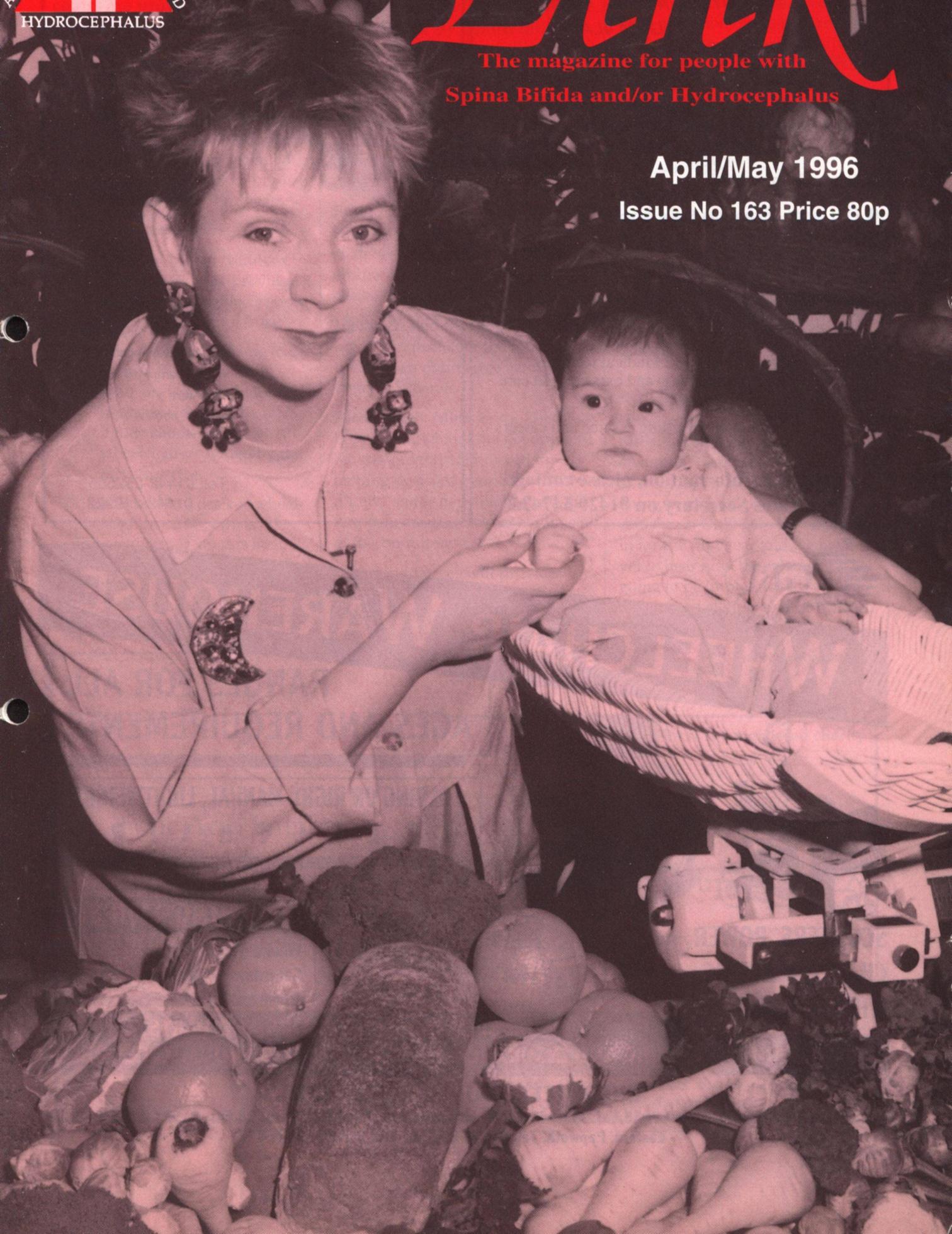


Link

The magazine for people with
Spina Bifida and/or Hydrocephalus

April/May 1996

Issue No 163 Price 80p





**LORD MAYOR
TRELOAR SCHOOL**
FROYLE ALTON HAMPSHIRE
GU34 4LA

Supported by the Treloar Trust Registered
Charity No 307103

**EDUCATION, INDEPENDENCE AND CARE FOR
YOUNG PEOPLE AGED 8-16 WITH PHYSICAL
AND LEARNING DISABILITIES**

- National Curriculum
- Full range of subjects to GCSE level
- Large Learning Difficulties Department caters for those who require a modified curriculum.
- A unique interdisciplinary programme (FLAME) run by a team of staff for young people with Cerebral Palsy
- Support from Therapy and Medical teams; Rehabilitation Engineering; and experienced care staff
- College Chaplain; counselling service and careers advice

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

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

It makes excellent sense to deal with

COMPUTER SENSE

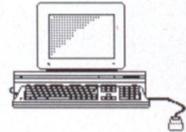
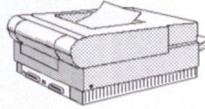
for all your Apple computer service and sales



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



WHEELCHAIR WAREHOUSE

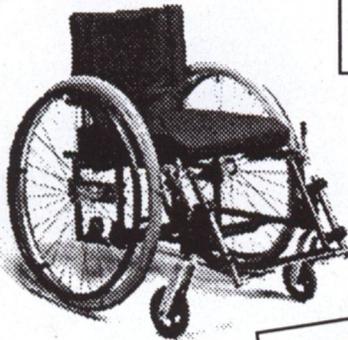
**RANGES FOR ALL
AGES AND REQUIREMENTS**

**FOLDING OR RIGID, MANUAL, LIGHTWEIGHT
W H E E L C H A I R S**



**SCOOTERS, POWER
CHAIRS, ELECTRIC,
WHEELCHAIRS**

Discount: Batteries



STAIRLIFTS

**Authorised Dealer
for: Sunrise Medical**

OPENING TIMES:

Weekdays 9.00am - 5.30pm
Saturdays 10.00am - 4.00pm

**NEW OR SECONDHAND, REPAIRS AND PARTS,
HIRE AND INSURANCE, FREE ADVICE, SHOWROOM ACCESSIBLE**

GBL WHEELCHAIR SERVICES LTD

Brentford. Tel: 0181 569 8955 Fax 081 560 5380 - Littlehampton. Tel: 01903 733528 Fax: 01903 733530
- Eastern, Papwoth. Tel: 01480 831212 Fax: 01480 831414

Government launch wheelchair vouchers

A £50 MILLION scheme which might transform the way wheelchairs are provided by the NHS and make powered wheelchairs available for the first time has been unveiled by health minister John Bowis.

Speaking in February at a conference in London, Mr Bowis announced that one of the two new measures would start in April and both would be underpinned by planned spending of £50 million over the next four years.

His announcement covers:

- ◆ powered indoor/outdoor wheelchairs to be provided for severely disabled people by the NHS from 1 April
- ◆ a new voucher scheme to be phased in to give wheelchair-users more choice and financial aid from the NHS if they choose to buy a wheelchair provided by the private sector.

"This is an exciting day for wheelchair-users", said Mr Bowis. "I have been working on this for some time and I am pleased to announce a major advance for thousands of disabled people.

"We have looked at the need for the NHS to provide severely

disabled people with powered indoor/outdoor wheelchairs. I have concluded that for some severely disabled people these chairs do meet an essential health need."

From April, an extra £6 million will be pumped into the NHS wheelchair service in England to provide electric indoor/outdoor wheelchairs.

Mr Bowis said that Lord McColl, in his 1986 report, laid the foundations for an optional wheelchair voucher scheme.

Alistair Burt, Minister for Disabled People, added that the government has an unparalleled record in helping disabled people live with dignity and independence and the new scheme was further evidence of its commitment.

"These initiatives will provide disabled people with a key to unlock their potential by giving them freedom of choice – something most of us take for granted."

Mr Burt commented that, at the moment, many disabled people have no option but to buy powered wheelchairs from the private sector at a cost of around £2,000. . . if a person chooses not to accept the NHS wheelchair, they will have the option of going to the private sector with financial help from the NHS."

Details of the scheme have yet to be worked out but it will be phased in gradually over the next four years by local health authorities, he said.

The wheelchair retail industry is not getting too excited about the scheme just yet.

Ian Laker, who runs GBL Wheelchair Warehouse which has three showrooms in Brentford, Littlehampton and Papworth with an annual turnover approaching £1 million, said: "I don't think it's going to make a great deal of difference. Only £6m is being put in for the first year and we have yet to hear how the scheme is going to be implemented, who is going to be eligible and how much the vouchers will be worth."

Continued on page 4

Contents

ASBAH is a registered charity

▲ Folic Acid launch	5	▲ Hydrocephalus News	i-iv
▲ Wheelchair details	8-9	▲ Local round-up	21-22
▲ Golden Oldies	10-11	▲ Dave's Diary	23
▲ 'Curse of Celts'	12-13	▲ Letters	24-25
▲ ASBAH Conference	14-15	▲ Aims and Principles	28

Cover: TV cook Sophie Grigson launches the Health Education Authority's folic acid campaign. See also on page 5.

STAFF NEWS



TERESA COLE has been elected vice-president of the influential International Federation for Hydrocephalus and Spina Bifida.

Teresa, our senior services manager, has served on the IFHSB board for the last six years.

The IFHSB spreads information and expertise throughout the world – as far afield as Brazil, New Zealand and Uganda, all three countries having joined in recent years

By holding its board meetings in different countries, the federation raises the profile of spina bifida and hydrocephalus and promotes awareness, often where there was little before. Meetings in Hungary and Austria, for instance, followed by workshops for families, revived interest in the work of these country's national organisations.

Since becoming vice-president last year, Teresa has been working with the World Health Organisation to produce a manual on spina bifida for community-based health workers in the third world.

The new jobs means that she sometimes rubs shoulders with high-level types. But Teresa says the post does for the most part stays decidedly unglamorous.

Meetings are more likely to be held in lowly Scout huts and youth hostels than at the WHO headquarters in Geneva!

Let's enjoy the patter of tiny feet!

NEWS of two ladies on maternity leave from ASBAH. *Link* editor **Liz Cawthorne** has been safely delivered of a baby girl, Catherine while finance assistant **Helen Holliday** (née Stevenson) has given birth to a boy named George. We look forward to seeing babies and their mums soon.

JANE WILLIAMS has returned to Disabled Living Services at ASBAH to help out with folic acid inquiries generated by the Health Education Authority campaign.

Jane worked as a disabled living adviser, specialising in continence management, before leaving ASBAH two years ago to take a degree. Thanks to a small HEA grant to help cover expenses, Jane is working for three months at national centre on Wednesdays and Fridays.



DERYK BROWN has replaced **Dave Austin** as our new fieldworker for north west and west London.

Deryk, aged 45, joined ASBAH in March and is part

of the regional team serving the South East.

In his last job, he covered half the country as a medical assessor for Possum – the specialist home controls systems company.

His ASBAH patch will be somewhat smaller but, says Deryk, he intends to “build bridges and stimulate interest” and expects his 17.5 hours a week with us will be very busy.

A “multi-trained therapist” (he is a qualified physio and OT), Deryk says he enjoys one-to-one work and is looking forward to meeting clients.

Two benefits under threat

THE GOVERNMENT has announced plans to withdraw the **Mobility Component** when a claimant is in hospital for longer than four weeks (adults) and 12 weeks (children),

The benefit will be reduced at the point of change in July 1996 – from the higher to the lower rate for people who have been in hospital for 12 months or more.

The mobility component will only be allowed to remain in payment where Motability agreements are currently in force when the person enters hospital, but not at renewal.

Draft regulations putting this change into effect have been issued and at the moment representations are being considered.

Copies of the regulations can be obtained from The Social Security Advisory Committee, New Court, Carey Street, London WC2 2LS, tel 0171-412 1510.

EDUCATION and employment minister Gillian Shephard will publish a review this month of the **Access to Work** scheme. It is expected to peg spending at £13.4million a year.

Mrs Shephard said the scheme must focus on existing commitments, and help people who have been unemployed for more than four weeks.

Vouchers, from page 3

Mr Laker, an ASBAH disabled living adviser until he set up GBL seven years ago, said that even a voucher worth £1000 would still leave many severely disabled people unable to afford good powered wheelchairs.

“It will end up with those shouting the loudest getting the help.” *See background piece, pages 7 and 8*

IN THIS ISSUE, LOCAL ASSOCIATION NEWS IS ON PAGES 21 AND 22

Launch for the national Folic Acid campaign

AN ATTEMPT to turn the tide of indifference towards the benefits of folic acid in pregnancy has been launched with a £2.3million campaign from the Health Education Authority.

They published a report at the end of February which showed that only 9% of women know that extra pre-conceptual folic acid will help give their babies a better start in life.

A TV commercial has been shown in all areas – except Northern Ireland, which has the one of the highest rates of spina bifida pregnancies in the world. Five million leaflets have been issued.

John Burn, professor of clinical genetics at Newcastle University, said that in his North Eastern area alone 500 pregnancies a year were affected by neural tube defects.

The availability of termination had



made the problem "largely invisible", he told the campaign launch in London.

And TV cook Sophie Grigson (pictured above), Channel Four's *Eat Your Greens* lady, added: "There's nothing worse for a women who is pregnant to have to

terminate at 19 to 20 weeks".

The campaign remains invisible to many members of ASBAH. Only half those at a Council meeting in March admitted to seeing anything to do with the campaign after chairman Godfrey Bowles called for a show of hands.

Officers & Staff

Patron:
HRH The Duchess of Gloucester, GCVO
President: Dr Jeffrey Tate, CBE
Chairman: Mr Godfrey Bowles, MA (Oxon)
Hon Treasurer: Mr Charles Ortner

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

Raising the Roof at Treloar!



Building work has already begun on the new boarding house at Treloar College, as a result of reaching the magic £1 million mark following an appeal launched in October '95. £2.6 m is needed for completion

AN APPEAL to raise funds for a new boarding house for disabled students at the Lord Mayor Treloar School in Hampshire has passed the £1million mark.

The appeal, referred to in *Link* last year, has attracted donations from several national organisations including merchant bank S G Warburg, the Mercers Company, Henry Smith Charity and the Save & Prosper Group.

Building work has already started and much of the external shell has been constructed.

The new boarding house will be for younger children who board at the school. At present, they are housed on two floors in an Elizabethan building which is no longer suitable to their needs.

Whereas 10 years ago, only a fifth of the children attending the school used wheelchairs, today the figure is nearer 80%, and the old building cannot be adapted to meet the demands posed by the increasing severity of their disabilities.

Educational director Hartley Heard said that students were also working hard to raise money by taking part in several events throughout the year – including a plant sale and fair on 19 May in the school grounds at Upper Froyle, a concert at the Mansion House in London on 30 April and a reception at the House of Lords on 21 June.

Donations to: Treloar Trust, New House Appeal, Upper Froyle, Alton, Hants GU34 4JX.

New Address for Wheelchair Supplier

A RANGE of specialist wheelchairs from Scandinavia has a new distributor, Electric Mobility Euro Ltd is the sole UK distributor for chairs like the Spirea, REA Comfort, Zoom and XLT.

The company's address is: Electric Mobility Ltd, Seaking Road, Lynx Trading Estate, Yeovil, Somerset, BA20 2NZ.

ASBAH on the Internet

ASBAH has joined the information superhighway. Since the New Year, we have our own pages on three web sites – Citygate, a site describing ASBAH's home city of Peterborough; the Glaxo Neurological Centre in Liverpool; and Disabilities Access, Leeds.

A firm called Intuition (UK) Ltd, which is operating Peterborough's Citygate site on the web, gave ASBAH five free pages just before Christmas. The pages cover: ASBAH; the disabilities; folic acid; officers, senior staff and regional centres; and donations to ASBAH.

People connected to the Internet can call up the Peterborough site at the address at the foot of the page and then get into the ASBAH pages.

The Peterborough site had 500 pages up and running before Christmas, compared with a mere 1,000 pages for the whole of Paris. It concentrates on giving hard information, not free advertising puffs, about firms, organisations and opportunities in the city of Peterborough.

Since August last year, ASBAH has also had a free page on a web site operated by the government-funded Connect group at Liverpool University for members of the Glaxo Neurological Centre, Liverpool, of which ASBAH is one. This is largely of local interest. The address for this site is: <<http://www.connect.org.uk/merseyworld/glaxo/>>.

ASBAH'S MAIN INTERNET WEB SITE IS AT <<http://www.demon.co.uk/citygate>>

Background to £50m wheelchair scheme

Notes (supplied by the Department of Health)

1 Over the next four years, the Department of Health plans to provide £50 million for indoor/outdoor powered wheelchairs and for wheelchair vouchers: £8m in year one (1996-97); £12m in year two; £16m in year three; £14m in year four.

2 Wheelchair voucher schemes have been looked at in the past, but have always been rejected largely because individual needs could not be met by a system which only offered standard voucher rates. And a system which placed a prohibitively expensive burden on the NHS would fail from the outset.

3 In 1986, the McColl Report urged an optional voucher scheme should be introduced. The Disablement Services Authority (DSA) was at the time embroiled in reforming a centrally-run service and devolving it to the NHS.

4 In 1991, the DSA estimated the number of NHS wheelchairs at 530,000. The numbers increase year-on-year.

5 In July 1994, health minister John Bowis announced in the House of Commons that the Department of Health would look at the feasibility of a wheelchair voucher scheme. A working group of officials sought views from disabled people, professionals, disability groups and the wheelchair industry. The group studied six wheelchair services to assess the cost of a national voucher scheme.

6 Currently, a disabled person is assessed by a professional (usually an occupational therapist) and offered an NHS wheelchair. If the person is not satisfied, the only alternative is to pay the full cost of a wheelchair supplied from the private sector.

7 The aim of the scheme is to give all disabled people who

need a wheelchair more choice. If a disabled person chooses not to accept the standard NHS wheelchair, he or she will have the option of an assessment by the NHS for a more sophisticated wheelchair. A voucher would be issued as a contribution towards the cost of a specified chair, providing the outstanding cost is met by the user.

8 The value of the vouchers will be calculated on the basis that they will be equal to the cost of a wheelchair which the NHS would have provided, given the needs of the user and available resources. If the user is to own the wheelchair and have responsibility for maintenance, the voucher value would reflect both the value of an NHS wheelchair and an estimate of the cost of maintenance that the NHS would have provided.

9 A voucher recipient will enter into an agreement on the

Continued on page 8

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.

Roadshow Roundup

Mobility shows are being held around the country this summer.

Ⓜ Scotland's third Mobility Roadshow is being held at the Royal Highland Centre, Ingliston, near **Edinburgh** Airport, from Friday 24 May to Sunday 26 May. Organisers are expecting over 10,000 visitors from Scotland and the north of England this year compared to 7,000 who attended the last one in 1994.

The event will include a test track, part of the Ingliston race track, where drivers can test-drive adapted cars. Wheelchairs, mobility accessories, safety equipment and mobile communication equipment will be on show both inside the centre and outside, together with community transport and organisations which provide advice and information.

Further details from: Inez Visser/ Sherry Wilson, Disability Scotland, 5 Shandwick Place, Edinburgh EH2 ERG, tel/minicom 0131 229 8632, fax 0131-229 5168.

Ⓜ Northern Ireland's equivalent roadshow 'Mobility 1996' takes place the following weekend, Friday 31 May and Saturday 1 June, at the King's Hall, **Belfast**.

The organisers, Disability Action in Belfast, say this is an exhibition of cars and adaptations, accessible vehicles, mobility aids & information, and personal & home equipment for disabled people.

Entrance is free and the show is open 10am-8pm on the Friday and 10am-6pm on Saturday. The venue is off the A1 Lisburn Road, south west of Belfast city centre, close to the junction with Balmoral Avenue. Balmoral rail station is nearby.

Ⓜ The first West Midlands Roadshow for people with Disabilities will take place on 14, 15 and 16 June at the Motor Industry Research Association (MIRA) at Watling Street, **Nuneaton**, Warwickshire.

Aiming to attract the whole family, the show offers helicopter rides

and sideshows alongside opportunities for disabled drivers to test drive car, check out car adaptations as well as scooters, bikes & even buses. The show is open from 10am to 5pm each day and entry is free. *Further details from the organisers on 01226 386677.*

Ⓜ **Sheffield** Arena is the venue for the Northern Mobility roadshow on 30/31 August and 1 September. Open from 10am to 4pm, entry is free and displays include adapted cars; powered and manual sports chairs; mobility aids and designer clothing! *More information tel: 0114 243 5355*

Wheelchair background, from page 7

terms which will include ownership and maintenance. The voucher would only be acceptable to authorised suppliers.

10 Before 1991, "Ministry" wheelchairs were supplied by regional artificial limb and appliance centres; generally, there was one centre in each region. The DSA was set up to manage the devolution from a centrally-resourced and controlled system to local health authority-based wheelchair services. In June 1994, there were 162 wheelchair services in England.

11 Occupational therapists or physiotherapists assess individual needs - at home, in hospital or at the local NHS wheelchair service. Normally NHS wheelchairs are provided on loan for as long as they are needed. Users are responsible for looking after their chairs, but the NHS pays for any servicing or repairs so long as they are not caused by misuse or neglect. GPs, local health centres, physiotherapy or occupational therapy departments have information about local wheelchair services.



Milton Keynes mayor Bruce Hardwick and organisers of the town's annual 10-mile road race presented the £2,300 proceeds to ASBAH.

NATIONAL SPINA BIFIDA WEEK 1996 WILL START ON 2 SEPTEMBER

Wheely switched on at northern Mobility Day

A mobility day with a difference was organised by ASBAH's Northern Region earlier this year.

A parallel programme was devised: while the teenagers were "racing around in their wheelchairs" and doing practical exercises, their parents listened attentively to speakers on issues ranging from wheelchair provision and pressure care to sports and leisure.

Ann Wild, ASBAH's mobility adviser (pictured, centre right), ran the young person's course with help from Ken Black, a sports development officer for people with disabilities.

Ann quickly recognised the different abilities of members of the group and built up a rapport with her students.

Ann instilled confidence in the youngsters, giving rise to comments like: "I won't be scared about falling out of my chair now that I know I can get back in by myself".



As ever though, Ann was disappointed with the wheelchair provision to the young people: several had been issued with wheelchairs which totally failed to meet their needs.

The adult carers involved in the study day also enjoyed themselves, particularly the opportunity to meet other parents and share experiences.

Their only complaint was that the workshops were not long enough. But it was not only a worthwhile day for families.

Ann had very much wanted to use a 'buddy' system for her mobility skills training – using one student physiotherapist or occupational therapist volunteer to help each wheelchair user.

After Northern Region contacted local OT and physio schools, they were inundated with volunteers. Many superb students had to be turned down.

The students usually receive only very basic training on wheelchairs, even though they will have responsibility later in life for wheelchair provision.

Helping at courses like *Get Moving* run by ASBAH gives these professionals of the future a valuable insight into the importance of appropriate wheelchair provision.

Get Moving was the first of what we hope will be a series of 'parallel' study days. Possible future topics might be education, health and sexuality. Watch this space.



Golden Oldies

It must be disconcerting to be told, when you're 21-years-old, that the oldest living person with spina bifida is 23! This is what happened to our diarist DAVID FULFORD-BROWN. But long life, spina bifida and hydrocephalus can and do go together as three of our older members have written to tell us. Now we can say that the oldest person in the UK with spina bifida is 84 years old..... unless, of course, you know different.....



I JUST thought I would write you a line after reading your "old wives tales" in the Feb/ March 96 edition of *Link*. The part that interested me was

that the oldest person with spina bifida was 23-years-old. So I thought I would tell you, dear Dave, that I am the oldest person with spina bifida in the UK. I am a Great Grandma age 84 and will be 85 in December this year. Many years ago, when I lived in Cowes, Isle of White, Mr D J S Sprake of the I O W Association told me that ASBAH wished to find the oldest Great Grandma. It took quite a long time, it turned out to be myself. I had a write-up in the *I.O.W County Press*, also *Link*. What I really wanted to say is; how right you are about the things people say.

One kind lady said "How lucky you are to have had a child". My daughter is 61. I went to Perth, Western Australia in '83 and '85 to stay with my sister for 3 months. I am partially blind and partially deaf, having had an implant in my left eye and a cornea graft in my right eye. Here I am, desperately trying to walk with a stick, my spina bifida and a split pelvis, and half these people have no idea what spina bifida means.

I have now lived in Nottingham for three years after leaving my lovely Island, so I could be near to my daughter here.

Mary Spencer
Stapleford, Notts

JEAN NIZANKOWSKI has spina bifida and has 16 great grandchildren - surely that must be another record for a person with spina bifida?

I am writing to tell you a bit about myself and my family. I am 72 years old in July and was born with spina bifida. I was operated on at 10 days old at Aston Infirmary, now Tameside Hospital. My parents were told I would never walk, but I did. It was when I was around about four-years-old, just as my mother was expecting her second baby. I have never stopped walking since, though it is with great difficulty now.

I have had two children, a boy and a girl. The boy is nearly 48 years old and the girl would have been 44-years-old, but unfortunately she died in 1994 with a rare form of leukaemia. Up until then everything was fine, except my daughter had two children and her eldest son was born with spina bifida. He is in a wheel chair but can also get about on two sticks. He is 24 years old in August. I am a member of Trafford & Salford ASBAH.

ELAINE BALY was in her 70th year (born 1922) when she developed hydrocephalus after the removal of a benign brain tumour which had been growing undetected for many years.

“ I was devastated at having to learn to live with a shunt, but I had an operation to have it fitted and was grateful to be able to get around, although I had my fair

share of falls in public places, losing my balance.

Then I collapsed at home alone and it was several hours before my daughter discovered me and got me to hospital. Luckily, the brilliant surgeon who first operated on me diagnosed a blocked shunt and operated to remove the debris.

I developed a further brain tumour on the top of my head, and I had another tumour growing on the original site at the back of my head near the spinal cord. A local surgeon thought I should have the higher tumour removed before it got much bigger but my original surgeon reminded me of my age (now in my 73rd year) and said he did not want to see me for two years!

I felt as though I was being put on the dust heap because of my age but, on the contrary, I am having the most wonderful treatment the NHS can provide.

Last December I gave a lecture in Japan and in May I gave a talk at Boston, Massachusetts. On both occasions I had help boarding planes at the airport and with disembarking. I arrived home feeling remarkably refreshed.

What is more I have had no more falls. I have no motorised transport, so I do my light household shopping with the help of a walking stick. I sit down at regular intervals and have heavy goods delivered.

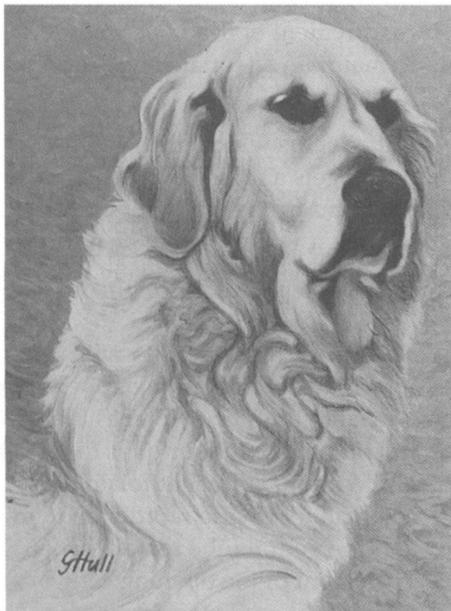
I keep mislaying items in everyday use and feared my mind was going, so I do the *Daily Telegraph* crossword for exercise and usually complete them!

A BOOKING FORM FOR OUR 30 YEARS AND COUNTING CONFERENCE IS ON PAGE 14

DESPITE growing up in the slums of Sheffield in the Depression, George Hull went on to become a commercial artist and continues to enjoy life in retirement. Here, he tells his story.

I was born in 1921 in the slums of industrial Sheffield, which then as now was devastated by economic recession. My father was a miner and was unemployed from 1926 to 1938.

We were a family of seven – mother, father, five children including a severely disabled one, existing on a



The pictures above and below are paintings by George Hull.

'means test' allowance just enough to live on. How we survived was a miracle of love and devotion by my wonderful parents.

At birth, I was handed to my mother with the words: "He has only a spark of life and, if he lives, he will never walk!" Some spark; some flame! I did!

We were a happy lot, existing on just pure love. At that time there were hardly any facilities for disabled children, ie schools etc. I had for the most part no education and was taught to read and write by my family. As a lad, my only means of getting around was my father's shoulders and a little box on wheels.

But I could draw almost from birth. At the age of 14, I won a scholarship

GEORGE HULL – ARTIST AND TEACHER

George Hull is 74 years old and has spina bifida, with severe curvatures of the spine and pelvis. Here he is relaxing with his "dear friend" Wendy.



to Sheffield University School of Art where I gained an 'Art Teachers Diploma in Drawing'. My first job was for Sheffield Newspapers during the war.

Then, I became a show card artist and designer for F W Woolworth. Finally, in 1949, I became an artist in the studio of a 'process engraving' firm where I remained until 1975 when I was made redundant.

Redundancy came as a shock because at 50 I could not see myself getting another job in art – not in Sheffield at any rate.

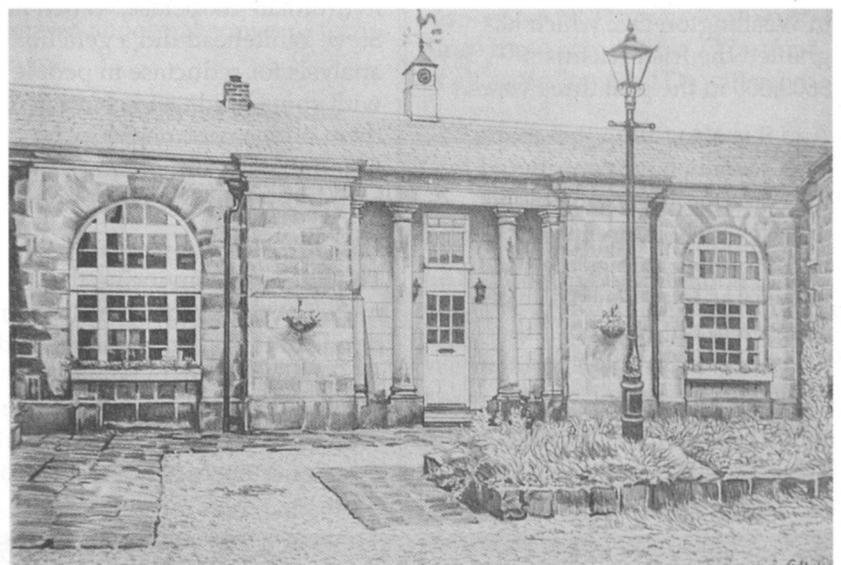
However, I was interested in the German language, so I applied to Sheffield University to do a degree in German language and literature and successfully gained a BA Honours degree.

Having lived a year in Dusseldorf in Germany, as part of my degree course teaching English, I got a job in Sheffield teaching German at Oakes Park school for children with spina bifida.

I am retired now and, as I look back on my life, I feel that I have been privileged in being disabled. It has been a wonderful life, a quality of life based on the rock of family love and devotion and supported throughout by the quality of my friends!

However, one must not be too complacent because, as you must know, there is another side to the coin. There must be tremendous heartaches and trauma in many, many disabled children's lives and that of their families.

I am just one of the lucky ones.



'Curse of Celts'

A BREAKTHROUGH in identifying causes of spina bifida and anencephaly could help to identify women at risk, enabling them to take preventative measures. KATHERINE HOLMQUIST reports on important new research at Trinity College, Dublin.

EVERY year in the Republic, 100 infants are born with spina bifida and anencephaly, of whom only 40 survive past their first birthday. These neural tube defects (NTDs) exact a huge emotional and economic toll on family services. The tragedy is that women could prevent this trauma simply by taking folic acid supplements in the two months before they become pregnant.

Traditionally known as "The Curse of the Celts", NTDs are at least twice as common in people of Celtic ancestry. So it is fitting that this 'curse' should now be lifted by the Irish scientists at Trinity College Dublin and the Health Research Board, in cooperation with the National Institute of Child Health and Human Development in Washington DC, which has granted the Irish scientists \$600,000 in the past three years.

And it is also fitting that many Irish women have contributed to the discovery by giving blood samples early in pregnancy. Some 50,000 of the samples are still in freezers at Trinity's labs, taken from pregnant women at the Coombe, the Rotunda and the National Maternity Hospital, Holles Street.

These samples are invaluable to the Trinity team, led by Prof John

Scott, of the Department of Biochemistry, and Dr Peadar Kirke, of the Health Research Board, as they put together the complex genetic puzzle which explains the cause of three-quarters of NTDs.

They found the first piece of the jigsaw when they learned that the risk to the foetus of developing a NTD varies eightfold, depending on how rich its mothers diet is in folate. A woman with a folic acid level of 400 ug per litre has a risk of 0.8 per 1,000 of having a baby with an NTD. But reduce her status to 150 ug – still within the normal range – and her risk will magnify to 6.0 per 1,000.

Diet was clearly significant, but folate levels alone did not explain the whole story. There had to be a genetic link, especially considering that NTDs are more common in some gene pools than others, regardless of folic acid levels.

The next piece of the jigsaw was the discovery that Irish women who subsequently gave birth to children with NTDs had abnormally high levels of homocysteine, a metabolite. This implicated any one of three possible enzymes, one of which was 5,10-methylenetetrahydrofolate reductase. When Prof Steve Whitehead did a genetic analysis for reductase in people with spina bifida and compared them with a control group, he found that abnormal reductase accounts for 13 percent of spina bifida.

The link is so convincing that mutations concerning this enzyme or one of the other two identified are almost certain to be responsible for another 60 percent of cases, in all accounting for three-quarters of NTDs, says Prof Scott.

The significance to the developing embryo of the discovery of the role of reductase is this: the enzyme needs folic acid to make DNA, and if the embryo cannot make DNA rapidly enough at the proper rate, it cannot divide cells fast enough. The genetic mutation in the enzyme prevents the embryo metabolising folic acid normally, giving them a higher-than-normal requirement of folic acid in order to maintain adequate levels of cell division.

If the foetus which inherits this defect gets a massive injection of folic acid from its mothers blood stream, it will probably be normal, but if it does not, it is likely to have a neural tube defect.

The astonishing rapidity with which this cell division happens is crucial to the story. It takes the neural tube only four days to close, and without sufficient folate the cells cannot divide rapidly enough and the neural tube remains open. The extent of the opening can vary from slight and insignificant to profound and fatal. Some people with NTDs are not diagnosed until they receive spinal X-rays in adulthood, while others are so badly affected that they die soon after birth.

This information is critical for any woman who is thinking about becoming pregnant, because NTDs occur during a critical window of development between the 24th and 28th day of gestation – before many women even know that they have conceived.

Six per cent of people inherit the genetic mutation which prevents them from metabolising folic acid properly and therefore puts them at risk of NTDs. So why are most of these not born with NTDs? A

THIS ARTICLE IS REPRODUCED BY KIND PERMISSION OF THE IRISH TIMES

may be buried

foetus which has this problem metabolising folic acid will be able to close its spinal column during the crucial four-day opportunity to do so – if it gets huge boosts of the micronutrient from its mother's bloodstream.

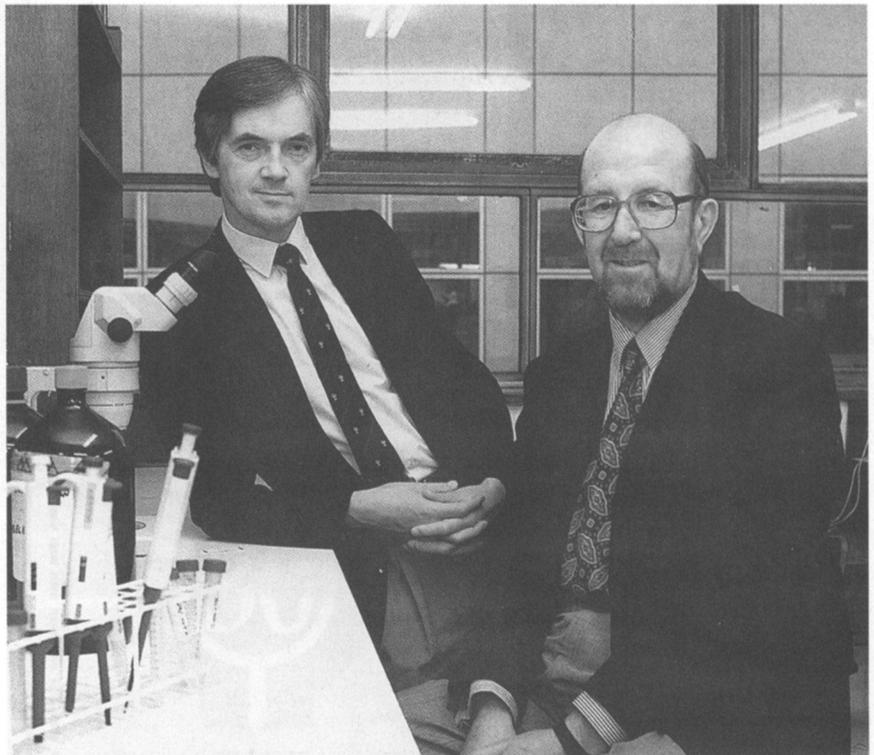
This is where supplementation comes in. While screening for the genetic defect it is a possibility, it may be more practical simply to fortify all women's diets with folic acid, not just those at risk.

Prof Scott predicts the government, including our own, will decide to fortify flour and bread with folic acid in an effort to prevent NTDs. Breakfast cereals are already fortified and some milks are as well.

The best advice is for any woman who could become pregnant – whether she is planning to or not – is to take 400 mcg of folic acid per day throughout her child-bearing years, either as a supplement or in fortified foods.

Another significant finding of the research is that fathers are almost as important as mothers in NTDs. In order to inherit a strong risk of spina bifida, the foetus must have two parents with the genetic defect.

In everybody's genes there are two copies of a piece of genetic information. Those two bits are



✿ Dr Peadar Kirke (left) of the Health Research Board, and Prof
✿✿ John Scott, of the Department of Biochemistry at Trinity
✿ College. Photograph: Paddy Whelan, Irish Times.

are read off and give a message to make a protein, which is an enzyme – in this case reductase.

If you are normal, you have two normal copies. If you are heterozygote, you have one abnormal and one normal copy, and if you are homozygote you have two abnormal copies of the enzyme.

In order to inherit the defect the

foetus needs to be homozygote – in other words it needs two copies of the faulty message, one from the mother and one from the father.

The Trinity team's breakthrough will eventually result in the identification of the other genes involved in the so-called folate responsive NTDs, says Prof Scott. Since these account for 75 percent of all cases, most NTDs will soon be avoided.

AIMS & PRINCIPLES: framework for the future

IN 1995, as we approached our 30th Anniversary, many local associations took part in a consultation to draw up a set of Aims and Principles for ASBAH – a document intended to guide all of our work in the future.

The results are presented on the back cover. They represent the end

of a lengthy process of discussion in which most levels of ASBAH were also involved.

The Aims and Principles offer us a number of benchmarks against which we can judge everything we do. They represent YOUR hopes and aspirations for national ASBAH. They're YOUR basic kit

for checking that our work matches up to your high expectations as we head for the year 2,000, and beyond.

We spent months working on them. They are more than just a few quickly-forgotten lines jotted down on the back of an envelope. Please... give them the priority they deserve.

A CONFERENCE TO CELEBRATE THE
EMPOWERMENT OF DISABLED PEOPLE

BOOKING FORM

Use block capitals and return this section to Tony Britton,
ASBAH, 42 Park Road, Peterborough PE1 2UQ.

Full name:

Address:

Daytime tel no:

If professional, please give the following information:

Job title:

Institution

Please reserve meseats (s) at ASBAH'S
30 YEARS AND COUNTING conference.

- Prices: ♦ £15 per professional
♦ £5 per able-bodied member of ASBAH
♦ No charge to disabled people or their enablers.

(Entry by programme: all places must be pre-booked)

Cut out or photocopy this form and put it in an envelope,
with a cheque or postal order to cover the amount due.
Please make cheques payable to ASBAH.

I require (tick as applicable):

- Wheelchair access
 Special diet (please state)
 Any other special requirement (please state)



Signed:

Date:

THIRTY YEARS

Thursday

6th June 1996

at the

Queen Elizabeth II

Centre,

Westminster

10.30 - 3.30

Conference

Conference takes place in The Churchill A

Pre-11am Arrival of HRH The Duchess of G

(Morning chair. Godfrey Bowles, Chairman

11.00 President/Chair welcomes

11.05 Minister for Disabled People
Mr ALISTAIR BURT MP

Opening Address: Rights and Op
for Disabled People

11.30 CLAIRE RAYNER, ASBAH vice-pr

Looking forward to the 21st Cen

11.40 STEFAN KRUSCHE
Association for Spina Bifida and
Hydrocephalus, Germany

Seeing beyond the Disability

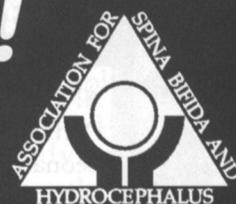
11.55 RICHARD GUTCH
Chief Executive, Arthritis Care,
Chair, Association of Chief Exec
National Voluntary Organisation

Users must be Stakeholders

12.35 SUE MACGREGOR
Presenter, BBC Radio 4 'Today'

Disability in the News

YEARS AND COUNTING!



1966 - 1996

Please
join us
in
London
as we
mark
the
30th
Year of
ASBAH



the programme

Auditorium

Gloucester GCV0

(of ASBAH)

Opportunities

President

Century

and

, and
executives in
ons

programme

12.45 - 1.45

LUNCH in the Pickwick Suite

(Afternoon chair: Terry Denyer, Your Voice in ASBAH)

1.45 **TANNI GREY**

British Wheelchair Racing Association

1.55 **PAUL DARKE**, film writer, Link magazine

Images of Disability on Film

2.40 **PETER WHITE**

BBC Disability Affairs Correspondent

2.50 **TRACEY PROUDLOCK**

Executive Committeemember of ASBAH

3.05 **TERRY DENYER**

Chair, Your Voice in ASBAH user group

3.15 **DAVID GRAYSON**

Chairman of the National Disability Council

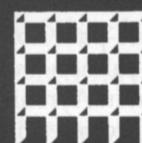
3.30 **PIERRE MERTENS**

President, International Federation for
Hydrocephalus and Spina Bifida

3.40 Closing remarks - Godfrey Bowles

Followed by TEA in the Pickwick Suite

The programme may be subject to alteration



The Queen Elizabeth II
Conference Centre



Darke at the cinema by Paul Darke

ANNE Bancroft, Daniel Day-Lewis, Leonardo DeCaprio, Patty Duke, Tom Hanks,

Dustin Hoffman, Holly Hunter, Marlee Matlin, John Mills, Cliff Robertson, Harold Russell, John Voight and Jane Wyman. What is the connection? Well, they have all won Oscars for playing people with either a mental or physical disability (and you should award yourself a treat if, and only if, you can name all the films they won them for).

Why is it that disabled people don't get to play themselves? The very fact that ordinary actors win prizes for portraying us is, in itself, perhaps the key to understanding their stranglehold over acting disabled.

The Oscars are the showcase in which acting and film-making are fore fronted in the consciousness of the public: acting disabled is the same, it is the showcase of acting.

Having a disabled person play either themselves or a character with a disability would fail to achieve that level of achievement

(as acting, that is). When we watch an actor in a general run-of-the-mill performance it is easy to think: "Oh, I could be an actor!"

Thus, regularly, roles are highlighted that make acting seem a far greater skill than it really is; playing disabled fulfils that role and purpose.

I am not saying acting is easy, but is playing a character with a learning difficulty or a physical impairment (and earning \$5-10 million for a few months work) any harder than working down a mine or in the NHS? The two don't really compare. The point I am making is that by acting a disability, acting seeks to legitimise its own sense of success and difficulty. Thus, and this is the crux, having a disabled actor play a character with a disability would not achieve that highlighting of the very process of acting.

Also, and this is probably equally significant, acting is about make-believe. Having an able-bodied actor play a role ensures that it is seen as such: a 'role'. Having a disabled person play a disabled

character is a little too real for comfort and – as I argued in a previous article for *Link* – entertainment is about comforting the audience, not challenging it.

The audience want to leave the cinema saying to one another: "Didn't he play that well, it was so real?" They do not want to leave thinking: "Isn't it sad, he's like that in real life." It isn't sad, but that is our image to the majority of people, perpetuated by and large in films.

The argument that drama schools are not producing enough disabled actors of quality – due to their inaccessibility, or their prohibitive financial demands – is missing the point, as is the view that disabled actors aren't big enough draws at the box office.

Acting disabled is the only chance actors get to prove that they are better actors than the rest of us. I am prepared to concede that inaccessible drama schools and lack of available disabled actors may be of minor significance but, sadly, I suspect that if those factors ever change they will change very little when it comes down to it.

HOLIDAYS * HOLIDAYS * HOLIDAYS * HOLIDAYS * HOLIDAYS

CHECKING OUT CHESHIRE

Accommodation and attractions in Cheshire, for visitors with disabilities are described in a 70 page booklet, 'Welcome to Cheshire' available free from Cheshire Tourism and Marketing, Goldsmith House, Hamilton Place, Chester, CH1 1SE.

FLY FISHING HOLIDAYS TO BE WON

An expenses-paid holiday, fly-fishing for salmon and trout on the River Doon in Ayrshire, is the prize in a special competition for disabled anglers, sponsored by a Manchester-based bathroom products manufacturer.

There are two holidays to be won

to be taken during August. The competition is open to disabled people of any age and their carers, and results will be announced in June.

Entry forms from Total Hygiene Ltd, 2 Newton Street, Stretford, Manchester M32 8LG, tel 0161-866 8080.

VISITING NATIONAL TRUST PROPERTIES

Which coastal birdwatcher's site has a wheelchair adapted to travel over sand? Where can sight impaired visitors touch the roman sculptures? Which parts of the Lake District countryside are accessible to wheelchair users? These and many other

questions are answered in The National Trust's booklet 'Information for Visitors with Disabilities 1996'. Its available free of charge from the *Disability Unit, NT, 36 Queen Anne's gate, London, SW1M 9AS.*

SUMMER CULTURE

Lord Mayor Treloar College, Hampshire, invite you to spend a fortnight on either their 'Artability' art course or 'Linguability' English language course being held from 15 to 29 July. The cost is £695 all in, including accommodation, meals, and full care. *Contact: Linda Gartshore, Manor House South, Upper Froyle, near Alton, Hants GU34 4JP, tel 01420-23548.*

Hydrocephalus Network News



SPRING 1996

ASBAH, 42 Park Road, Peterborough PE1 2UQ

Tel: 01733 555988 Fax: 01733 555985

Reg Charity Number 249338

Network Co-ordinator: Rosemary Batchelor

Tell us, please

HAVE YOU ever been refused as a blood donor because you have hydrocephalus? One of our members has and our Medical Advisory Committee is taking up the matter.

If you have been refused by the blood donor service, please let us know where and when this was and what reasons you were given.

Write to :

*Rosemary Batchelor,
DLS Co-ordinator at ASBAH.*

HN reader tells her own story

Second Opinion saved my Life!

I WOULD like to tell readers about my hydrocephalus problems through which I nearly lost my life.

In 1991 I think it was, shortly after Christmas 1990, I began to get terrible headaches. I could not even stand the sound of the television, my record player or lights in the house, I also came out in a dreadful red rash, so I was admitted to a children's hospital where all my life I had been a patient. I was kept in for two whole weeks for various tests. Numerous doctors came to visit me because, in the beginning, I was told that I had sinusitis, which was a load of rubbish. I gradually got worse and my

parents became more and more distressed at seeing me in this condition. After a week, the registrar came to see us and said: "Chantel can go home", but this was terrible news because I was getting no better, in fact I was worse. My dad was so angry that he said: "There is no way that I am taking my daughter home in this state". I even had to keep putting my head back because of the pain, the doctors saw this and said to my parents: "I'd be in pain if I put my head back like that". That was a total insult!

A couple of days later, a surgeon from another hospital came to see me. When I described my symptoms to him, he knew straight away what was

wrong. He said that I had a blocked valve which needed attention, so at first I thought: "Oh, not another operation!", but I didn't care as long as I was fit and well again. On the following Monday, I was admitted to another hospital under the care of Mr May, who is a neurosurgeon and, to my relief, I didn't need another operation. I was given a dose of tablets called Acetazolomide and, thanks to my parents and Mr May, I am fit and well again. If I stayed in the other hospital hospital I would have died!

PLEASE ALWAYS - IF IN DOUBT - GET A SECOND OPINION. WE DID AND I LIVED TO TELL THE TALE!

Chantel Briody

The Doppler Effect

In recent years there has been rapid expansion in the use of ultrasound for the investigation and management of children with hydrocephalus. The initial diagnosis of hydrocephalus in a newborn baby is now usually made after an ultrasound scan of the head, which is a rapid and safe investigation. However, as the fontanelles start to close during the first year of life, the ultrasound scanners become less informative and more reliance has to be placed on computerised trans-axial (CT) scanning of the head. This involves exposure to X-rays, which can be appreciable if frequent follow up scans are required over a prolonged period. Such relatively large cumulative doses of X-rays should be avoided whenever possible, but alternative methods of assessment, eg magnetic resonance scanning, are not as readily available at present.

At the Hospital for Sick Children, Great Ormond Street, we evaluated the use of transcranial Doppler sonography in the assessment and monitoring of children with hydrocephalus.

This technique relies on the transmission of non-harmful, pulsed ultrasound waves through the thin part of the skull at the side of the head and reflection of these waves back from the flowing blood within the cerebral vessels. (Fig 1). There is a change in frequency (frequency shift) of the reflected waves caused by

MR IAN POPLÉ FRCS, of Frenchay Hospital in Bristol, explains the use of trans-cranial Doppler sonography in the assessment and monitoring of children with hydrocephalus.

the movement of blood either towards or away from the direction of the probe (the Doppler effect) and this frequency shift varies according to the speed of blood through the artery. Hence, the velocities of blood flowing through the vessel are measured and, by using an appropriate equation, the shape of the waveform output can be summarised numerically using Gosling's pulsatility index (PI)¹. This index varies according to the resistance beyond the artery and therefore changes when intracranial pressure is high or when the vessels beyond the artery are constricted, eg as a result of hyperventilation. In our study, we chose to examine the middle cerebral artery due to its ease of identification.

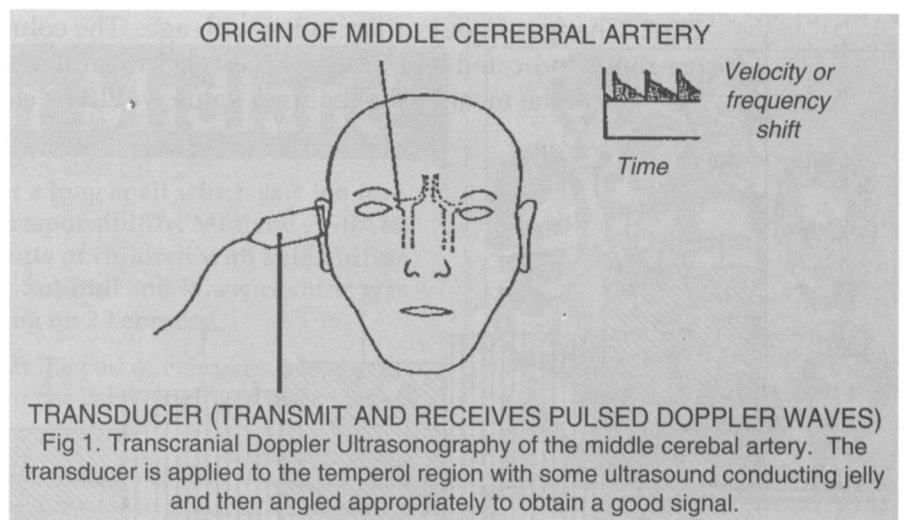
During initial work by Dr Michael Quinn in 1988 it became clear that large changes in the pulsatility index (PI) occurred after babies with progressive hydrocephalus had undergone their initial cerebrospinal shunt insertion and that a raised index also occurred in older children when their shunts became blocked². We investigated this further and found that, when compared to the group of similar children with functioning ventricular shunts, the 32 children that we

examined during the last two years with blocked shunts had significantly higher indices. We also found that the intracranial pressure of these patients, when raised, correlated strongly with their PI. As a possible test to detect raised intracranial pressure in children who had symptoms of a shunt blockage, transcranial Doppler sonography appeared to be potentially very useful.

Blood flow velocities within cerebral arteries change with age and a reference range of values for children with controlled hydrocephalus was not available for comparison with the readings we had obtained during our study. To create this reference range we studied 250 asymptomatic children with ventricular shunts, who were attending routine outpatient follow-up appointments. Their hydrocephalus we presumed to be controlled if they were completely well, without signs of raised intracranial pressure. It was felt to be unjustified to perform invasive tests on all the children just to confirm that the shunt was definitely still functioning. Each transcranial Doppler examination took, on average, five minutes and was successful in 86% of cases. In 12% of the examinations the child (usually a toddler) did

not keep still enough to obtain a satisfactory reading and in 2% I could not achieve a signal in co-operative children, due to abnormally thick temporal bones. Only one parent of a child who had previously had unpleasant experiences with CT scanners declined the test and many parents were keen for their child to be tested on subsequent occasions.

The reference range allowed us to say whether an individual child's reading was normal or abnormal for his age and using this we were able to analyse the results obtained from studying the children admitted with symptoms of a blocked shunt. Ninety-seven per cent of the children whose symptoms settled down without the need for an operation had a PI within the reference range, whereas 56% of the children who definitely had a blocked shunt and needed a shunt revision had an abnormally high PI. We therefore concluded that a raised PI predicts the need for a shunt revision with high accuracy, but that a normal PI does not exclude shunt blockage. We felt that it could provide very useful additional information in cases where the diagnosis could not be made on clinical grounds, by tapping the shunt or by CT scanning. This occurred particularly in children with very small ventricles due to previous shunt over-drainage. We believe that the sensitivity of the test could be increased by documenting the PI of children with shunts each time they come to outpatients, so that changes of PI within the individual child who develops symptoms of blockage can easily be detected. Twenty of



TRANSDUCER (TRANSMIT AND RECEIVES PULSED DOPPLER WAVES)
 Fig 1. Transcranial Doppler Ultrasonography of the middle cerebral artery. The transducer is applied to the temporal region with some ultrasound conducting jelly and then angled appropriately to obtain a good signal.

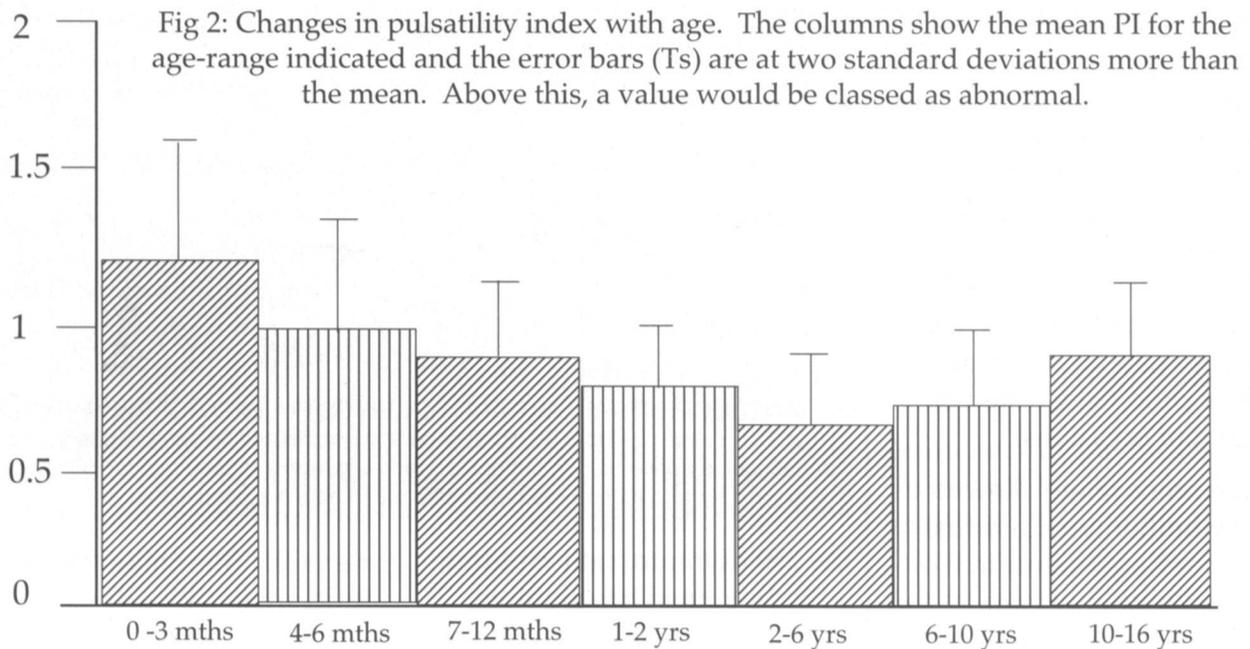
the 250 asymptomatic children with presumed functioning shunts, who had been tested as outpatients, were subsequently admitted with symptoms of shunt blockage. Eleven had operations for confirmed shunt blockage and nine of these had abnormal Doppler readings, when previously they had PI values well within the reference range. Apart from the gradual age-related changes observed in our studies there was little variation in the PI within each child when they were tested on different occasions, under similar circumstances (mean variation per individual: 4.8%). This means that a large increase in the child's previous outpatient PI could be more helpful in picking up a shunt blockage than the actual reading taken when the child was admitted with symptoms.

The PI appears to correlate well with intracranial pressure only when it is raised. This has been confirmed by other research workers³. In situations of overdrainage of cerebrospinal fluid from the ventricle, where the intracranial pressure is lower than normal, we have found that there is no relation between the PI and the

pressure. This means that low intracranial pressure syndromes cannot be diagnosed by transcranial Doppler and direct pressure measurements in the lying and standing positions are still needed.

In addition to detecting shunt blockage the transcranial Doppler technique can be helpful in the initial assessment of babies with newly diagnosed hydrocephalus. The decision to insert a ventricular shunt into neonates is often made on the basis of changes in their head circumference and whether any symptoms or signs of raised intracranial pressure are present. In the early stages the rate of progression of the hydrocephalus is frequently not clear from radiological and clinical finds and the decision to operate must be delayed. In these cases we have found that the PI of the middle cerebral artery is highest when there is a rapid rate of the progression of the hydrocephalus. If a diagnosis of arrested or non-progressive hydrocephalus is made and the child is followed up regularly without having a shunt the measurement of the PI

continued on page iv



The Doppler Effect from page iii

provides a useful, non-invasive way of monitoring the condition. When the PI fails to follow the normal pattern of decrease during infancy, the intracranial pressure can be assumed to be chronically raised and shunting can be done before developmental delay occurs (Fig 2).

Out-patient monitoring of children with shunts using transcranial Doppler is simple, quick and non-invasive. The

technique can be learnt easily by the clinical staff seeing the children in the clinics and reproducibility of results between different observers is reasonably good. Like all ultrasound techniques, there is a learning curve for the operator, but the reproducibility of our readings were acceptable after only two weeks of practice. Regular follow-up examinations of children, eg three-monthly for eighteen months and yearly thereafter, could provide

useful longitudinal data to relate to their ultimate outcome, as well as providing baseline readings to use when diagnosing blocked shunts. Since our work at Great Ormond Street was completed there has been another study by a team at Valhalla, USA. They have confirmed our results and we may therefore expect more units to employ this technique for the management of patients with hydrocephalus.

References

- 1 Gosling RG, Dunbar G, King DH et al. *The quantitative analysis of occlusive peripheral arterial disease by a non-intrusive ultrasonic technique.* *Angiology* 1971;22:52.
- 2 Quinn MW, Bayston R, Harward R, Grant N. *The Doppler characteristics of hydrocephalus.* Abstract, Cambridge, England.
- 3 Chaddock WM, Crabtree HM, Blankenship JB. *Transcranial Doppler ultrasonography for the evaluation of shunt malfunction in pediatric patients.* *Child's, Nerv Syst* 1991;7:27-30.
- 4 S Riftinson-Main et al. *Transcranial Doppler ultrasonography in the evaluation of shunt function in the patient with hydrocephalus and spina bifida.* Poster presentation at 38th Annual Scientific Meeting of S.R.H.S.B. Hertford, USA 1994.

Acknowledgements

Special thanks to Mr E Datnow and Dr A Datnow for their generous financial assistance and to Roger Bayston and staff of Great Ormond Street Hospital and the Institute of Child Health.

Closure for Midland

MIDLANDASBAH, has closed after a long spell which saw too few volunteers coming forward to take responsibility. Midland ASBAH, formed 30 years ago to support parents of children with spina bifida and hydrocephalus in Birmingham, Solihull and Warwickshire, was dissolved at an extraordinary meeting on 2 February.

Its office in Shirley, Solihull, closed at the end of February. Members have said farewell to Diane Britt, who has been employed as MASBAH secretary for the last 21 years.

"We were set up to support and advise families as they struggled with the care of their disabled children. But now these children have grown up and are themselves coping with the challenges and rewards of independence", said outgoing chairperson Eileen McCabe.

"They want to do their own thing. We were still in a position to offer financial support to individuals and families but we have seen a marked reduction in volunteers willing to take up key positions. Rather than continuing to encourage dependency and watch the association gradually decline, I decided to recommend it be dissolved."

Remaining assets will be transferred to national ASBAH, and these will be earmarked for use in the MASBAH area. National has committed itself to continue to employ two fieldworkers in the area.

Before it folded, MASBAH gave funds to three projects which benefit local people with spina bifida and hydrocephalus:

- ◆ Artingstall House in Stirchley, managed by Sanctuary Housing Association, which offers tenancies to nine young disabled people with a project enabler on site;
- ◆ Research into the treatment of hydrocephalus being carried out at Nottingham University by Dr Roger Bayston, ASBAH's honorary consultant in hydrocephalus;
- ◆ The Phoenix Sheltered Workshop in Sparkhill, formerly the Spina Bifida and Hydrocephalus Sheltered Workshop.

New Year's Dip!

ANDREW RYAN became a real daredevil when he joined his dad Matthew and other members of a local ASBAH for their annual mid-winter dip in the briney!

With a stiff wind blowing off the coast and the temperature of the water close to freezing, 35 members and friends of Ballymena ASBAH took part in their 25th annual New Year's Day swim in Carnlough Harbour, Co Antrim.

The event, supported by dozens of local folk quite content to watch

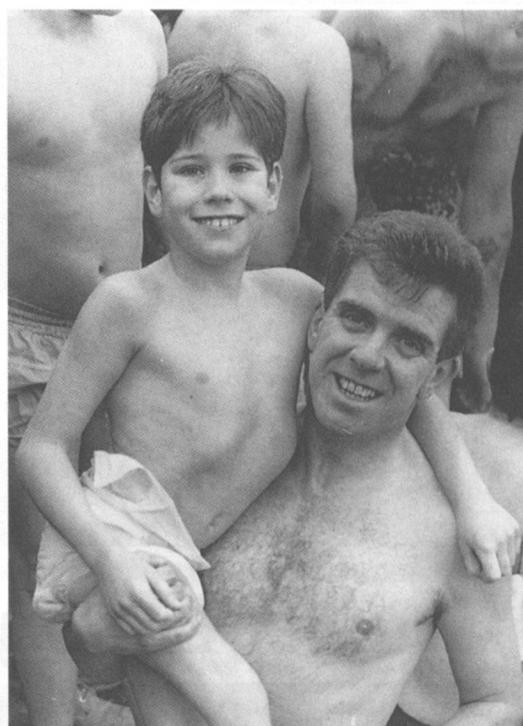
from the quayside, is believed to have raised about £1,000 for this Northern Ireland branch.

Eight-year-old Andrew, (*Pictured above*) who has spina bifida, took part in the event for the first time after insisting that he wanted to join older brother Christopher in the water.

His mother, Mrs Anne Ryan, commented: "I didn't want Andrew to do it at all because I was frightened about his legs. But he wasn't in long enough for it



LOCAL ROUND-UP



New Year's Day dip for Andrew Ryan and his dad, Matthew (see story below).

to do any harm!"

Afterwards, the survivors trooped off for a sing-a-long and a warming glass of toddy in the Londonderry Arms on the Larne coast road.

ASBAH fieldworker Marian Doherty, who passed the photo over to Link, added that Ballymena ASBAH raises most of its funds at the New Year's Day swim, which always has a strong local following.



LOCAL ROUND-UP

Volunteer of the Year

IT WAS the end of an era for St Helen's and District ASBAH when 120 members, families and friends turned up at the Grove House Social Club to say farewell to Nancy Maddocks, who retired after 25 years as secretary.

And, as our photo shows below, Mrs Maddocks introduced two faces for the future for the association on Merseyside – Joanne Barrett, who took over as secretary on 1 March, and new vice-chairman Philip Orchard.

Mrs Maddocks, who is 76, has been named the Whitbread Volunteer Youth Worker of the Year for the North West to mark her retirement from voluntary work.

"Last year, I suddenly thought I had been involved with ASBAH and many committees for so long that it was about time I spent more time on some of the other things I enjoy doing – gardening, flower arranging and all sorts of crafts", Mrs Maddocks told Link.

"My husband died in 1980 and a fortnight later I found out that I had cancer of the larynx, which was cured. I decided then that, as I had been given a second chance in life, I would make the most of it. I wasn't going to mope about, feeling sorry for myself."

From that point on, Mrs Maddocks started building an impressive portfolio of contributions to the voluntary and social work of her home town – joining organisations like the Community Health Council and the Council for Voluntary Service.

This work was in addition to St Helen's ASBAH, which with husband Norman she helped found in February 1971 by taking on the job as secretary. Until very recently, she was involved with about 10 different committees.

Mrs Maddocks – who was presented with an inscribed rose bowl and a subscription to a needlework magazine as thanks for her work for St Helen's ASBAH – helped the association for their future by working with chairman John Glover to bring through people with disabilities to key jobs on the committee – young folk like Joanne and Philip. "They'll do very well. Philip has already proved his leadership skills in other groups", she added.



Another Lottery Winner!

ST HELEN'S & District became the second local ASBAH to be given a first-round grant by the National Lotteries Charity Board – for £11,175, to cover the cost of six lightweight wheelchairs.

"As our young people get to the age of 17, subject to a specialised medical and aptitude assessment, we provide a course of driving lessons", said chairman John Glover.

"We have quite a few youngsters able to drive cars and be quite independent – except one of the problems is that, after they get into the driving seat, their

wheelchairs are so heavy that they can't lift them in.

"It's a bit ridiculous if, having won more independence, they then have to take someone along for the drive to handle the wheelchair!"

For their bid for a first-round grant – when they had to satisfy the assessors that a successful application would help alleviate poverty – the association pointed out that lightweight wheelchairs would vastly improve mobility of their members, several of whom simply could not afford to buy one.

THE APRIL edition of *Link* heralded the arrival of *Challenge*, a new sports magazine for disabled people. I'm sure that the editor (Marshall Thomas) is right when he talks about the mainstream media's coverage (or non-coverage, to be accurate) of disability sport. Indeed the topic of disability in general is largely absent from the mainstream media and its outlets.

I have noticed that, if you walk into any of the big magazine shops and ask for magazines for the disabled, handicapped or whatever, you get met with polite noises and a scurrying of helpful assistants, but all around end up with blank expressions and you leave empty-handed.

That isn't to say that there aren't any publications for disabled people (there are but you have to know what you want and order it specially), or that no-one is talking about sport for the disabled. There seem to be rather a lot of people talking about sport!

Don't get me wrong! I wish *Challenge* and everyone who does sport very great success. I respect and admire people who decide that sport is their thing and go for it in a big way. But I must admit that the thought of entering 'pogo marathons across the Pennines' for the good of soul and body just leaves me cold. What exercise I do, I do for basic maintenance and life support. The bending of the drinking elbow and the pressing of remote-control buttons are far

more likely to feature in my exercise programme than enforced yomps up Lake District mountains.

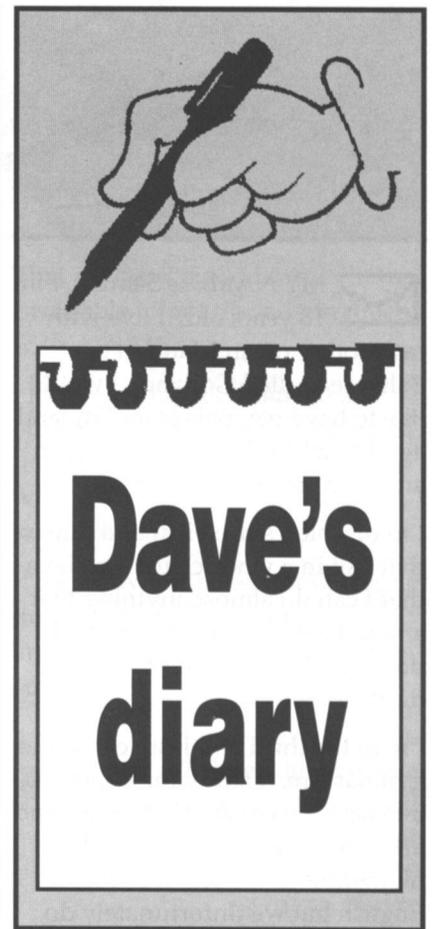
Sadly for me, activities involving partying and/or TV soap marathons (and generally not involving Arctic survival clothing), seem to be interests which are largely absent from the pages of *Link* (or any other magazine, to be fair).

Is it just me? Am I the only disgusting degenerate slob on ASBAH's books? Is sport really the only activity that occupies readers' minds? Or are there hundreds of people out there silently praying for an end to this talk of fresh air and healthy living and instead seek discussions on the merit of 'Coronation Street' versus 'Brookside', art, science fiction, country music, fudge-making, beer-drinking, 'dungeons & dragons', rave parties, computer games and the thousands of other subjects that occupy readers' minds!

I appreciate that there are publications which cover items such as cooking, fishing, astronomy and building your own nuclear bunker! These will hardly ever mention disability, however, but is that any reason for 'our side' not to bring it up?

What I'd like is for readers to send me a list of their favourite activities. I love audience participation!

Pick up that pen – gentle exercise is good for you. Don't forget that



every activity has some merit. Not just the ones we are supposed to be doing (like working, tidying up, getting a life etc).

I bet everyone lists 'sport' as their favourite activity - just out of spite!

THANKS, Mrs Spencer, for writing in response to my last column. It is good to know that I've a few years to go before I become the oldest person with spina bifida (*Editor's note: see page 10*).

Since then, I've been away up north, come down with the 'Black Death' which left me stuck in bed, had a week-long visit from a friend with seriously deteriorating hips (very painful), been told a friend had a serious bike smash and a cousin has died. I am going to the funeral tomorrow. Not the greatest few weeks by any stretch of the imagination. I am amazed that wretched Chinese satellite didn't fall on me just to finish the job off!

David Fulford-Brown

If you don't like Sport – Try Music

SHARE music residential courses are held in July and August at wheelchair accessible venues and provide an opportunity for young people aged 17-40 to take part in musical activities. Carers/relatives welcome. Cost £225 includes full board.

The course venues are:

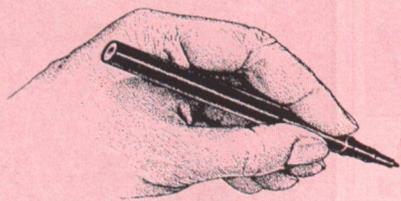
South – July 20 to 27 at Crabhill House, Redhill, Surrey

Wales – July 20 to 27 at The Stackpole Centre, Pembroke, Dyfed

North - July 27 to August 3 at The Calvert Trust Centre, Keswick, Cumbria

Northern Ireland - August 10 to 17 at The Share Centre, Lisnaskea, Co. Fermanagh

Write to Dr Michael Swallow, 15 Deramore Drive, Belfast, BT9 5JQ.



Letters



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.



MY NAME is Samuel, I'm 18 years old. I live with my mother on an island in the Baltic sea called Gotland. I would like to have pen pals from England age 17 - 20, both men and woman are welcome to write to me.

I'm disabled since birth and due to that I sit in a wheelchair. I believe that I can do almost anything that a non-disabled person can and I don't really see myself as a disabled person.

I'm in the third and last year in the gymnasium. I study for example business, Swedish, ADP, civics and art. My favourite subject at the moment is art. But it was before English but we unfortunately do not have the subject anymore.

In my spare time I watch TV, bake, cook, read car magazines, go to the cinema, play computer games, listen to music. I listen to almost everything except opera, jazz and techno. My favourite group at the moment is "Def Leopard".

I also like to travel. I have been to Spain, Germany, Norway, Finland, Denmark, and The Canary Islands. Last summer I and my father went for a weekend to London. We stayed at the Copthorne Tara. It was really great and I hope to have the opportunity to go back there soon.

After that I have finished my studies in the gymnasium I would like to move to either England or USA for a period of one or two years to work or study.

Samuel Ahlstrom
Stenkumlavag.
3CS-621 46
VISBY
SWEDEN



I AM a physiotherapist working with a number of people with disabilities, some of whom are disabled by spina bifida. I wonder if any of your other readers were struck by the three stories that caught my attention in Dec 95/Jan 96 edition of 'link'. Poppy born without disability after her mother courageous decision to continue the pregnancy; Victoria whose disability came as a shock when she was born; and Kristen who is clearly living life to the full as she prepares for the birth of her own first baby. I suppose it is just a remarkable coincidence that the three stories appeared together in the same edition. Having read them, I am moved to question this policy of advising termination if

disability is apparently detected - particularly to challenge the notion that this is the best 'solution'. I am particularly concerned about the insidious effect such a policy must have on the self - esteem and confidence of people who are affected personally by the disability. I would be glad to open up the debate, and to hear any personal views. Perhaps Link might provide a forum.

P.S. I was also relatively recently ordained as a priest in the Church of England.

Revd Mrs Jill Bentall
Andover
Hants



I AM writing in response to the article in the Dec/Jan edition of Link regarding the pioneering scheme to give talks to local pupils in comprehensive schools in Leicestershire about disability issues.

Whilst I congratulate the organisers on their scheme, I must say that theirs is not the first and only scheme to be started. I have been giving talks to year seven students at the local middle school and years 9 and 10 students at the local comprehensive school in Cheddar for the past eight years, seven of which while I was working on the ancillary staff. These talks were done as part of the schools Social Studies course.

I am sure that there are other schools who do something similar, especially as disabled children are now being integrated into mainstream schools.

I have found that the children I have spoken to about my

disability (spina bifida and hydrocephalus) are very interested in how I cope with life in a wheelchair. It gives them a greater awareness of disability issues.

Ian McArdle
Member of Somerset ASBAH



MY I, through your columns ask if anyone is, or has been in the following situation:

Living in totally inappropriate accommodation that cannot be adapted; that was bought before the disability was acquired or known about; and cannot afford to move.

If so, I Would be very pleased to hear from them, especially if the situation was resolved satisfactorily.

Mrs I P McGeorge
19 Vanbrugh Fields
Blackheath
London, SE3 7TZ



I READ with interest the item in the

December issue of Link on *Planning ahead for the future care of someone with special needs.*

My wife and I are caring for our 18-year-old son. He is an 'arrested hydrocephalic' and at present is not shunted. He is registered blind but it is his mental inability to cope on his own which will be of increasing concern as we all get older.

The item by Paul Muldoon of Peterborough solicitors Bryan Barnes & Co states that one "must always... seek professional advice from a specialist in this field". But how exactly does one assess the relative expertise in this field of solicitors in one's own area?

Does ASBAH have a list of recommended firms, or would

our ASBAH regional office have any suggestions?

Although I made a will years ago when my son was just a toddler, the full extent of his disabilities was not then known and my wife and I should like to make up-to-date wills which are as watertight as possible in safeguarding his future security.

Any suggestions you may have would be welcome.

Name and Address Supplied.

Editor's note: Mr Muldoon says that a Law Society scheme called Lawyers for People with Learning Disabilities can advise on which of their members have experience in this area of probate work.

Contact them through their administrator: Mr Christopher Gates, The Smokery, Greenhills Rents, Cowcross Street, London EC1M 6BN.



I HAVE spina bifida and I am still trying to set up a local ASBAH group, even though an attempt to do so some months ago produced just one response – from the grandmother of a man in America who has spina bifida.

That did have a good result, in that I was able to put the lady in touch with ASBAH.

I have now moved home to a bungalow with just one step up at the front and one at the back. So it will be much easier for disabled people to visit.

If anybody is interested in meeting informally, to share experiences and exchange information please contact me.

Tony Sprague
17 Coleridge Avenue,
Crownhill,
Plymouth
PL6 5JP,
tel 01752-768171.

24 April

ASBAH Bristol parents support group, first meeting, Children's Centre, Frenchay Hospital, Frenchay Park Road, Bristol, 7.30 - 8.30pm. *Phil Sommerton, staff nurse, ward 8, tel 0117 970 1212, Julie Knight, ASBAH fieldworker.*

29 April

Milton Keynes ASBAH carers support group, Centre for Integrated Living, next to Church of Christ the Cornerstone, central Milton Keynes, 1-3pm. Guest: to be announced.

21 - 23 May

Midlands Naidex, National Exhibition Centre, Birmingham.

24 - 26 May

ASBAH Family Weekend, King's Park Centre, Northampton, for families with a child aged 5 or under with hydrocephalus and/or spina bifida and their brothers and sisters. *Lynn Thomas, ASBAH, tel 01733-555988.*

DATES FOR YOUR DIARY

24 - 26 May

Scottish Mobility Roadshow, The Royal Highland Centre, Ingleston, near Edinburgh Airport, 10am-5pm daily. Free entry. *Inez Visser, Disability Scotland, tel/minicom 0131-229 8632, fax 0131-229 5168.*

29 May

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

31 May - 1 June

Northern Ireland Mobility Roadshow, Kings Hall, Belfast, opens 10am both days. *Disability Action, tel 01232-491011.*

June 8 - 15

Special Families – Special Needs awareness week, raising awareness of the lives of families affected by rare specific cond-

itions. *Carol Youngs, Contact a Family, tel 0171-383 3555.*

14 - 16 June

ASBAH Eastern Region Adventure Training Weekend, King's Park Centre, Northampton. *Rebecca Sewell, tel 01733-555988.*

26 June

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

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. *Tel 01392-438123.*

24 - 26 September

Naidex International, Wembley Exhibition & Conference Centre, London.

HOLIDAY ACCOMMODATION

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



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.

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.

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.

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.

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
Ardsley, 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
Chylesmere
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

HERTS & S BEDS

Mrs S Riseborough
45 Frankland Road
Croxley Green
Herts WD3 3AS

HUDDERSFIELD

Mr Stephen Bolton
41 Fields Way
Kirkheaton, Huddersfield

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 822985

LEEDS & BRADFORD

Anna Waddington
Mullion Cottage
Main Street
Hawksworth, 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

LINCOLNSHIRE SOUTH

Mrs P Mason
67 Boston Road
Heckington, Sleaford, Lincs

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

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

SALISBURY & DISTRICT

Mrs J Renshaw
1 Phillip Court, Coronation Rd
Salisbury SP2 9DA

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 Freelands 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

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, Rusper
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
Beaminstor, Dorset DT8 3EA
Tel: 01308 862614

WIRRAL

Mrs M Appleyard
28 Stavordale Road
Moreton
Wirral, Cheshire L46 9PR

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 L D Morris
Penrhyn Arms
Pendre Road, Penrhynside
Llandudno LL30 3BY

South Wales

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

NORTHERN IRELAND

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

NON AFFILIATED ASSOCIATIONS

Blackpool & Fylde

Mrs Diane O'Hagan
34A Lennox Court
Lennox Gate, South Shore
Blackpool FY4 3JR

Calderdale

Mr A L Crowther
12 Elm View
Huddersfield Road
Halifax HX3 0AE
Tel: 01422 341497

Cannock & Walsall

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

Chesterfield

Mrs K Tomlinson
23 Hathern Close,
Birmington Common
Chesterfield, Derbys

Cornwall

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

East Anglia

Mrs L Turner
7 Stow Gardens, Wisbech
Cams 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

Nottinghamshire

Mrs W Purselglove
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

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.



Association for Spina Bifida and Hydrocephalus

AIMS

ASBAH works in partnership with people with spina bifida and/or hydrocephalus and their carers to achieve its aims as follows:

- ◆ To promote positive attitudes towards, and counter discrimination against, disabled people.
- ◆ To influence legislation and policy for the benefit of people with spina bifida and/or hydrocephalus, their families and informal carers, campaigning on issues and securing services commensurate with their needs.
- ◆ To provide advisory, advocacy and other services to people with spina bifida and/or hydrocephalus and their families.
- ◆ To provide information on and improve awareness of spina bifida and hydrocephalus and to promote the primary prevention of neural tube defects.
- ◆ To consult and listen to the views of people with spina bifida and/or hydrocephalus in forming policies.
- ◆ To promote good practice and attitudes among those working with and for people with spina bifida and/or hydrocephalus.
- ◆ To work with local Associations by providing an active information service and clear national policies on significant issues.
- ◆ To promote and fund research into the causes, effects, prevalence and prevention of spina bifida and hydrocephalus, and into effective education and treatment.

PRINCIPLES

- ◆ All measures should be founded on the explicit recognition of the rights of disabled people.
- ◆ All people are to be regarded as of equal value.
- ◆ Disabled people should be involved in and consulted about any decisions affecting their lives.
- ◆ All services should be designed to meet individual needs and goals.
- ◆ All individual progress is relative to individual potential and particular circumstances.
- ◆ ASBAH believes in co-operation and communication between all those who work with and for people with spina bifida and hydrocephalus, locally, nationally and internationally.

April 1996