache and eventually had to be admitted into Birmingham Hospital for an emergency valve insertion in order to control his hydrocephalus.

Mrs Towser had never heard of hydrocephalus before and she was shocked by the news.

She decided to find some old photographs of Andrew to show me how tiny his legs were when he was born. She hurried up and

down the stairs and came back with six photograph albums.

We looked through the albums together, the photographs were arranged in a random manner, many were missing and many were loose. There were many photos, mainly of Andrew and Mark.

Mrs Towser commented: "If you did not know that they are the way they are, you would not guess it from the photos."

I agreed and thought to myself that indeed they looked odd ones out among the other children from their special school, most of them looking like they had Down's Syndrome.

I commented on how jolly they always looked on the photographs. She replied that, if I wanted, I could have them for a week and laughed.

Mark goes to mainstream school once a week. Mrs Towser showed me the white building through the curtains. He goes as part of an insertion programme. Since he has been going, he has made a lot of friends with the local children.

Mrs Towser pointed out that some of them used to tease him before he began the insertion programme whereas now they come and play with him.

Mr and Mrs Towser insisted that I should take some of the photographs back to Cambridge with me. I turned down their offer and said I could not possibly do that. However, they insisted and since they would not let me go without any, I agreed to take three, of which I would have copies made and return the originals.

Mrs Towser said it was "important for me to take photographs to show them in Cambridge, for people to understand. . ." Mr and Mrs Towser had planned to take me to visit the centre where Mark and Andrew were staying. Although they had told me the respite home was quite close, it felt like a long drive to get there. . .

We arrived and we were told that Mark and Andrew were in their bedroom. The door opened onto their bedroom, we glanced at each other and the faces from the photographs were finally moving. Their father introduced them to me and I shook their hands.

The respite home was bright and we all went to sit in the lounge. There was a little girl sitting on the sofa, crying and eating her fist. I felt sad. I sat next to Mark on a sofa, Mrs Towser sat on the floor and Andrew sat on his Dad's knees. Mrs Towser asked them about their day. Andrew's speech was easy to understand whereas Mark's was not. He said a few key words and accompanied them with sign language. Andrew was very talkative and we learnt that he had been painting at school on that day.

They had both been putting their clothes away, getting ready to go home the next day; Mark said the word "case."

Mr Towser told them who I was and Mark pinched the skin from the top of his hand and pointed to it with his index.

Mr Towser understood he was asking if I was going to inject him with something or take blood. We both reassured him and I smiled at him.

Travelling through the village Mark had recognised one of his aunts, he said "Bus .. aunt." Mrs Towser guessed which one he meant. Mr Towser told Mark I had come by train. He looked at me and said: "train?" so I replied "yes", he then said: "car?" and I replied that I preferred travelling

by train since I could read or sleep and that was impossible in a car. He looked at his father with his eyes wide open and said: "car .. schleesss?" and seemed worried. I understood that the prospect of sleeping while driving worried him.

While Andrew was talking to his father, Mark put his fist to his right ear and said: "phone". I asked him if he phoned anybody and he pointed at his dad and looked at me. Mr Towser said that he could remember him ringing me at the laboratory the week before.

While Andrew and his parents were having a conversation, Mark focused on whoever was speaking. He did not seem to miss out on any of the conversation.

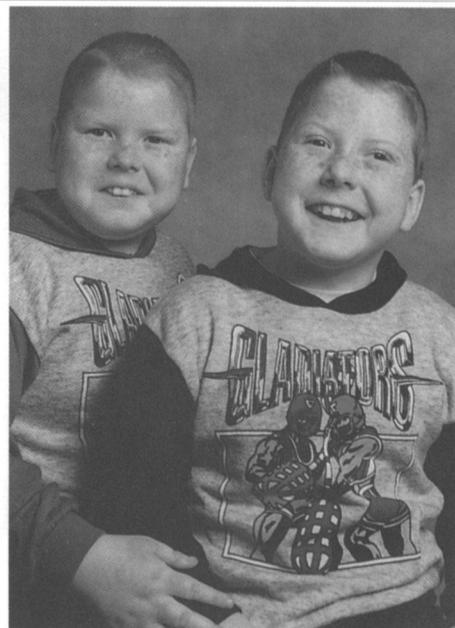
Mr Towser asked them if they would show me around the home. Andrew jumped off his seat and led the way followed by Mark and myself. Both of them walked using the front of their feet only.

Andrew had a very noticeable lordosis but he walked the fastest (I had to keep up with them). He was told by his mother not to run too fast. Mark was a little slower with his feet noticeably facing inside. He was also heavier than Andrew.

As we went around the house, Andrew announced each room very clearly: "kitchen, toilet, shower ..."

We went back to the lounge where we were offered a cup of tea by the caretakers. Being too far away from the coffee table, I balanced mine on my knees. Mark took one long look at it and said: "fall." I agreed with him and put it on the floor.

Mark and Andrew went off to have their supper and Mr Towser asked me what I thought of them. I said that I found them very alert



and aware of everything going on around them.

Mr Towser agreed and said that what he notices most is how they are changing and progressing all the time, and how good their memory is.

Mrs Towser said how glad she was I had met them, and that I could now explain to everyone in Cambridge what they were like. She said she no longer feels the early frustrations of not knowing what was wrong with them, with the never-ending blood test requests – every time fearing the worst for her sons.

Mr and Mrs Towser are proud of their sons. I understood that much from this visit. They are pleased and hopeful to see that they are growing up and changing as time passes. We did not talk about the future and their fears about that.

I was amazed to find two happy little boys when I met Mark and Andrew. In retrospect, I had no idea what to expect. Reading clinical notes and papers gives a picture of what is abnormal. On my visit, I met Mark and Andrew and their family, not just two patients affected by a rare disease caused by an L1 mutation. I learnt a lot from this trip.

Meeting the boys



Darke at the cinema by Paul Darke

BACK IN March, I was invited to a seminar at the BBC by Charles Denton (the retiring head of BBC Drama), *Portrayal and Participation*, and being ever inquisitive (and a bit of a celebrity spotter) I went. The event was organised by the *1 In 8* team and led by Richard Rieser, a leading activist in trying to get better images of disability in to all forms of the media, especially on our television screens.

The seminar lasted the entire day and a sumptuous lunch was provided (I easily got my television licence fee back). The first part of the day involved us sitting through a very lengthy lecture by Rieser followed by a discussion of that lecture and, in the afternoon, we had an open 'creative thinking' session where an ideal drama was imagined which did not tread on the sensitive toes of us critics of the negative portrayal of disabled people. There was no lack of talent in the audience: most people

involved the DPU (Disability Programmes Unit) at the BBC; those involved with ITV's flagship disability programme *LINK*; representatives of RADAR and Equity; people from the soaps *Emmerdale* and *Eastenders*; and numerous actors (for example, Gareth Hunt and Arabella Weir), executives of the BBC (Alan Yentob) and distinguished writers and producers (Kieran Prendiville and Kenneth Trodd).

The lecture covered the usual ground - disability used to signify evil and dependence etc. - but even so it was a revelation to many there and, to their credit, they were prepared to admit their ignorance. Kenneth Trodd (the producer of most of the late Dennis Potter's dramas) made an interesting point when he noted that the representation of disability in the work of Dennis Potter is ignored because it is so realistic and astute, and not in any sense clichéd. The writer of *Soldier, Soldier*, Lucy Gannon,

noted the responsibility writers have and also connected images of disability with images of black people; in fact, her eagerness to take on board issues of disability made me very keen to see what she writes in the future.

All in all, it was a very useful day which will no doubt enable a few more disabled actors to get roles in television and in movies, along with material made that is more sensitive and aware of disabled people's feelings and perspectives. It was also encouraging to see many disabled writers vocalising their existence along with an openness on behalf of the able-bodied producers both within and outside of the BBC - the most open media broadcasters in relation to disability at the moment - to listen to and consider projects about and by people with disabilities (so get those scripts and ideas in now!). The only danger for the future - and it is a very real danger, if not a reality already - is the creation of a disability media Mafia.

Watch this space.

HOLIDAYS * HOLIDAYS * HOLIDAYS * HOLIDAYS * HOLIDAYS

B & B WITH A DIFFERENCE

At their traditional stone cottage in Pendeen, West Cornwall, Tracey and David Watkins run a Bed & Breakfast with a wheelchair-accessible bedroom and shower. They also offer 12 hours of support a week so that, if you care for someone with a disability, you can holiday together - yet spend some time apart. *Tracey Watkins, 'Mara', 2 Boscaswell Terrace, Pendeen, Penzance, Cornwall. Tel: 01736-787406.*

SMOOTH RIDE IN THE STATES

Smooth Ride Guides: these are a series of guides for travellers in wheelchairs, who wish to travel to destinations further afield. The

guides provides practical information in advance of travel. The latest *The United States Eastern Seaboard* is out this month. Guides to other parts of the States, Canada, France and Spain are in the pipeline. *FT Publishing, tel: 01279-777966.*

SAFE BLOOD ABROAD

The Blood Care Foundation provides screened blood, resuscitation fluids and sterile equipment, in emergencies, to its members in any part of the world. This may be of interest to those travelling to destinations where lack of sterile clinical condition gives rise to concern about the safety of blood

products. *The Blood Care Foundation, tel: 01732-742 427.*

GUEST HOUSE IN CO DOWN

A guest house for disabled people opened in Portaferry, Co Down, Northern Ireland, in May. Called *The Narrows* is on the seafront overlooking the mouth of Strangford Lough. Eight of the 13 bedrooms are level, with fittings that can be used by wheelchair-users and non-disabled guests. En-suite bathrooms include some wheel-in showers and baths with bath seats. Rates from £24 B & B, mini-break rates on application. *James Brown, The Narrows, 8 Shore Road, Portaferry, Co Down BT22 1JY. Tel: 012477-28148.*

Hydrocephalus Network News



SUMMER 1996

ASBAH, 42 Park Road, Peterborough PE1 2UQ

Tel: 01733 555988 Fax: 01733 555985

Reg Charity Number 249338

Network Co-ordinator: Rosemary Batchelor

Are you insured? Check – before you travel!

IF YOU are going abroad this summer, do make sure that your holiday insurance covers the member of the family who has hydrocephalus, in the event of any shunt problems.

One of our colleagues read a letter in a woman's magazine recently, from a reader whose insurance company refused to pay up for shunt-related problems as she had not informed them about the hydrocephalus when taking out the policy.

It is up to the customer to tell

the insurance company any "material facts" which might affect their offer of cover.

If you have a problem with obtaining travel insurance, our Information Department can give you details of companies who do accept people with hydrocephalus.

Please note that, although the Information Department does have lists of neurosurgery facilities in the USA and France, unfortunately they do not have this information for other countries.

Bits 'n pieces

ALERT CARDS: let us know if you lose your shunt alert card, or if it has got very dog-eared round the edges! We can supply a replacement very quickly.

LIZ CAWTHORNE, fresh back from maternity leave (having had first baby Catherine), will return to

the editor's chair from the next issue. Please write to her if there is anything you want included, or anything special which should be put in. It's best to write because Liz will be working mostly from home, but messages can be left with colleague Tony Britton in the news room at ASBAH (tel 01733-555988).

What have you been missing?

ASBAH publishes a lot of material about hydrocephalus in its magazine *Link* which, because of pressure on space, does not find its way into *HN News*.

Recent articles include:

Link No 164

- ◆ *Dr Roger Bayston's research on CSF shunts.*
- ◆ *Behind the Wheel - BSM's work with L-drivers.*
- ◆ *The brothers with inherited hydrocephalus - researcher describes her home visit.*
- ◆ *Your Voice in ASBAH, Playing a Part*

Link No 163

- ◆ *'Golden Oldies', feature including Elaine Baly, who developed hydrocephalus when she was 70.*

Link No 162

- ◆ *'Language comes First', a speech therapist explains problems likely to be experienced by children in reception classes and some practical first steps to help children succeed.*
- ◆ *MRI scans: a personal view (letter).*

Copies of these articles can be obtained free of charge from our Information Dept at Peterborough, but please enclose SAE. Alternatively you may like to subscribe to Link. It costs £4.80 a year. Please send cheque (payable to ASBAH) to Publicity Manager at above address.

A Winner Never Quits!

SOME 20 years ago, PAUL LIDSTONE'S hydrocephalus left him unable to speak, walk or eat solid food and it seemed that he might have to be in hospital indefinitely. Today you might find him in hospital - but not as a patient. For Paul has recently qualified as a nurse. This is his story.



UNTIL the age of eight, I had been a typical young lad, playing all the rough games and getting into scrapes synonymous with growing up. However, in January 1974, much of that was to change. . .

The vomiting that my mother thought was simply a stomach bug had not cleared, and when I was sick for the third time in as many weeks my mother took me to the doctor the following morning – a Saturday. She explained that I would be sick without any warning, but would be able to eat anything immediately after.

My mother recalls the doctor looking into my eyes with a light, and immediately sending myself and my younger brother on an errand for him. Alone with the doctor, my mother was told that I was seriously ill, and that if I was the doctor's son and he could have got me into

hospital there and then, he would. My mother would hear from him again later that day.

Dumbstruck, my mother went to my father at work. They told me that I would be going into hospital soon. My parents tried desperately hard to make it sound like an exciting holiday, and bought me new pyjamas and wash bag. They recall how desperately difficult it was for them to hide their fear, and at the same time, cope with my enthusiasm to go into hospital.

The doctor rang, and said he would be visiting with a paediatrician from Torbay Hospital. After they had been, the following day I was admitted to Freedom Fields Hospital, Plymouth, with a suspected brain tumour, one week before my ninth birthday.

Numerous tests, x-rays and scans were performed, after which it was decided to insert a shunt to drain excess fluid which was putting pressure on the brain.

I remember I was due to have an operation on my birthday, but the surgeon cancelled it when he found out, and also gave me a card and small gift. The children's ward also had a birthday cake made for me.

I was in no mood to do schoolwork, and I used to

dread the sight of the teacher on the ward who, whilst only doing her job, would try to ensure that some form of work was done by each child on the ward who had their eyes open! However, the friendly face and cheerful voice of the "comic man" distributing the papers nearly made up for it.

The hospital meals were somewhat less than appetising, yet the nurses would insist that I ate. Fortunately, the canteen did a nice line in ham rolls I recall, at least sufficiently nutritious to keep the nurses at bay! I also remember drinking ice-cold milk by the gallon to quench my thirst. My most vivid memory, and that which left the biggest psychological scar, was coming round after an operation with a shaven head. The physical pain can be forgotten, but being deprived of a part of your personality leaves a wound that never quite heals. In later operations it was only partially shaven.

The doctors found that the ventricles were too narrow to allow fluid to pass through the brain. As a result, I was in hospital for six weeks. On one occasion, I remember being conscious going to theatre. Some months later I recognised someone from theatre in a pub, and he came and talked to my parents.

My brother, younger than me by five years, suffered in a different way. He became disruptive at school and quite volatile. On one occasion he ran away from school, only to be dragged back, kicking and screaming, by a senior teacher. He recalls drawing beards and moustaches on a large 'Slade' poster on my bedroom wall in an attempt to gain some attention, but has lived with the guilt ever since. He more than made up for it in later years, however, by giving me a poster with a motto which I still quote to people today when asked about my outlook on life: 'A winner never quits. A quitter never wins.'

In June 1974, I had another relapse and was re-admitted to hospital for two weeks for the shunt to be renewed. I remember being aware of wetting myself when things were going wrong, but being unable to do anything about it. The pain of the headaches was intense, but the fear of the procedures was even more acute, particularly those where I remained conscious, such as boring a hole in the catheter to obtain some fluid for testing.

In September 1974 I had to be readmitted to Freedom Fields for further surgery. According to my parents, this was the worst, and longest period of surgery – sometimes twice a day. The shunt was removed, replaced and moved from side to side. All the neuro staff were baffled. I was in hospital for three months.

At this point, after 14 shunt revisions, my parents were seriously discussing whether or not to consent to any more surgery, believing that enough

was enough. However, they decided that if I had any chance, they had no right to deny me it.

The next stage took place at Great Ormond Street Hospital – we all went as a family. Here, over a period of two weeks, I underwent more tests and an operation. My brother remembers being constantly taken for walks in the park, nearby. Whilst at Great Ormond Street, my brother experienced further trauma, losing a treasured toy. However, the hospital staff let him keep one of theirs, a gesture he remembers with great affection.

The tests at the hospital revealed that the shunt was working and, as was thought, there was no tumour.

I returned to Plymouth, to Freedom Fields Hospital, where semi-permanent hospital accommodation was being discussed for me.

However, my parents flatly refused, and returned home to Brixham with me.

I was in a very bad way – incontinent, unable to speak, very little control over my mouth movements, and able to eat only liquidised food. My father used to carry me on his back up and down the stairs. Simple exercises involving lots of movement, such as clapping hands and raising legs were undertaken by my parents in liaison with a local physiotherapist. I improved very slowly and was able to walk to the garden where there were exercises with a ball. Exercises with numbers, shapes and colours continued along with simple puzzles.



Gradually, I was able to resume playing cards, a pastime which I still enjoy to this day.

Regular trips for check-ups were made to Freedom Fields Hospital. On one visit I was assessed to attend Dame Hannah Rogers' Special School at Ivybridge, but my parents wanted me to remain living at home, and hoped that I would re-enter mainstream education.

I then seemed to go from strength to strength, and one evening whilst watching television, I spoke – 'Rubbish!' I was still nine years of age.

I became stronger, and returned to junior school – mornings only at first. Physical education was allowed, but no contact sport initially.

My progress continued to the 11+ which I passed. I was off to Churston Grammar School! I was holding my own academically and though unable to play rugby, for reasons that I understood, I was able to play football,

continued on page iv

continued from page iii

provided I did not head the ball, and was good enough to play for my year.

Whilst I was very pleased, indeed proud, to be at Grammar School, it came at a price. I have vivid memories of having to constantly turn the other cheek in case a fight broke out, and having to take insults and abuse without returning it in case of provoking violence. However, the point at which I still regard as being my lowest was when I was advised by

News from 'down under'

IN 1992, Penelope Wilkinson set up Hydrocephalus Education, Action and Development (HEAD) in Australia – for people just with hydrocephalus.

A letter in a women's magazine produced a first harvest of 15 inquiries, the first from a mother in New Zealand. Fourteen more joined up the following year, then seven in 1994 and 18 in 1995.

"We now have over 40 members. Five of them developed the condition as adults, so (contrary to what many people think) it is not just just a condition experienced by children", writes Penelope.

I hope we will achieve the education, action and development that our condition deserves.

my surgeon to stop playing football for fear of getting hit on the head.

I had a further relapse at the age of 13. This time, however, it was quickly resolved in two weeks with a new shunt in place.

A normal, active life followed. I joined the local athletic club, where I was elected club captain for a period, went to discos and learnt to drive.

At the age of 19, the shunt needed renewing. I remember telling Jill, my girlfriend at the time, that I would understand

if she she did not want to carry on the relationship. We have now been married for over seven years!

I gained 'O' and 'A' Levels and my experiences led me to work in the caring professions, including special schools similar to the one for which I was assessed.

I have recently gained a Diploma in Higher Education (Nursing) and qualified as a Registered Nurse for the Mentally Handicapped (RNMH).

Question Time

I AM an 18-year-old girl with hydrocephalus. There has been a lot of media coverage recently about Folic Acid, and I have noticed that there are two different doses to take. I am confused about what dose I would have if I wanted to start a family.

S L, Derby

It would really depend on the cause of your hydrocephalus. Folic Acid is taken to decrease the chances of having a baby with a neural tube defect, like spina bifida. In the main, hydrocephalus is not classed as a neural tube defect and therefore the lower dose of 0.4mg could be taken. It is not easy to give advice without knowing

your full history, so it would probably be best for you to talk to your GP.

I AM going on holiday and worried about going swimming. I am worried about the effects of water on my shunt. Can you give me any advice?

L J, Milton Keynes

Please don't worry about swimming with a shunt. It is perfectly safe, and the water will not harm it in any way.

I HATE hearing sick jokes on TV about people having 'water on the brain'. It's no laughing matter. Can anything be done to stop it?

I P, Blackpool

People can be insensitive clods. Give ASBAH full details, and we shall take up your complaint.

Your Voice In ASBAH, Playing a Part

THE 'YOUR VOICE IN ASBAH' (YVIA) Steering Group identified a need for training courses to help young people with spina bifida and/or hydrocephalus take a greater part in the activities of their local or national ASBAH. A pilot course designed specifically to meet this need was held at Hereward College, Coventry, in March. The trainer was Ann Macfarlane (who is disabled) from Consultant Disability Services.

A group of YVIA members attended the course along with Teresa Cole, ASBAH'S Senior Services Manager, who acted as a co-ordinator. Hereward College is a specialist college for disabled students and has excellent staffing and facilities to meet the wide range of needs of their students. ALAN TWYFORD of YVIA describes the weekend.

Friday 29 March:

On arrival, we were introduced to a member of staff who would remain in the background throughout the course but was always there to help if required, before being shown to our rooms.

A buffet supper was followed by an "ice-breaking" session with Ann, our trainer. We talked about our involvement in disability issues and our expectations of the course. After our discussions, some members retired to bed but others stayed up to read some of the 17 items contained in the course training pack which helped to 'round off' the topics covered during the evening.

Saturday 30 March:

After a hearty breakfast we assembled to start the main part of the course.

In a 'brain-storming' session we looked back at how our families must have felt soon after our birth. This exercise effectively introduced the issues to be explored over the weekend. Much of what was said showed the negative side of the so-called 'medical model' of disability which looks at people's inabilities and their medical conditions. We then went on to look at the 'social model' of disability – preferred by disability groups – which

emphasises the person's strengths, wants, needs and how society can enable the person to utilise those strengths.

During coffee, our animated discussions continued as we started to come together as a group. Afterwards we began to look at the Disability Movement. The group had a wide age and disability experience range: some of us were present or former local ASBAH group members; others were working on or with their committees and a few were involved with local access or disability groups for people with any kind of medical condition.

A clip from a video showed that Sweden has an enlightened attitude towards its disabled people. The transport system is largely wheelchair accessible.

They also have a specific whole-life disability pension scheme for disabled people which must be a marker for other countries, surely?

Look at Risk-Taking

The Saturday afternoon session started with a look at risk taking. It is quite often the case that those of us with disabilities grow up over-protected. This is understandable, but can lead to people becoming dependent solely on others and lacking motivation. It was pleasing to find, when groups recounted times that they had taken risks, that we all had something positive to contribute.

Independent Living Schemes

Independent living was our next

continued on page 22





Kevin Towner holding his prize for being the winner of the general knowledge quiz.

continued from page 21

topic. An Assisted Independent Living Scheme is when Social Services work with a disabled person to assess his or her needs and then grant a sum for personal care. This is then used by the disabled person for recruiting and employing a PA or personal assistant, whose duties could vary from housework to help with bathing, dressing and continence management.

Although some Social Services departments started this some years ago, they had to stop (or find a loophole to enable them to continue the scheme) when the Treasury declared that direct payments were illegal under the 1948 National Assistance Act. The Government are relenting and it is hoped that a Bill will become law in the autumn to empower councils to introduce direct payments and Independent Living Schemes. Several of our group felt they would be likely to want to make use of these schemes if they are available in their area.

The Disability Movement

Following on from our discussions about the empowering nature of ILS, we then looked at the control of disability organisations by disabled people, and the Disability Movement. Some of the activities of the Disability Movement have been 'risk taking' by those who have taken direct action, for example trying to get on a bus with a wheelchair and then clamping themselves to the bus. This type of action has gained some publicity and highlighted difficulties faced by disabled people.

Other action from the Movement has been subtler, shifting control of local organisations of disabled people to 50% or more disabled members. This has allowed for speedier and more imaginative working alongside social services staff, such as funding given to run holiday, equipment and other grant schemes for disabled people. It was explained that, in some areas, disabled people were able to set up their own Centres for Independent Living (CILs) where social services departments worked with local groups to fund service provision for and by disabled people. The range of services provided under these schemes varies from area to area.

All work and no play...

After a very full day we had a fun social evening with a general knowledge quiz hosted by Teresa and her husband. Everyone took part, including Ann and her PA, Babette, from Norway. There was something for everyone and prizes were duly awarded.

The final day

Our final morning was taken up with looking at the practical aspects of committee work and the factors to be taken into account before

during and after a committee meeting. This included the need to take into account those extra requirements which might be needed to enable a disabled person to take an equal part in the meeting. Other points were covered such as declaring in advance the time to be spent on each item, to ensure that meetings are not too long and to allow for each item to be debated. We also role-played a scene from a fictitious committee to see what it might feel like, and to see how body posture or language could play its part in meetings.

Action

We assessed the weekend and talked through the things we would be able to take forward and how this could be done. Everyone felt they had gained from the weekend.

We agreed that we would have a YVIA group meeting as soon as possible to 'dissect' the weekend and prepare a plan for others wanting this kind of training. The weekend was successful and gave us all the chance to take new skills and enthusiasm back to use with our own groups (ASBAH and other). It was also a strengthening exercise for all the group.

YVIA is the user group forum of ASBAH. It advises on all matters of policy concerning the service ASBAH provides for disabled members.

How to contact YVIA

To find out more about YVIA please contact *The Chairman, through Teresa Cole, Senior Services Manager, ASBAH House, 42 Park Road, Peterborough PE1 2UQ or telephone 01733 555988.*



Confidence came at the quad bike club

AS A THREE year old, our son Danny who is now seven, had the problem like so many other children with spina bifida and hydrocephalus; that he was old enough to be wanting to get around outside, yet too small for a wheelchair. This problem was overcome by a Christmas shopping trip and the purchase of a battery-operated quad motorbike. This allowed Danny to move around the garden with ease, as the only requirements needed were a little steering co-ordination and a thumb to press the "GO" button.

This was the start of a love for motorbikes, and most importantly an early "step to freedom", though it did have its downfalls, in the shape of large chips from the skirting boards and forever having to get him up and turn him round everytime he hit a chair; as there was no reverse gear. But, above all, he was able to get from A – B outside without grazing some part of his body.

After about eighteen months, we started to see Danny thrusting himself forward on the bike as he was riding it, then came the big statement: "This bike isn't fast enough." This was true enough and not only that but he had grown out of it. Then came the big problem of what do we to replace it. After many trips to numerous toy shops, we had come up with no answer – as all the larger version were foot operated. I then thought of all the many ways I could adapt one of these machines, when I remembered I had seen a larger petrol-version on a farm, and wondered if they made a child's version.

Upon the second phone call that I made, I was told by a Suzuki motorcycle shop that they now have the ideal thing. I immediately drove round the shop to find a bright yellow 50cc quad motorcycle awaiting my inspection. Apart from it looking a little on the large side, it was perfect. All the controls, accelerator, brake, and cut-off switch, were hand-operated. It even had a speed regulator from which the bike could be reduced to walking pace and, at the back, a pull-cord so a supervising adult always had total control.

On return home, I explained everything to my wife. She could not wait to see it. So the next day we all went to have a look and let Danny have a sit on it. Apart from the size problem (which was not really a problem because, even if his feet could touch the pegs, he would not have felt them anyway) it was perfect. Then came the big crunch – finding £900.

But, with some assistance from our fieldworker, numerous charity pots dipped into (including ASBAH's) a few months later we had managed to raise enough money and Danny became the proud owner of a Suzuki LT50 Quad Motorcycle.

This opened up so many new areas to Danny. No longer did he have to be pushed through muddy fields or along bumpy awkward paths. He could now see the countryside for himself and under his own steam. It was not an overnight success, as it took him months to get to grips with all the co-ordination needed to



BOY RACER: pictured above is seven-year-old Danny Brown on his 50cc Suzuki Quad Motorcycle

confidently control the bike – although you would not think it now, if you saw him doughnutting it in the mud, or see a blur wizz past you at 40 mph. What is best of all, and what I would like other parents to be aware of, is how much independence he has gained, and the sheer joy on his face when he rides it. The question we are so often asked is: "Has he ever fallen off it?" The answer is yes, and several times, but so would an able-bodied child.

Danny now fancies himself as the next budding Barry Sheen, and to this point I would like to draw your attention. I am trying to start a Disabled Children's Motorcycle Club, so that other children can enjoy the same freedoms as Danny, and to which funds have already been promised. This is one sport where wheelchair children can compete as equals to able bodied children, if anyone would like any further details please contact:

Mr or Mrs Brown on 01904 639393, for THE GREAT OUT OF WHEELCHAIR EXPERIENCE.



 LAST year I returned after my single-handed 285-day record-breaking voyage around the world on my yacht Spirit of Birmingham. The voyage lasted 285 days and was an experience which tested my courage and stretched my endurance to the limit.

In November I was honoured to meet 16 other equally outstanding and courageous people all of whom had remarkable stories to tell. We were at a special luncheon

hosted by HRH the Princess Royal to receive a RADAR 'People of the Year' award.

RADAR is the country's leading disability charity and annually it recognises a special group of people who have distinguished themselves through their courage, service or achievements.

There was the AA patrolman who rescued two people from certain death whilst putting his own life at great risk; the two doctors who carried out a life-saving operation

Information is power

ONE OF Britain's best-known scientists, Professor Heinz Wolff (pictured below), has presented the first *Getting the Message Across* awards to mark outstanding achievement in informing disabled people.

Organised by the 15-year-old National Information Forum, the awards ceremony at London's BT Tower honoured work which tackled problem areas which result in disabled people suffering heavy penalties for missing out on information – wrong decisions, lost opportunities, wasted time and money, and exclusion from community life.

Selected from 59 nominations, the awards included initiatives to enable blind people to read menus, follow country trails, explore public buildings and find their way around the London Underground. Other bright ideas included free info from a market stall, route-finding and access maps for disabled motorists and a wind-up radio.



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

aboard a plane 30,000 feet in the air; the teenager who reported her ex-boyfriend to the police for his part in a violent racist attack, even though it meant her life was threatened.

And this is where I am asking for your help. RADAR is already planning the 37th 'People of the Year' awards luncheon which will be held in November. They would love to hear from any reader with a nomination for this year's awards. It is entirely up to you who you suggest – a well-known celebrity or perhaps somebody you know in your area who deserves wider recognition.

Nomination forms are available at your local branch of Abbey National or simply send your idea to Sue Wallis, RADAR, 12 City Forum, 250 City Road, London EC1V 8AF by 1 July at the latest.

Thank you for your help.

Lisa Clayton

 I WOULD like a male pen friend, aged between 20 and 30 years old, who has either hydrocephalus or Dandy Walker syndrome.

I would like my pen friend to come from the United Kingdom, Eire or Northern Europe.

In my spare time, I enjoy cycling and taking an interest in other sports. I am currently employed on an assisted placement scheme as a customer services assistant with the Halifax Building Society.

Melvin Crutchley
59 Moordale Avenue
Bracknell, Berks
RG42 1TB

26 June

ASBAH Bristol parents support group, Children's Centre, Frenchay Hospital, Frenchay Park Road, Bristol, 7.30 - 8.30pm.

Contacts: Phil Sommerton, staff nurse, ward 8, tel 0117 970 1212, Julie Knight, ASBAH fieldworker.

28 June

Hydrocephalus Study Day, organised by Sussex ASBAH, De La Warr Pavilion, Bexhill-on-Sea, 9.30am-3.15pm. Speakers: Carl Hardwidge FRCS, Leonie Holgate, Jeanette Robertson. £15 professionals, £6 parents/adults with spina bifida and/or hydrocephalus. *Mrs Anne Bush, tel/fax 01798-813663.*

28 June

Celebrity golf day for ASBAH, Mill Ride Golf Club, North Ascot. Visits from Glen Hoddle, Red Arrows.

30 June - 1 July

Pathways 96, at Westpoint, Exeter, 10am - 5pm both days. Major west country exhibition for people with disabilities, their carers, families and friends. *Details: tel 01392-438123.*

22-26 July

"Towards Womanhood", a 4-day conference organised by ASBAH for young women aged 16-25 (or thereabouts), plus carer/husband/boyfriend/mother. University of Nottingham, Rutland Hall.

DATES FOR YOUR DIARY

Lynn Thomas, Disabled Living Services, tel 01733-555988.

Monday 29 July

Milton Keynes ASBAH Support Group, Centre for Integrated Living, next to Christ the Cornerstone Church, central Milton Keynes, 1-3pm.

15 - 29 July

Artability summer holiday art course or Linguability summer holiday English language course, Lord Mayor Treloar College, Hampshire, £695 each all-in. *Details: Linda Gartmore, Manor House South, Upper Froyle, near Alton, Hants GU34 4JP, tel 01420-23548.*

19 - 22 August

"Summer Experience", residential activity course for 12-16 year olds, organised ASBAH's START service, £80 (non-returnable deposit of £20), Nell Bank, near Ilkley, West Yorkshire. *For more details: tel Rose Hinchliffe at 01943-609468.*

30 August - 1 September

Northern Mobility Roadshow, Sheffield Arena, Broughton Lane, Sheffield, 10am-4pm daily. Free entry. *Leaflet on how to get there from Sheffield City Trust (Eve Croft), tel 0114-243 5355.*

2 - 8 September

Third annual National Spina Bifida Week. Campaign messages about Folic Acid and spina bifida.

Tony Britton, ASBAH, tel 01733-555988.

Saturday 21 September

ASBAH AGM, Peterborough.

24 - 26 September 1966

Naidex International, Wembley Exhibition & Conference Centre, London.

21 - 23 October

"Keeping Fit and Looking Great", an ASBAH South East region sports and exercise event for young people aged 12 to 16, Guttman Sports Leisure Centre, Stoke Mandeville, Buckinghamshire. Families of participants will be asked to pay £25 towards the cost of this residential event.

Denise, ASBAH South East, tel 0181-449 0475.

Tuesday 22 October

Disability Alliance training day, Benefits and Residential Care, London Voluntary Sector Resource Centre, 356 Hollway Road, London N7.

Vincent Luttman, tel 0171-247 8776, fax 0171-247 8765.

* NEWS IN BRIEF * NEWS IN BRIEF * NEWS IN BRIEF *

SECOND-HAND EQUIPMENT

IF you are looking for an adjustable bed, reclining chair or accessible motorhome, try the well-established Disability Equipment Register. It is pretty good on moving secondhand trikes or wheelchairs, too.

Set up by John Selby, this non-profit making service produces a monthly magazine devoted to buying and selling used

equipment. A subscription costs £6 for six months (£10 a year). The ad can then be placed.

Disability Equipment Register, 4 Chatterton Road, Yat, Bristol BS17 4BJ, tel 01454-318818, email disabreg@bbcnc.org.uk.

WHEELCHAIR SERVICE

A NEW service for wheelchair users able to afford to move into the private sector has opened at the Lord Mayor Treloar College, Hampshire.

It focuses on assessing and advising users wanting to buy manual wheelchairs, powered wheelchairs, posture-control.

The Treloar service is not tied to any particular manufacturer and can call on the college's own rehabilitation engineering department to adapt existing equipment.

For an application form and details about fees, tel 01420-547403.



Dave's diary

Here's David Fulford-Brown once again – with his very own personal views about disability and society

ONE OF the great things about living near a city is getting access to a decent library. 'Access' doesn't just cover a dry place to park my Shopmobility scooter and the lift I use to get into the library, but also access to facilities like the Internet (More on this at a later date).

I was using the library's Internet link to have a look at ASBAH's World Wide Web page. Or at least I was trying to. Just when I thought I was getting somewhere, the librarian got a bomb alert and everyone had to leave.

I went down two flights of stairs will all the élan that such occasions merit – chucking women and children behind me!. This is a slight exaggeration, but what's the alternative in a situation like this? I read that some bright spark has designed fire-proof 'cupboards' to put in public buildings, where disabled people may stay until they can be rescued. I am way too paranoid for that! How can I be sure that someone will come back for "that awkward git who was hogging the Internet terminal!"

Leaving the library didn't make me feel any safer as the whole of the surrounding shopping mall, while wonderfully accessible for wheelchairs, was covered in glass. Another classic design! If a bomb had gone off, all that glass flying about would have caused much more than just a flat tyre! The excitement of it all made me so thirsty that I wandered off for a quick pint.

As I supped, I thought about building design and how, as time goes by, it is supposed to become more disabled-friendly. The pubs

round here are a classic example of the old ways being superior to the new. Where in the old pubs you have got wide areas and flat floors around the bar, many modern pubs seem obsessed with putting little raised 'islands' all over the place. These 'islands' with their little two-up and two-down steps can be a nightmare, particularly when the room is dimly lit and I'm carrying the drinks. Call me old fashioned, but tripping up and showering someone with two pints of lager is not my idea of a polite introduction!

When businesses do things like build in obstacle courses, it makes me feel unwanted (boo hoo!). Or at least that they don't want my money. But then for them to turn round and complain about not having enough sales and times are hard, just leaves me gob-smacked!

I don't spend all my time in the pub! Sometimes I go to the cinema. There are several around here, in various shapes and sizes. I don't know if the excellent Paul Darke would agree with me but – for design, accessibility and sheer convenience – the open-plan multiplex gets my vote every time over the old-style theatres with 10 flights of stairs and tiny toilets. To the most accessible will go the cash. It's as simple as that!

These are just places I encounter almost every week. I'm sure readers have some classic examples of awkward places. Write to me at the usual address, c/o the *Link* editor at ASBAH.

Perhaps we could get a competition going for the worst/best places.

New Hampshire service for private wheelchair users

A NEW service for wheelchair users able to afford to move into the private sector has opened in Hampshire.

The service – at the Lord Mayor Treloar National Specialist College at Holybourne, near Alton – focusses on assessing and advising users wanting to buy manual wheelchairs, powered wheelchairs, posture-control products and pressure-relieving products.

"This is a service for people who feel that their needs cannot be met by statutory provision", said manager Christine Turner.

The Treloar service is not tied to any particular manufacturer and can call on the college's own rehabilitation engineering department to adapt existing equipment.

For an application form and details about fees, tel 01420-547403.

HOLIDAY ACCOMMODATION

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

WEYMOUTH BAY

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

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.*

FRANCE - Ile d'Oleron, near La Rochelle.

Mobile home for wheelchair users. Fully adapted (shower etc), sleeps five, near beach. Ex-Spinal Injuries Association owned. Tetraplegic owner. *Brochure from M Mardle, 6 Arcadia Road, Burnham on Crouch, Essex CM0 8EF. Tel: 01621-785899*

SELSEY, WEST SUSSEX (SASBAH)

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

MOLD NORTH WALES

Luxury, wheelchair-accessible bungalow. Sleeps 4/5. All mod cons. Two bathrooms, private south-facing garden. Ideal base. £250 weekly. *Brochure: Mrs Dowling, 23 Gleneagles Road, Great Sutton, South Wirral L66 4NF (tel: 0151-339 5316).*

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 Diane Woodley, tel 01843-834909.*



Mar Y Sol - Tenerife

Wheelchair accessible apartments. Heated pool with hoist. Restaurant, poolside bar. Equipment hire. Ring today for cheapest summer and winter prices.

Algarve - Portugal

Wheelchair-friendly luxury villas with swimming pools or friendly hotels with adapted rooms.

Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX. Tel: 01753-685718.

NEW FOREST

Fully equipped caravan designed for wheelchair access throughout. Sleeps 5-6. Club house, indoor swimming pool, shop, sited at Bashley Park, New Milton, Hants. *Contact Joan Searle, tel 01705-376816.*

FOR SALE

'The Parry' hydraulic car-top hoist, easy to fit-easy to use, complete with slings. Fits Nissan Prairie. Cost £424, will accept £200 ono. *Tel: 01903-716531.*

LINK Rates

Link ISSN 1360-323X
Acting Editor: Gill Winfield

Published by ASBAH,
ASBAH House,
42 Park Road,
Peterborough PE1 2UQ
Telephone: 01733 555988.

LINK SUBSCRIPTION 6 EDITIONS - 12 MONTHS

UK £4.80
Europe and Overseas Surface Mail £7.50
Air Mail £15.00

All payments should be made in Sterling.

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

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

Small adverts for the next issue of LINK (December) should be submitted by Friday, 4 November. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

AFFILIATED ASSOCIATIONS

BARNSELY

Mr Geoff Jenkinson
12 St Leonard's Way
Ardley, Barnsley
S Yorks S71 5BS
Tel: 01226-292546

BEDFORD

Miss C Merry
6 Thurne Way, Brickhill
Bedford MK41 7XD
Tel: 01234-346344

BOURNEMOUTH, CHRISTCHURCH & DISTRICT

Mrs G Lanning
23 Seaway Avenue
Christchurch, Dorset
Tel: 01425 273 255

BRISTOL & DISTRICT

Mr G Egan
64 Rookery Road
Knowle, Bristol
Tel: 0117 9777942

BUCKS & EAST BERKS

Mrs Margaret Humphreys
15 Brackley Road
Hazlemere, High Wycombe
Bucks HP15 7EW

BURY & BOLTON

Mr David Clyne
51 Cuckoo Lane, Whitefield
Manchester M45 6WD
Tel: 0161 798 7804 (after 4pm)

CAMBRIDGESHIRE

Mr Tony Proud
10 Newlands Road
Whittlesey
Peterborough PE7 1YX
Tel: 01733 203872

CHESTER & DISTRICT

Mrs P Ithell
34 King Edward Street
Shotton, Deeside
Tel: 01244 811074

COVENTRY

Mrs N Newman
11 The Earls Court
Cheylesmere
Coventry CV3 5ES

DERBYSHIRE

Mrs A Hewitt
St Merryn
20 Burley Hill
Allestree, Derby DE3 2ET
Tel: 01332 841893

DUDLEY & WOLVERHAMPTON

Mrs Lorna J Wootton
14 Leveson Road
Wednesfield, Wolverhampton
West Midlands WV11 2HF
Tel: 01902 738724

GRANTHAM

Mrs J Asken
88 Goodliffe Road
Grantham, Lincs NG31 7QB
Tel: 01476 60679

GREENWICH & DISTRICT

Mrs M Mears
29 Wellmeadow Road
London SE13 6SY
Tel: 0181 244 3526

HAMPSHIRE NORTH, W SURREY & S BERKS

Mrs Liz Selby
Buryfields House, Buryfields
Guildford, Surrey GU2 5AZ
Tel: 01483 571736

HAMPSHIRE SOUTH

Mrs Joan Searle
68 Windmill Grove
Portchester
Fareham, Hants, PO16 9HH
Tel: 01705 376816

HUDDERSFIELD

Mr Stephen Bolton
361 Bradley Road
Huddersfield HD2 1PR
Tel: 01484 424479

HULL & DISTRICT

Mr Philip Brown
233 Cranbook Avenue
Hull HU6 7TX
Tel: 01482 857 165

JERSEY, Channel Islands

Mrs Mollie Buesnel
Villa Acacia
Sunshine Avenue
Five Oaks, St Saviours
Jersey, CI

KENT

Mrs S Stevens
6 Croftside, Vigo Village
Meopham, Kent DA13 0SH
Tel: 01732 822885

LEEDS & BRADFORD

Anna Waddington
Mullion Cottage
Main Street
Hawthornthwaite, Guiseley
West Yorks LF20 8NX

LEICESTERSHIRE

Mrs A Twomlow
29 The Crescent
Market Harborough
Leicestershire LE16 7JJ
Tel: 01858 432967

LINCOLN & MID LINCS

Mrs P Malson
"Pinfold," Chapel Lane
North Scarle, Lincoln LN6 9EX
Tel: 01522-778781

LINCOLNSHIRE SOUTH

Mrs P Mason
67 Boston Road
Heckington, Sleaford, Lincs
Tel: 01529 460322 (after 6pm)

LONDON N WEST

Mrs H Prentice
37 Milton Road
Hanwell, London W7 1LQ
Tel: 0181 579 4685

LONDON SOUTH

Mrs S Cudd
15 Woodvale Walk
Elder Road
W Norwood,
London SE27
Tel: 0181 761 2400

NORTHAMPTONSHIRE

Mrs J Cockings
45 Grafton Road
Rushden, Northants

OXFORDSHIRE

Mrs Shirley Dale
14 South Row
Chilton, Didcot, Oxon
Tel: 01235-834785

PRESTON

Mrs S Thompson
34 Beatty Road
Southport
Merseyside PR8 6LB

ROTHERHAM & DONCASTER

Mrs Katie Hemmings
40 Bentley Road
Bentley
Doncaster DN5 9TA

St HELENS & DISTRICT

Joanne Barrett
10 Halefield Street
St Helen's WA10 2DE
Tel: 01744-612860

SHEFFIELD

Mrs Celia Nicholson
104 Townend Lane, Deepcar
Sheffield S30 5TS
Tel: 0114 288 4131

SOMERSET

Mrs J Eastley
46 Hamilton Road, Taunton
Somerset TA1 2ER

SOUTH THAMES

Mrs Margaret Holmes
Flat 3, 4 Freeland Road
Bromley, Kent BR1 3AQ
Tel: 0181 290 1330

SOUTHAMPTON & DISTRICT

Mr S J Fitzgerald
32 Ellis Road, Thornhill
Southampton SO2 6ER
Tel: 01703 402644

STAFFORDSHIRE

Mrs J Davies
8 Oakhill Avenue
Oakhill, Stoke on Trent ST4 5NJ
Tel: 01782 45365

STAINES, HOUNSLOW & DISTRICT

Mrs Pamela Page
237 Upper Halliford Road
Shepperton
Middx TW17 8SP
Tel: 01932-783991

STOCKPORT & TAMESIDE

Ms Christine Walker
8 Elm Court, Maplecroft
Offerton, Stockport
Cheshire SK1 4JY
Tel: 0161 429 9042

SUNDERLAND

Mr J Pounder
42 Gowanburn, Fatfield
Washington
Tyne & Wear NE38 8SG
Tel: 0191 415 1725

SURREY

Mr Alan Twyford
86 Tolworth Park Road
Tolworth, Surbiton
Surrey KT6 7RK
Tel: 0181 390 0853

SUSSEX

Mrs M White
Averys, Ruspur
Horsham
W Sussex RH12 4PR
Tel: 01293 871217

TRAFFORD & SALFORD

Mrs T Gaynor
Davis Court, Cyprus Street,
Stretford
Manchester M32 8AX
Tel: 0161 865 0222 (A.M. only)

WARRINGTON & DISTRICT

Miss Nancy Gleave
16 Hilltop Road
Woolston
Warrington
Cheshire WA1 4PD
Tel: 01925 819329

WESSEX

Mr T Poole
123 Gerrards Green
Beaminster, Dorset DT8 3EA
Tel: 01308 862614

WIGAN, LEIGH & DISTRICT

Mrs Pat Stridgeon
24 Greendale Crescent
Leigh WN7 2LQ
Tel: 01942 676091

WIRRAL

Mrs M Appleyard
28 Stavordale Road
Moreton
Wirral, Cheshire L46 9PR
Tel: 01516 784409

WORCESTERSHIRE

Mrs G Doleman
9 Pelham Road
Droitwich
Worcs WR9 8NT

YORKSHIRE NORTH

Miss Faith Seward MBE BA
45 The Paddock, York YO2 6AW
Tel: 01904 798653

WALES

Llanelli

Mrs Anthea James
61 Westland Close
Loughor, Swansea SA4 2JT

Mid Wales

Mrs J Carter
12 Lambeth Close, Craven Arms
Shropshire SY7 9QY

North Wales

Mrs E Seddon
42 Pehrros Drive
Penrhyn Bay
Llandudno LL30 3LP
Tel: 01492 549162

South Wales

Mrs Brenda Sharp
4 Lakeside, Barry
S Glamorgan CF62 8SS
Tel: 01446 735714

NORTHERN IRELAND

Mr J Rippey
Long Eaves
24 Tulleywiggan Road
Cookstown, Co Tyrone
Tel: 0164 87 62290

NON AFFILIATED ASSOCIATIONS

Blackpool & Fylde

Mrs Diane O'Hagan
9 Elizabeth Street
Blackpool
Lancs FY1 3JB

Calderdale

Mr A L Crowther
12 Elm View
Huddersfield Road
Halifax HX3 OAE
Tel: 01422 341497

Cannock & Walsall

Mr Ken Hall
17 Wallhouse Street
Cannock, Staffs
Tel: 01543 504847

Chesterfield

Mrs K Tomlinson
23 Hathern Close,
Brimington Common
Chesterfield, Derbys
Tel: 01246 272724

Cornwall

Helen Youngman
26 Penalverne Avenue
Penzance, Cornwall TR18 2RL
Tel: 01736 51962

East Anglia

Mrs L Turner
7 Stow Gardens, Wisbech
Cambs PE13 2HS
Tel: 01945 466205

Essex

Mrs R McCarthy
26 Brixham Gardens
Ilford, Essex IG3 9AX
Tel: 0181 594 1852

Isle of Wight

Mr D J S Sprake
Springfield, Town Lane
Chale Green, Ventnor
I W PO38 2JS
Tel: 01983 551234

Lancaster, Morcambe & District

Mrs Dyson
25 Royds Avenue
Heysham
Morcambe LA3 1PA
Tel: 01524 851340

Nottinghamshire

Mrs W Purseglove
122 Chesterfield Road
Huthwaite, Sutton-in-Ashfield
Notts NG17 2QF

Rochdale

Mrs Anne Lawton
20 Spencer Street, Chadderton
Oldham, Lancs
Tel: 0161 6524487

Teeside

Mr J Gray
148 Lingfield Ash
Coulby, Newham
Middlesbrough, Cleveland

Whitchurch (Salop)

Mrs E Calder
Southfork
Sedgeford, Whitchurch
Salop SY13 1EX
Tel: 01948 663627

OTHER ASSOCIATIONS

SCOTTISH SBA

Executive Officer:
Mr Andrew Wynd
190 Queensferry Road
Edinburgh EH4 2BW
Tel: 0131 332 0743

IRISH ASBAH

Ms Claire Gill
Hon Secretary, Irish ASBAH
Old Nangor Road
Clondalkin, Dublin 22
Tel: Dublin 003531 4572326

Association secretaries requiring changes to this list should contact: **LINK EDITOR, ASBAH, 42 PARK ROAD, PETERBOROUGH PE1 2UQ Tel: 01733 555988 Fax: 01733 555985.**