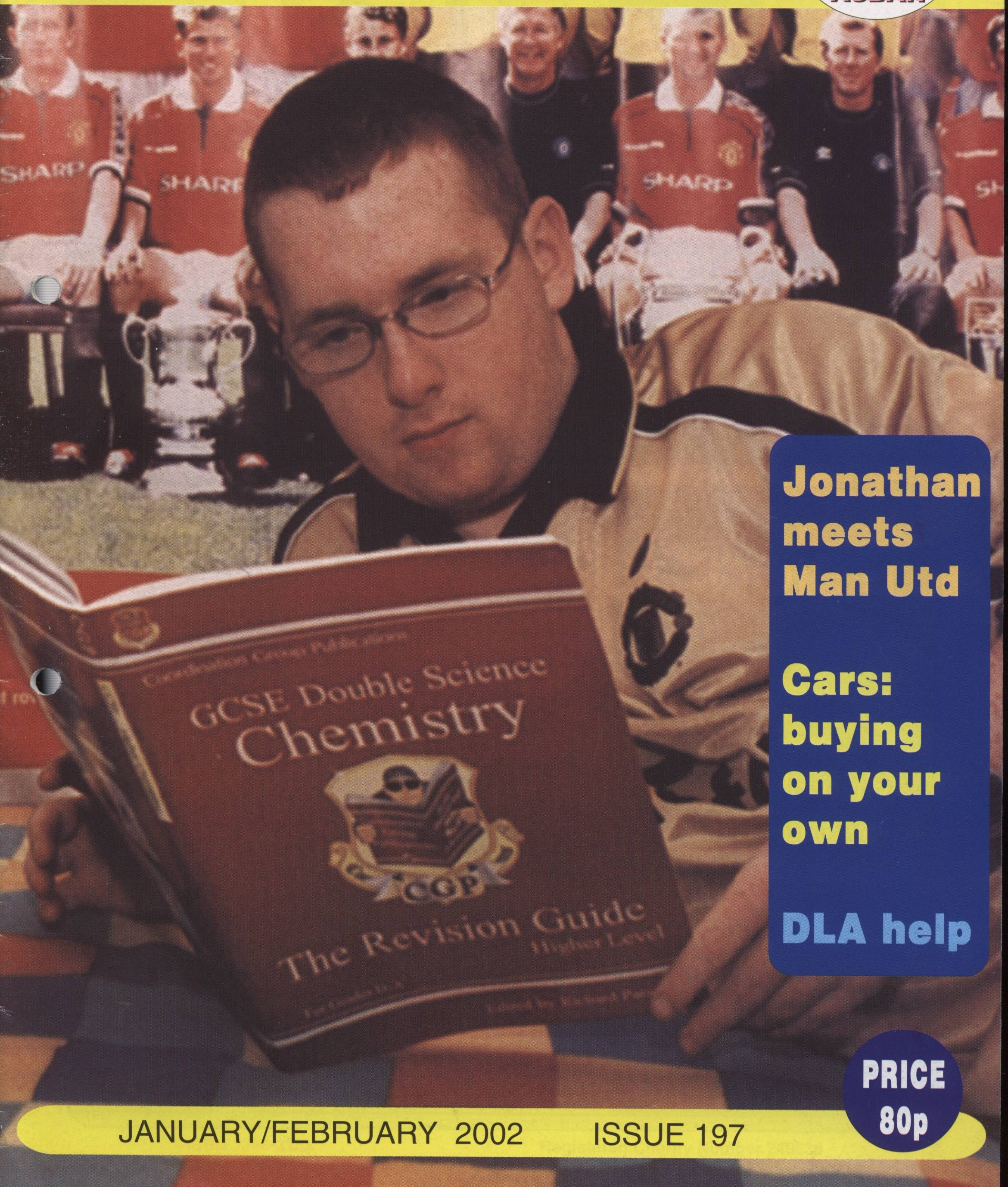
LINK

The magazine for people with Spina Bifida and / or Hydrocephalus

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS
ASBAH



Jonathan meets Man Utd

Cars: buying on your own

DLA help

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JANUARY/FEBRUARY 2002 ISSUE 197

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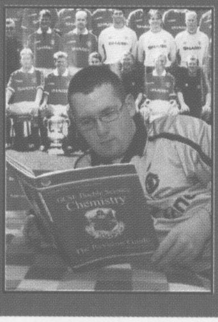

Cover: Manchester United fan Jonathan Prenter gets to meet the team in a trip of a life-time. Story on page 12

Editorial

ASBAH fought back after two child health experts urged further delay to plans to fortify bread with folic acid. Professors Brian Wharton and Ian Booth wrote in the *British Medical Journal* that a field trial should be conducted to test for possible ill-effects.

Our executive director, Andrew Russell, did the rounds of the TV and radio shows on 23 November to point out that these reservations had been considered carefully by an expert Government committee two years ago, and been dismissed by them.

Since then, the Government had taken no action. This had been at the expense of hundreds of women whose pregnancies have since been affected by one of the most preventable birth impairments in the world.

Mr Russell said that a field trial in the UK, which would involve millions of participants, was impossible. "In any case, experience in the US fulfills this requirement. Flour fortification has been in place there since 1998, with full public acceptance, minimal costs and no hazards emerging – in a population of a quarter of a billion people."

● Backbench MPs, led by Labour's Helen Clark, also challenged Government complacency on the issue. *See page 6.*

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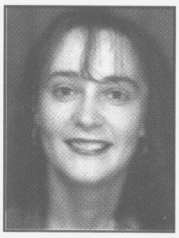

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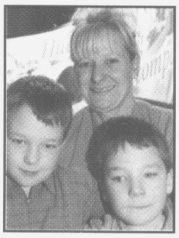

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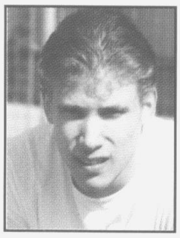

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ASBAH's vision is a future where everyone with spina bifida or hydrocephalus can get the most out of life.

ASBAH's mission is to work with people with spina bifida and/or hydrocephalus, their families and carers to promote individual choice, control and quality of life.

link@asbah.org
www.asbah.org

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It's your call

PHONE companies could do better says a new independent report looking at services for disabled and older customers.

Ricability's 16-page report, *It's Your Call – telephone services for older and disabled customers*, explains in clear, no-nonsense language what services the eight major telephone companies offer and how to get them.

The guide shows that not all companies give the same level of service. For example, only three out of the eight publish clear guidance to their services.

Disappointingly, only one firm has made any real progress since Ricability's last report in February.

The report describes widely available services which disabled people may find helpful:

- A priority repair service if your phone should stop working.
- Free directory enquiries if you are unable to use a phone book.
- Bills in alternative formats, ie large print, Braille or tape.

For a copy of the report, send an A4 SAE and 33p in stamps to: Ricability, 30 Angel Gate, City Road, London EC1V 2PT. Large print, Braille and tape formats available. Also on website www.ricability.org.uk

Row with Motability over parent's income

Mum's the word?

AN ASBAH mum is convinced that Motability passed on misleading information about her – resulting in her being hauled up in front of the Benefits Agency fraud squad. Motability has denied doing so.

Ella Quinn and her 28-year-old disabled son, Stuart, (*pictured right*) gave details of their income and expenditure when applying to a special Motability fund for Stuart's first car.

Nine days after sending off the application, Mrs Quinn – who's on Income Support – was shocked to receive a letter from the BA fraud squad, asking her to go in to discuss her benefits.

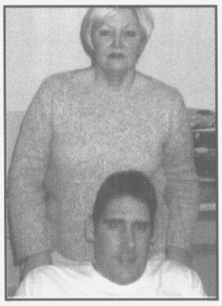
At the meeting, Mrs Quinn, from Liverpool, was asked why her ex-husband's name was on her gas and electricity bills.

She said: "I pointed out that Mr Quinn left my home more than 14 years ago. As Stuart nearly died seven and a half years ago when a series of operations didn't work, it didn't seem important to change the name on my bills."

Mrs Quinn believes Motability contacted the utility companies to see if she had an account with them, was given the name of Mr C Quinn, and then passed this information on to the BA.

Luckily, Mrs Quinn pays by standing order so had proof that she paid the bills.

But she was furious, particularly when Motability then asked for her credit card transaction details.



A Motability spokesman said: "It is important for Motability, as a charity, to distribute charitable funds fairly and only to those who have genuine needs with no other source of funding.

"Anyone seeking financial assistance from Motability must verify all household income and expenditure.

"We have not received any copies of utility bills, and therefore have not and could not have passed any information on to any other agency."

He added: "Credit card payments are essential when considering an application, we have to look at how the income of the customer is being spent. If a customer is using a credit card to pay for luxury items, when the money could be used for making a payment towards their mobility, we are unlikely to assist with the full cost, if at all."

Stuart's ASBAH adviser, Angela Lansley, said: "A parent of an adult disabled person shouldn't be responsible for funding their needs. It's irrelevant how wealthy the parent is.

"What items someone has got on their credit card is way beyond what Motability needs to know."

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Fax: 01248-679 141
elini@asbah.org

Cars – Marcia and Paul buy their own

ASBAH'S Marcia Conroy is glowing with pride now that she's the proud owner of a racy little black number on four wheels.

She and her husband Paul, who both have spina bifida, thought long and hard before deciding to buy independently, without the help of Motability.

But they got a nice surprise when paying – they saved £2,500 as disabled people and their families are VAT exempt.

They chose a Golf 1.6 automatic which, at first, they thought would be expensive to insure. But the Disability Discrimination Act states insurance companies must apply the standard rates to disabled people. Even better, the 'no claims' on Marcia's previous insurance policies were also taken into account.

Marcia, our Greater Manchester adviser, said: "We wanted to go for something different than what is offered by Motability and we found it much less expensive than we'd thought.

"It pays to shop around for quotes on loans and insurance. We also shopped around for a car, looking at boot size and getting the best deal.

"We had no problem getting a loan and insurance – we accepted both from Volkswagon as they bettered what the bank had quoted us."

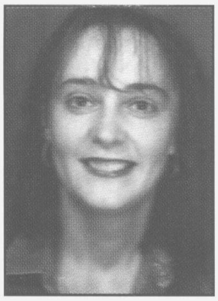
Hand control fitters got involved before the car left the garage.They charged £310. The controls will last three years and can be serviced with the car.

Marcia (30) said: "You've got to really think about going it alone as there's a financial burden for a longer period of time and more responsibility than owning a Motability car. For example, you don't have the security of break-down support. But, in five years' time, we'll have a car of our own to sell on or maintain and drive."

Lottery lights up the way for Kent ASBAH

VITAL support for 400 families in Kent will continue for another three years thanks to the local association there winning a grant of £42,861.

The money, from the National Lottery's Community Fund and matched by Kent ASBAH, will ensure that KASBAH members go on receiving the help they need and to increase professional and public awareness.



Development co-ordinator for South Kent, Fiona Godfrey (*pictured above*), will be joined by a new counterpart for the northern part of the county for the next three years.

The work started three years ago with an audit of members' needs, which was presented to the members, healthcare professionals, social services and education departments.

Other areas of work have involved establishing various groups including a social group for adults (stemming from personal development training), a summer activity group and a support group for families with pre-school children with hydrocephalus, the production of a bi-monthly newsletter and links have also been made with ethnic minority groups.

All these activities, plus regular contact with the media and relevant professionals, will continue. A new area will be a study into the educational needs of members, then research on training and employment. Issues like isolation, mobility and transport will come under the spotlight in the third year.

Fundraising, publicity and links with other voluntary groups will also be emphasised.

ASBAH takes to the airwaves

HOPES and aspirations voiced by some of our youngest service-users kicked off a BBC radio appeal in Northern Ireland.

The five-minute broadcast, profiling ASBAH's work in the area, was featured twice on the same day on BBC Radio Ulster.

The main narrator was TV and radio producer, Jacqui Berkley, who ASBAH regional manager, Margaret Young, met five years ago as the folic acid campaign in Northern Ireland was about to take off.

The 4 November broadcast had the dual aim of increasing public awareness about ASBAH Northern Ireland as it entered its10th anniversary year, as well as raising funds for the region.

MPs re-ignite fuse on our folic acid campaign

NEW pressure was put on the Government in November to fortify flour with folic acid.

Their failure to act on advice issued almost two years ago has resulted in 800 women unnecessarily having their pregnancies affected by spina bifida.

Peterborough MP Helen Clark added fuel to ASBAH's campaign by tabling an early day motion in the Commons.

The motion, which was slowly gathering support in November, regretted that no progress had been made on the mandatory fortification of flour with folic acid. This was almost two years after the measure was backed by the department's own experts on the Committee on Medical Aspects of Food and Nutrition (COMA).

The motion said the move would help protect the health of the most deprived mothers and children in the UK.

One thousand pregnancies are affected every year in the UK by spina bifida. COMA said in its January 2000 report that spina bifida incidence would be cut by 41% if 240 micrograms of folic acid were to be added to every 100 grams of flour.

ChairAbility – MPs slaughtered

A TEAM of MPs and city councillors were slaughtered by wheelchair-users in a game of basketball after lining up for ASBAH's ChairAbility Challenge.

MPs John Denham (Itchen), Sandra Gidley (Romsey) and Alan Whitehead (Test), and city councillors for Southampton were defeated 12–2 by regular players. The Hampshire Hedgehogs. The MPs' team was swelled by John Denham's son, Edward.

It was the first time Southampton & District ASBAH had staged the fun event but they gained lots of publicity that showed the positive side of disability. They got their name on Radio Solent and pictures were taken by *The Southampton Echo*.

Treasurer Cora Bugden said: "It was quite hilarious really. Alan Whitehead scored twice for the MPs but only after The Hedgehogs had given them the ball. It was a very entertaining evening."

Spectators at The Chamberlayne Leisure Centre in Weston also saw wheelchair dancing by The Badgers – including the début of six-year-old Amy Hayter, who has spina bifida.

Independent living and housing – your views count

DO YOU live in Greater London? Would you be interested in joining a new service development group?

ASBAH's independent living and housing advisers, based in London, want to set up a consultation/discussion forum. People who have spina bifida and/or hydrocephalus who would like to take part are invited to make contact.

The aims of the group will be to share ideas about several aspects of support:

- To learn about the experiences people have of independent living, and find out what training is needed but not available.
- To find out how to provide useful information, about what people need and how to make this accessible.
- To stimulate discussion on how to build up peer support.

Judy Hunt, our independent living adviser, said: "We hope these discussions will help ASBAH to develop services that disabled people want and enable more disabled people to use their experience to provide each other with very valuable support."

Contact Judy on 020-8363 4110, judyh@asbah.org or Lucy on 0118-9343 452, lucyh@asbah.org Or write to: ASBAH's South East Region Office, 209 Crescent Road, New Barnet, Herts EN4 8SB.

Got a strong opinion on any of the stories in *Link?* Email link@asbah.org now

Disability Living Allowance (DLA)

Disability Living Allowance (DLA) is the main benefit for children with disabilities. It is paid regardless of how much you earn or the savings you have. It does not affect any other benefits you receive and in some cases can actually increase them.

DLA is given as recognition that caring for a child with a disability will place a much higher financial burden on families than if their child does not have a disability. Your child does not require a specific diagnosis, it is more about the extra help your child requires (even if they do not currently receive any) that results from their disability.

Your child must have had the disability for three months before DLA is paid unless your child has a terminal illness. If there is a chance that your child may die in the next six months you do not have to fill out a DLA form and can claim DLA straightaway.

Applying for DLA

Ask for a DLA Claim Pack – form DLA1 Child (for children under 16 years). These are available from any DSS office or the Benefits Enquiry Line 0800-882200. In both cases, they will be date-stamped from the date you requested them which means that, if you are successful, DLA will be back-dated to this date. You have six weeks to complete the form and send it back.

Be aware – if you receive a form from anywhere else, eg your local CAB, it is not dated and so you can only claim from the date when the form is received by the DSS office.

DLA is split into two sections or 'components' as they are known, and each is offered at various rates.

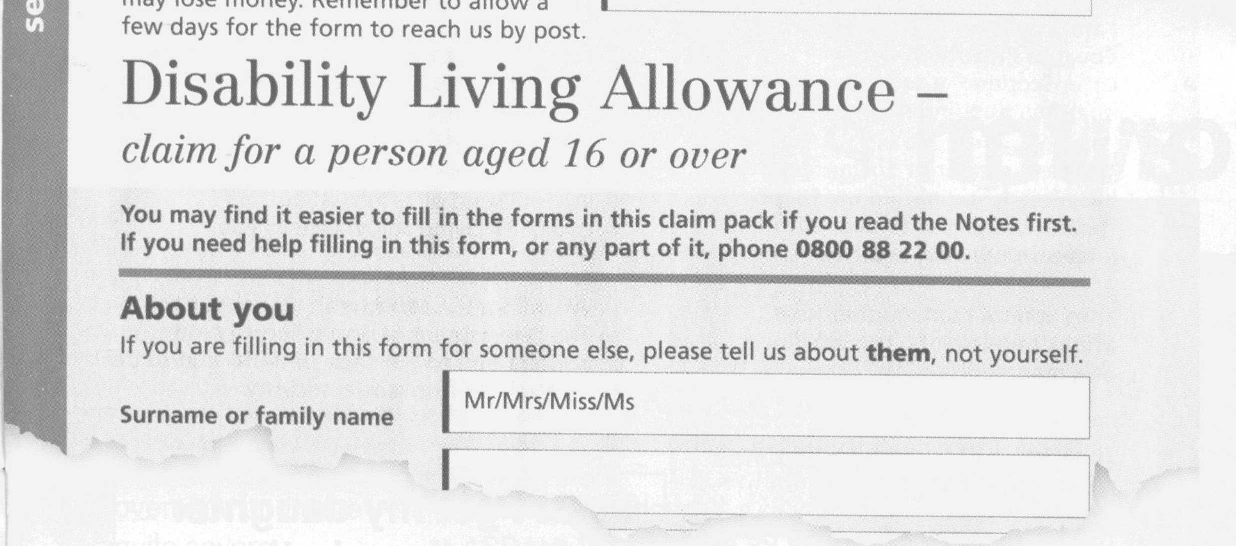
Care Component – children over three months can receive this if they need extra help with their personal care because of their disability. They may require help with washing or using the toilet or need someone to keep an eye on them whilst performing these tasks. Offering verbal instructions can be seen as extra help. There are three rates to the care component.

Mobility Component – children three years and over receive this if they need help getting around. They may not be able to walk at all or have difficulties, be both deaf and blind so need support when outdoors or be unsafe walking unattended, eg not recognise danger on the roads. There are two rates to this component.

Always fill out both the care and mobility section as it is the DSS which decides the components and the rate you will receive. Your application may show you are entitled to one even if you do not think you are.

Claiming DLA can help with getting extra support. These may include:

- **Invalid Care Allowance (ICA), Disabled Child Premium or Enhanced Disability Premium** – these premiums help you to apply for more **Income Support, Council Tax or Housing Benefit .**
- **Access to Mobility Scheme to help you buy or lease a car.**
- **For those on Working Families' Tax Credit or Disabled Person's Tax Credit, you will receive an extra Disabled Child Credit.**



may lose money. Remember to allow a few days for the form to reach us by post.

Disability Living Allowance –

claim for a person aged 16 or over

You may find it easier to fill in the forms in this claim pack if you read the Notes first. If you need help filling in this form, or any part of it, phone 0800 88 22 00.

About you

If you are filling in this form for someone else, please tell us about **them**, not yourself.

Surname or family name	Mr/Mrs/Miss/Ms

- **Family Fund** can help with a whole host of extras, eg holidays, washing machine, driving lessons. (Your income cannot exceed £21,300 and savings of more than £8,000).

Filling out the DLA form

Give it high priority; remember that awards are made for several years at a time and most are worth several thousand pounds per year. Ask a friend or relative to help, don't underestimate how difficult a task this is.

- When there is plenty to say, fill up the box, add extra sheets if necessary.
- Don't just give the diagnosis. DLA is about how your child's disability affects every-day life. It is not asking what help you currently get but about the help you actually need with ordinary tasks. Parents can underestimate how much they do for their child.
- Tell them about the bad days.
- Write down in detail exactly how you child manages at meals, bath-times etc. Note all the adjustments to ordinary family life that you make to meet the extra demands of your child.
- Remember to keep saying in detail how your child's needs are substantially greater than other children of the same age. Make comparisons between younger able friends or siblings.
- Give examples of where your child hasn't had help and the consequences.
- Obtaining supporting evidence can sometimes be difficult but if you have been to your GP about problems sleeping then this can be corroboration.
- Get a supporting statement from someone who really knows your child.
- Don't rely on anyone to send off your form, obtain a proof of posting.
- Send supplementary evidence, eg a medical report. (Be careful as school reports can sometimes accentuate the positive).
- Take photocopies – it will help in appeal and for renewal.

If your application is rejected

Firstly, don't despair! If you were not given reasons why you were rejected on the decision letter, contact the DSS office asking for written reasons for the rejection. This needs to be done within 14 days of your decision.

You can ask for a reconsideration or appeal against a decision. This must be done within a month of the decision letter. If you are not happy with the reconsideration, you can still appeal. You have one month to appeal after the reconsideration decision.

Appeals are organised by the Appeals Service by way of a tribunal hearing. Take advice from your local ASBAH adviser, CAB or Welfare Rights Officer. Ask to attend the tribunal in person as you have more chance of winning that way.

It could be that your child's current needs are similar to those of other children who do not have a disability, but as they become older, the differences may be more apparent. It may be a case of re-applying for DLA at a later stage.

- If you want to know more, contact ASBAH National Centre, Services Department, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988. If you need help filling in the form, you should contact your local Citizens Advice Bureau or Carers Centre.

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link.forum

WE RECEIVED no replies from readers on the first problem in our link.forum section. So, if you would like this new *Link* service to continue, please let us know.

Remember, we would like to hear about YOUR experiences – whether you are a young disabled person, a parent or an adult.

This is what one ASBAH adviser suggested in response to last issue's problem (reprinted opposite).

She said: "The best way round this problem would be for the parents to negotiate weekday and weekend bed-times with the student. A reasonable time to switch off the telly during the week would be 10pm and lights out at 10.30pm."

If you think a different solution should be tried – or would like to submit your own problem – please email link@asbah.org or write to: ***Link.forum, ASBAH, 42 Park Road, Peterborough PE1 2UQ.***

Here's last issue's problem –your comments and other questions to discuss are welcome

I can't get my daughter up for college in the morning because she's been watching TV all night. She's 20 and has hydrocephalus. What should I do?

Sport puts a sparkle in Tom's life

FINDING sports he was good at changed a 13-year-old wheelchair-user from being depressed and frustrated to bright and enthusiastic.

The positive experience was topped this autumn when Tomas Docherty won the *Andy Wallace Award For Those Showing International Promise* at the 2001 National Junior Games, organised by the British Wheelchair Foundation.

The Shrewsbury teenager was helped to get there with a contribution from ASBAH. Although he had never seen fencing or zone hockey before, he narrowly missed out on third place in the fencing competition and his hockey team achieved bronze.

When Tomas started mainstream secondary school, little more than table tennis was offered and his spirits sank so low that he was referred to a clinical psychologist. But getting involved in wheelchair sport outside school was the turning point.

His mum, Monica, said: "It was quite hard to find anything locally. We do a 160-mile round trip to train with The Rugby Rockets at the Ken Marriott Leisure Centre in Rugby. "

This year, Tomas wants to enter small races and join the Shrewsbury Disabled Cricket Club. On Thursdays he does wheelchair basketball in Telford.

Mrs Docherty continued: "The National Junior Games were something we were leading up to. Tom suddenly realised how many children used wheelchairs and some were a lot more disabled than himself. The amazing thing was that everybody did something and was enjoying themselves.

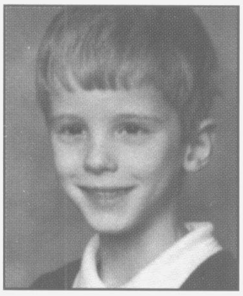
"Speed is the exciting thing for Tomas. Other boys his age are out on bikes, climbing trees, kicking a football. By doing these sports he feel 'normal'."

The Dochertys, who are now raising money for a sports chair, had trouble changing Tomas's NHS chair from a Bluebird to a Roller 2000 which they had seen in Birmingham. It was only by meeting up with the salesman supplying their local wheelchair centre that they established that a Roller 2000 could be available locally.

If in doubt, check it out

AS a baby, my son Darren had seven shunt revisions and the symptoms always came on overnight and were quite severe.

So I thought I knew what to look out for. But what happened when he was eight was a totally different ball game. I believed the symptoms – appetite loss, headaches, personality changes, tearfulness and then sickness – were a result of Darren being bullied at school and him grieving for his nanna, who had just died.



When I phoned ASBAH, I was told to make an appointment to see our GP right away.

Within a few hours of seeing our GP, Darren was admitted to hospital for a CT scan and then put on the emergency operations list.

His shunt had become disconnected and each part was blocked. It had been like that for the last couple of years.

So there's always something to learn and you can never be too careful.

Jennie Pattison, Goole, East Yorkshire

Mum seeks contact

I AM a mum of two beautiful, happy children who were both diagnosed with hydrocephalus.

My daughter was diagnosed while I was pregnant. When she was born she had numerous tests 'til she was seven months old. Then her hydrocephalus dispersed on its own and there was no need for a shunt.

My son, now two and a half, was also diagnosed with hydrocephalus while I was pregnant but, unfortunately, he wasn't so lucky. He needed a shunt at four days old and, when this became infected, a second one was inserted at five weeks old. He also has epilepsy.

If anyone wants to write to me to compare notes, I'd be grateful.

Rachel Mist, 48 Telekebir Road, Hopkinstown, Pontypridd, Mid Glam CF37 2RL

Well done Kylie!

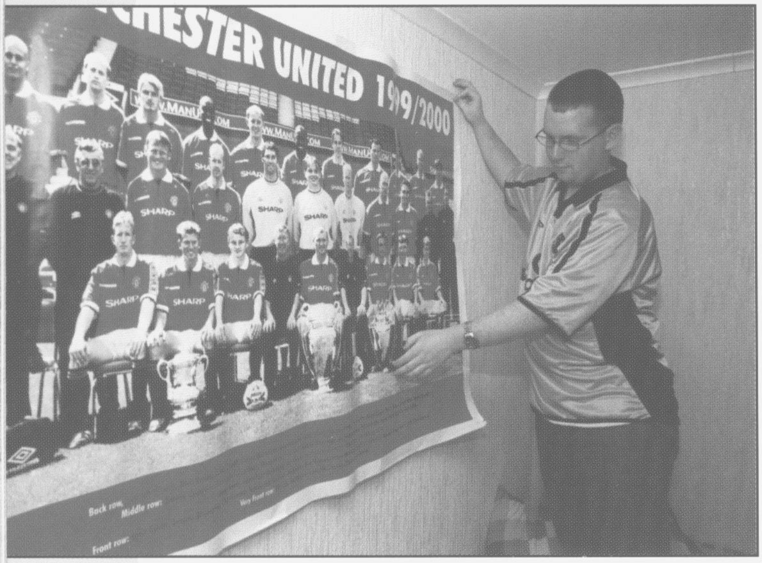
A YOUNG ASBAH fundraiser was shortlisted for a local achievement award after being nominated by her sister.

Thirteen-year-old Kylie Pratten came away with a framed certificate, a medal and a cheque for £30 at the Achievement Over Adversity Awards ceremony, held at Grimsby's Humber Royal Hotel.

Kylie, who has hydrocephalus and epilepsy, has undergone 14 operations and gets headaches which can lay her up for three days in a week. Despite this, her sister Kirsty told the judges that Kylie tries to be like other children and, when she was very young, she raised a fantastic £1,652 for ASBAH by doing a tricycle ride.

Her mother, Gill, from Cleethorpes, said: "Kylie had a super time and was made to feel very special, along with the other nominees. We are very proud of her."

The awards were run by the *Grimsby Evening Telegraph* and Hartwell Ford garage.



Match of a life-time

MAN UTD-mad Jonathan Prenter had the weekend of a life-time when he got to meet some of the team at a practice session at Old Trafford, attended a match and received a behind-the-scenes tour.

The 17-year-old, who has posters of the world-famous Red Devils plastered over his bedroom walls, applied to Dreams Come True Charity to make the trip from Belfast.

Jonathan, who has hydrocephalus and is studying for six GCSEs at home due to ill-health, loves to play football when he's feeling well with friends in The Ardoyne, North Belfast.

He said: "It really is a dream come true for me. Going to see Manchester United is something I've wanted since I was very young."

Jonathan's other big interest is bull mastiff terriers and, with help from his ASBAH adviser, Rosemary Whalley, he successfully applied for a £500 grant from The Prince's Trust to train and show a pedigree puppy. Unfortunately Toya died but he is all set to get another.

Jonathan, who features in ASBAH's promotional *Northern Ireland Review* said: "My dad used to breed bull mastiffs when I was younger. They're big in stature and very placid. I love them."

Off to the summit

A WHEELCHAIR athlete, who was introduced to sport by his local ASBAH adviser, will reach new heights of achievement when he climbs to the summit of Mount Kilimanjaro as part of a team of ambulancemen and women.

In preparation for the 'big one' in 2003, John Hanks will join the Surrey team in an expedition to the top of Mont Blanc later this year.

The 24-year-old, of Ashtead, Surrey, earns a living building ignition coils for Formula One racing squad, Tag McLaren.

He is supported in the challenge by The Leatherhead Swans Club which offers recreation, education, sport and leisure opportunities to disabled people. John attends the club to socialise, swim and canoe.

Expedition co-ordinator, Elaine Lush, said: "We are delighted to be helping John complete these challenges and reach his outstanding goals."

John's achievements so far include: 16 marathons (including five London); 29 half-marathons; several 10K events and numerous track races in the UK and overseas. His best marathon time (1 hour, 44 mins, 04 seconds) was in Berlin in 2000.

Hitched in Vegas

ONE of the new generation of South Wales ASBAH officials flew to Las Vegas to get hitched after finding her ideal wedding venue on the Internet.

Angelina Humphreys and fiancé Ceri Jones put the USA at the top of their location list to keep the occasion small and avoid a church wedding.

Ceri had been to the gambling mecca before and liked it as access was good and disabled people were treated as equal to everyone else. He thought Angelina would love it. So the bride-to-be surfed the 'Net and found a hotel specialising in medieval themed weddings.

Angelina, the new secretary of South Wales ASBAH, explained: "I always wanted to get married in burgundy velvet as white doesn't suit me, and when I found *The Excalibur*, it seemed perfect."

The bride and groom mingled with characters like Sir Lancelot and Guinevere and were entertained by jugglers, minstrels and jesters.

Angelina (33) said: "With casinos in every hotel, Las Vegas is a bit like Disney World for adults, and I did gamble a little. But there's plenty of other things to do – a Madame Tussaud's and Houdini Museum."

Nurse celebrated by her homeland

A RETIRED nurse, who was the first black person in the UK to become matron of an NHS hospital and who has helped ASBAH for more than 20 years, has picked up an accolade from the country where she was born.

Daphne Steele, a former chairperson of our Five Oaks Committee and a former ASBAH Executive and Services Committee member, was awarded a certificate by the Guyanese Government for her professional success in Britain.

Miss Steele, who is still involved in Leeds & Bradford ASBAH, became matron of a maternity home in Ilkley in 1964 which, she says, caused quite a stir. But she felt a great affinity with the Yorkshire town and made it her home.

Miss Steele came to England from Guyana to train as a nurse, then a midwife, at London's St James's Hospital, serving the newly-created NHS.

She said: "I was doing a job I loved. I wasn't in nursing by accident. Then after so many years your Government recognises you. It's smashing."

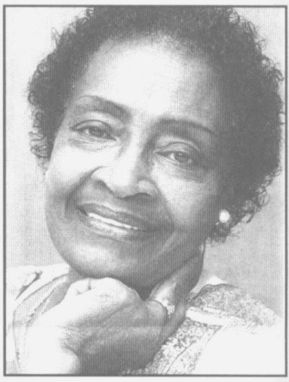


Photo: Ilkley Gazette

Twins share courage prize

RUSSELL Shepherd, who was once only given hours to live, shared an award his with his twin brother.

The eight-year-old, has hydrocephalus and has undergone 46 operations. But thanks to his determination, and the dedication of his mum, Linda Senior, and the understanding of his brother Tom, he is now enjoying life.

The Courage Award was run by *The Huddersfield Examiner*.

Mrs Senior has set up The West Yorkshire Forget Me Not Trust to raise money for a respite care unit in the Huddersfield area.

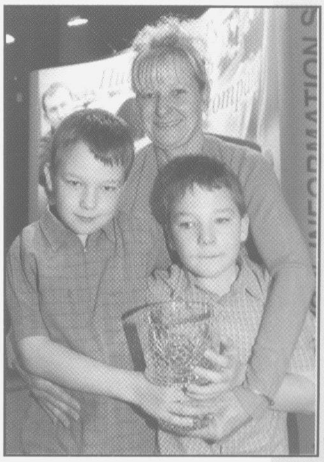


Photo: Huddersfield Examiner

dates for your diary

World's largest mobility event

A CHANCE to test-drive adapted cars, 4x4, skid cars and go-karts on the Donington Park Race Circuit will come your way as the world's largest outdoor mobility event moves to Derbyshire.

The Mobility Roadshow – with free admission, parking and free courtesy buses from Derby station – aims to give anyone with a mobility problem the chance to see what's available in a 'no pressure' environment.

It will be held in Castle Donington from 20–22 June, from 10am daily. If you want to test drive, don't forget your driving licence.

You will see infra-red switching systems; lightweight, sports, power and manual wheelchairs; hand controls; hoists; car seats; vehicles; battery chargers; trikes and scooters; walkers; rotating car seats; specialist wheels and tyres; suspension systems; power steps; ramps; seat clamps; wheelchair restraints; floor tracking; hi-tech mirrors; lifts and numerous gizmos and gadgets to make mobility easier.

Younger family members will be amused too, by jugglers, clowns, magicians, face painters and balloon sculptors, and there's a creche.

Getting together

FAMILY and friends of one local association grabbed the opportunity of meeting each other at an annual get-together.

The pre-Christmas event, at a hotel in Bolton, was organised by Bolton and Bury ASBAH.

Upcoming events

Northern drop-in

Wed 2 January, Leeds
ASBAH House North, 65 Bagley Lane, Farsley, Leeds. 10–noon *Tel: 0113-255 6767.*

Bromley Coffee

Monday 14 January
Coffee morning organised by South Thames ASBAH, 10–noon, United Reform Church, Bromley. *Peter Winterton, tel: 01959-574868.*

Dunstable meeting

Monday 14 January
Monthly meeting for parents/carers of children/young people with SB/H, organised by the South Bedfordshire Support Group. 1–3pm, Disability Resource Centre, Poynters Road, Dunstable. *Valerie Bottoms, tel: 01582-757745.*

Northern drop-in

Wed 6 February, Leeds
ASBAH House North, 65 Bagley Lane, Farsley, Leeds. 10–noon *Tel: 0113-255 6767.*

Bromley coffee

Monday 11 February
Coffee morning organised by South Thames ASBAH, 10–noon, United Reform Church, Bromley. *Peter Winterton, tel: 01959-574868.*

Dunstable meeting

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ASBAH Family Weekend, Cornwall

Fri 1 – Sun 3 March
Three-day ASBAH residential course at Sands Resort, Porth. For families with a child aged 6 and under with SB/H, their brothers and sisters. £65 per family. Supported by the BBC Children in Need Appeal. *Details: Rosemary Batchelor, tel: 01733-555988, rosemaryb@asbah.org*

ASBAH Summer Experience, Cumbria

Tue 4 – Fri 7 June
Four-day activity holiday for teenagers with spina bifida and/or hydrocephalus at the Kepplewray Centre, Cumbria. Canoeing, climbing and abseiling, archery, hill 'walking' for all, fishing, kite-flying and others. *Joan Pheasant 0113-255 6767, joanp@asbah.org*

Mobility Roadshow, Castle Donington

Thu 20 – Sat 22 June
Mobility Roadshow 2002, Donington Park, near Derby. *Tel: 0870-770 3222, choice@gtnet.gov.uk www.justmobility.co.uk/roadshow*

Making your point

DID you know that by mirroring the mannerisms of the person you're speaking to, you are more likely to be successful in getting across your viewpoint?

This was one of the ideas presented to 13 people with SB/H who attended a one-day course in Peterborough.

Organised by Your Voice, ASBAH's disabled users' working group, *Reach For The Sky!* aimed to make delegates more successful communicators.

It was facilitated by Jon Burke – a neuro-linguistic programming practitioner and ex-co-ordinator of Your Voice.

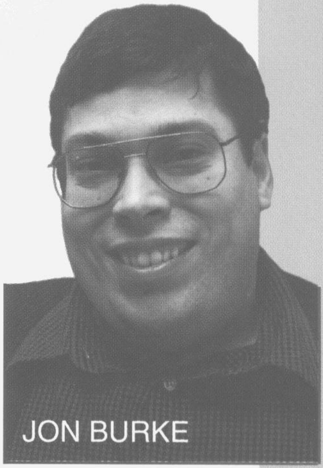
Delegates, with varying communication abilities, were taken through an Introduction to Communication; Building Rapport; an Introduction to the Language People Use; Goal-Setting (and well-formed outcomes); Creativity and an Introduction to Time Lines (setting time objectives).

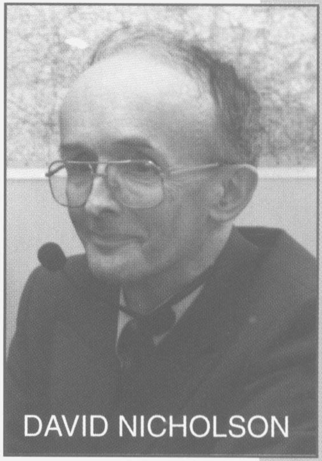
Jon said that, in general, people fall into one of three groupings:

- Vision-based (those who are good at recalling what people and places look like);
- Sound-based (those who are good at remembering what people say) and
- Logic-based (those who prefer to know how something works and what it does).

David Nicholson, a Your Voice steering group member who attended the course, said: "The idea is to work out which grouping the person you are speaking to belongs to, and use their language to communicate your point effectively to them. We learnt that if you try to come back at them with their mannerisms, that will put them at ease and you will be much more successful.

"Ideally, you should even aim to adopt their breathing rate! We went away with quite a few things to practise and read about."


JON BURKE


DAVID NICHOLSON

YV looks to the future

YOUR Voice laid out its plans for training weekends for people with SB/H in 2002 at a meeting in November.

The steering group – 12 representatives of ASBAH's service-users – outlined themes for a weekend on sports, hobbies and leisure, and another on human rights, the Disability Discrimination Act and computer skills.

Also at the meeting were ASBAH executive director, Andrew Russell, and researcher Sue Thompson, who spoke about her study for the Department of Health's National Service Framework for people with long-term neurological conditions.

Assistant director (policy and marketing), Linda Hams, talked about ASBAH's Strategic Plan and asked how Your Voice could work within it. Linda was presented with a leaving gift as this was her last steering group meeting.

Janet Waugh continues as Your Voice steering group chairperson until February while Mary King was elected chairperson of the new Disabled Users' Advisory Committee which will be elected from the Your Voice membership and will support ASBAH in policy issues.


JANET WAUGH


MARY KING

fundraising

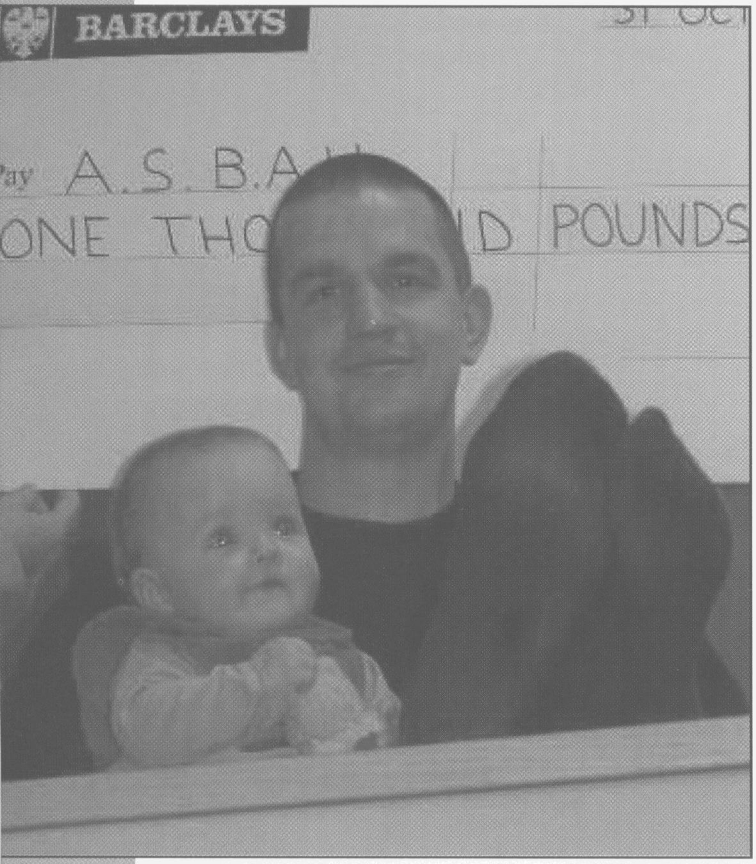
Firefighter on the run

SUPERFIT firefighter Andrew Wright raised a magnificent £1,000 for ASBAH when he joined 7,500 runners in the Robin Hood Half-Marathon in Nottingham.

The half-marathon passes the city's Queen's Medical Centre where his baby Katie Louise had shunt surgery. Eleven-month-old Katie was found to have hydrocephalus after she was born 10 weeks prematurely. She is doing fine now.

Andrew (34), his wife Paula and their first child Katie live at Stilton, near Peterborough, and have been pleased with the support they have received from ASBAH.

Andrew's first half-marathon was eight years ago – a fitness-proving run before he joined the fire brigade. He took up running again after Katie was born as a stress-reliever, and raised money for ASBAH as a way of saying thank-you.



As the Wheel turns

ASBAH fundraising manager Donna Treanor travelled north to Durham where she was presented with a cheque from a group of businesswomen.

Donna thanked members of the Inner Wheel Club of Durham, particularly immediate past president, Judith Turner, who chose ASBAH as her charity of the year.

Mrs Turner's son Christopher (40) has spina bifida.

A cheque for £1,505 was presented to Donna *(above left)* by Mrs Turner at The Ramside Hall Hotel in Durham.

Golfers make our day

THE LADIES section of a golf club in the West Midlands raised a magnificent £1,700 for ASBAH after their captain chose us as her charity of the year.

Pam Tillott, whose family has been affected by spina bifida in two generations, chose ASBAH when she became captain at Druids Heath Golf Club in Aldridge, Walsall.

Mrs Tillott lost a baby girl with spina bifida at just one week old. Then, two years ago, her son and his wife lost their baby who was severely affected by the same condition.

Hundreds of pounds were raised by lady members in raffles, bring and buy sales, a book loan scheme and donations from the men's team and the 'Ancient Druids.'

Mrs Tillott said: "The club does a lot for charity and members are very generous."

A cool and casual £450

OFFICE staff paid for the privilege of casting off collars and ties, and heels and tights, in favour of more casual gear, and raised almost £450 for ASBAH.

Insurance company NIG Corporation has branches up and down the country whose staff regularly take part in 'Dress Down Days' for charity.

Jane Rodger at NIG's Peterborough office nominated ASBAH for one of these special days, and staff in London, Leeds, Birmingham and Manchester all followed suit in her charity choice.

Pictured below are Jane and her boss Colin Hearn, with ASBAH fundraising manager, Donna Treanor, holding several cheques from NIG branch offices, totalling £449.

A big thank-you to everyone at NIG for helping ASBAH continue our work.

Luton study day, thanks to Rotary

SIXTY-FIVE ASBAH service-users and professionals from health, social services and educaiton got together for a hydrocephalus study day, generously sponsored by the Rotary Club of Luton and the city's Chiltern Hotel.

Living With Hydrocephalus was widely regarded as a success, with experts addressing many of the issues associated with the condition, and giving the opportunity for audience discussion.

Topics included *Hydrocephalus – Its Causes and Treatments; Hydrocephalus – the Learning Issues, and Hydrocephalus and Work.*

The driving force behind the Rotary Club of Luton's decision to sponsor the day – immediate past-president Trevor Holland – was described by many as 'an inspiration.'

Mr Holland, who has spina bifida, had 17 operations before he was six years old but went on to university and to enjoy a successful business career. He did not walk until he was 11 and, by the time he was 19, could walk without callipers or strapping.

He said: "That was a time when there were no support groups and certainly no ASBAH, which I only found out about three years ago. I was delighted when Rotary members took up my suggestion that we adopt ASBAH during my presidential year."

Rotary money left over after the conference had been paid for – a fantastic £2,991 – went to our Eastern Region team. This included £600 from a sponsored tandem parachute jump by Rotary member John Horn.

● *Picture shows ASBAH regional manager Mary Malcolm with, from the left, Trevor Holland; hotel manager Simon Wilson and current Rotary president the Rev Nick Bell.* Luton News

What about your HUMAN rights to a good education?

WE HAVE seen a lot of coverage in *Link* on the SEN and Disability Act, particularly the new Code of Practice on Special Educational Needs on which we have vigorously lobbied for change to give children with spina bifida and/or hydrocephalus a better deal in education. A 'new improved' version of the Code is expected shortly – watch this space for news on this.

However, we are also seeing evidence that the Human Rights Act 1998 – enforced in October 2000 – is starting to have an impact in education.

It brings the rights set out in the European Convention on Human Rights into our own legal system. The Convention was drafted in the post-Second World War period and was mostly concerned with civil and political rights.

Although there are few references to children's rights in the Convention, no age-limit is placed on the enjoyment of rights. As a result it does have implications for many aspects of child and family law, including education. Before the Human Rights Act came into force, the only remedy available to a person who alleged a violation of their rights was to take the case to the European Court of Human Rights in Strasbourg.

Judgements of that Court were binding on the British Government but the Convention was not. With the passing of the Human Rights Act, things have changed considerably. It makes the Convention part of our law and requires all 'public authorities', including Education, to comply. Therefore, not only are Local Education Authorities (LEAs) covered but also the Special Educational Needs Tribunal, independent schools and the governors of mainstream schools.

By Joanne Grenfell and Bruce Graham
ASBAH Education Advisers

The following examples show how the rights might apply to education:

● No person to be denied the right to education.

This is not just limited to what is taught. It is more a right to access facilities rather than a right to a particular school and has important implications for refugees or children of Travellers.

It may be useful in gaining support for pupils permanently excluded from school, perhaps by the school setting and marking work or the provision of a home tutor.

● The prohibition of torture and inhuman or degrading treatment.

Any action that involves disciplining a pupil should be recorded clearly and chronologically. Schools should have in place an anti-bullying policy as well as, ideally, behaviour policies including sexual and racial harassment.

● The right to a fair trial.

Governing bodies need to ensure they follow the law to avoid possible challenges at admission, exclusion or disciplinary hearings. For example, appeal panels should ensure they hear the views of the pupils themselves if they wish to be heard. Another example follows a recent court case. Parents can be prosecuted under the Education Act 1996 if they fail to send their child to school. It is not a defence under this Act for parents to argue they had tried their best to get their child back into school. However a recent decision of a Magistrates' Court suggests that to prosecute a parent where a child fails to attend school, despite their best efforts, breaches Article 6 of the Human Rights Act.

● The right to respect for privacy.

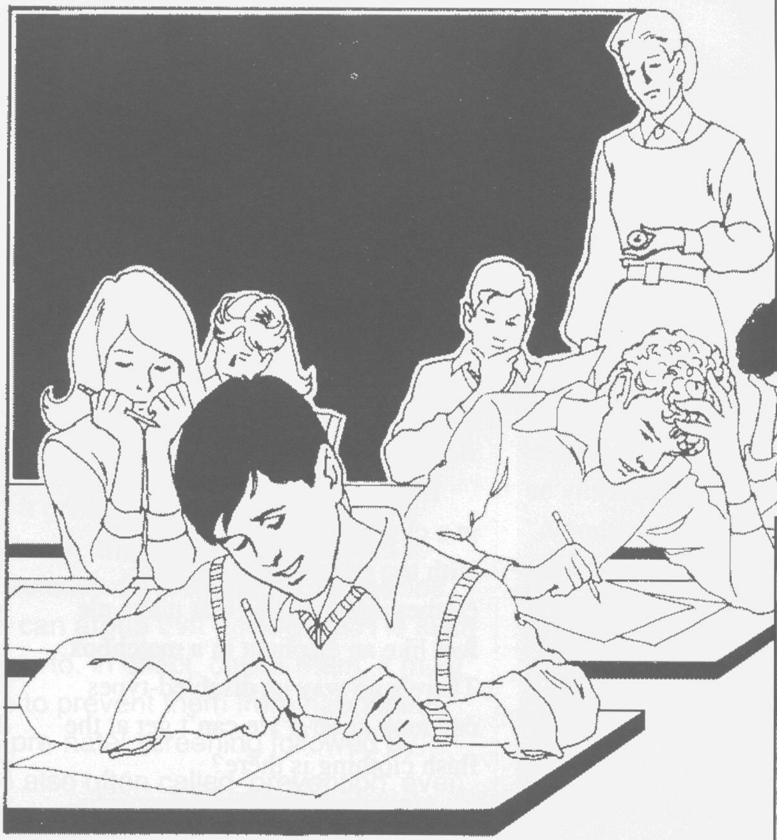
School staff should not carry out random searches of pupils or their property. Staff should only conduct searches with pupils' permission, unless it is necessary to protect others or prevent a crime. If such is the case they should also contact the police.

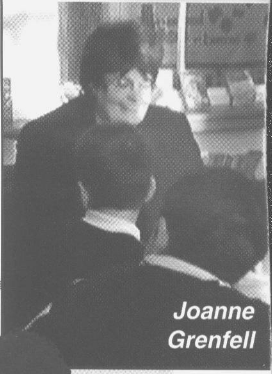
● The right to freedom of thought, conscience and religion.

The most common example here is that time off should be given to staff / students who wish to observe religious festivals, adopt a particular dress code, diet etc.

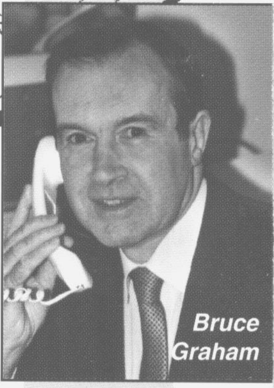
● The right to freedom of expression.

This may have relevance in uniform disputes. Schools can have a dress code but must ensure it is clearly understood by all staff and pupils, and it must not discriminate against pupils of different sexes, religion or race.





Joanne Grenfell



Bruce Graham

● The right to the prohibition of discrimination.

Not all differences in treatment are discriminatory, but only those which have no objective and reasonable justification. This right can only be applied if there is another Convention right at issue. For example, a young wheelchair-user is on a trip with her class to an outward-bound centre. The teachers organise a 12-mile hike over difficult terrain but, having carried out a risk assessment, they decide the wheelchair-user will be unable to go for health and safety reasons. They arrange for her to do archery instead. The Draft Code suggests the decision not to take the girl on the hike is likely to be lawful as the risk assessment was carried out in relation to this particular pupil in the particular setting in which she would have to travel. It showed the health and safety of the pupil and her classmates, could be jeopardised if she was to attempt the hike.

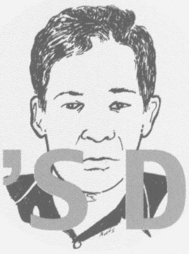
It is still relatively early days but, as the above demonstrates, the Act could have quite an impact.

If you have any experience of the way the Act is used we would welcome hearing from you. Similarly, if you feel that your rights have been infringed please do let us know.

● Bruce Graham (Wales, Central and SW England), tel: 01865-847 332, *Brucelgraham@aol.com*

Joanne Grenfell (North), tel: 0113-255 6767, *joanneg@asbah.org*

Got a strong opinion on any of the stories in *Link*? Email link@asbah.org **now**



DAVE'S DIARY

david.fulford-brown@ntlworld.com

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APPEARANCE is a very important thing. Our clothes and hair style say a lot about us. So it's not surprising there are loads of programmes and courses on how to 'look better.'

When someone's appearance changes radically it can really be shocking. My brother Anthony recently went off on a world tour. So before he left he got a hair cut. But not just the usual trim. No, he completely ditched his normal, office-suitable cut and had it shaved down to the bone!

Anthony's new look took a bit of getting used to. I was a bit mean and teased 'old baldy' about it a bit much. (Sorry Ant!) But it did make me think it was time I changed my look too.

My look has always been boring and 'normal.' As a teenager I never experimented with my look. No dyed hair, no ripped t-shirts, no tattoos, no holes where nature (or a surgeon) hadn't put them. I was more concerned about looking presentable and covering up any 'defects' than expressing myself. To be fair, shopping for new clothes was and is a big problem.

Even today I'm not comfortable in a clothes shop. They're filled with too many wrong-shaped clothes and cubicles that make me feel like an elephant in a matchbox. There's no way us disabled-types can look good if we can't get at the flash clothing is there?

Also, thanks to the hydrocephalus (or being a man!) I'm hopeless about choosing something new. Why can't I grab the old shirt out of my cupboard, go to the shop and get one exactly the same (minus the gravy stains)?

The hydrocephalus also stops me from changing my hair style. I'd love a skin-head cut like Anthony's, but if I have my hair too short the shunt's scar shows. I know some people don't mind their scars showing. But I do.

If I can't shave my hair off, I can still dye it. I've wanted to dye my hair ever since it started turning a dull grey. At the tender age of 33, I am almost as white as a snowflake! I could be dramatic and put this down to a hard life, but it's just genetic – my dad went white early too. But I wasn't going to stay that way. Down at the hairdresser's I spent an hour feeling a right prat as she smeared foul smelling glop on my head. I wasn't after anything too radical. I'm new to this self-expression business. I just wanted my original colour before the grey. But, looking at the result, my 'original colour' must have been boot-polish black!

And the result my middle-aged teenage rebellion? Well, I feel great. But apart from that, nothing! Nobody has said a word! Only my mum noticed and she just giggled a bit! What do I have to do to get a reaction? Go bright green?

Directories for school-leavers

GET the low-down on further education and supported employment from two directories published by Disability Information Services.

The Directory of Further Education Opportunities focuses on special provision in mainstream colleges for disabled people. It provides information on more than 250 colleges throughout England including access, support staff, courses and qualifications.

The Directory of Supported Employment Opportunities gives details of more than 360 supported workshops including their client group, products, services and the tasks undertaken.

The directories cost £25 each, including p&p, or you could ask for them at your local library.

Phone Disability Information Services on 01306-875156; fax: 01306-741740, email: Leonie.Riddett@diss.org.uk website: www.diss.org.uk

Got a strong opinion on any of the stories in *Link*? Email link@asbah.org now

letters

We welcome letters for publication.
Please write to: Editor, ASBAH, 42
Park Road, Peterborough PE1 2UQ.

'Abortion is not prevention'

I HAVE spina bifida and read with much interest the letter by Chris Page, suggesting that 'primary prevention' of SB/H is discriminatory to those who live with the conditions, and the letters replying to him.

I think perhaps a distinction needs to be drawn between different types of action, both of which, confusingly, are often described as 'prevention.' Research leading to a greater understanding of the factors that cause neural tube defects, and the use of folic acid to prevent the occurrence of them, actually do prevent the disabilities from occurring. Thus, unless one can argue that having SB/H is such a desirable thing that it is legitimate to, in effect, cause them, it must be both acceptable and desirable to prevent them from happening.

On the other hand, very often pre-natal screening followed by abortion if the baby has SB/H are also often called 'prevention' even though they are completely different actions. Abortion no more 'prevents' SB/H than would killing me now. It only prevents an already living, though yet unborn, baby from continuing to live.

I am very happy for ASBAH to support true prevention of SB/H, in addition to its work of helping those who live with the conditions. However, I am very much opposed to any involvement by ASBAH in the destruction at an early age of babies with SB/H, which would be inimical to its role of promoting our equal rights and dignity.

Alison Davis, Dorset

My last word on genes, for now!

THANK you for printing my previous letters in *Link* (192 &195) which I am sure challenged some peoples' assumptions on spina bifida and hydrocephalus, and the work of ASBAH. I feel the need to clarify some points raised in the responses to my letters.

Firstly, when I voiced caution about research into our conditions, I meant just that – I have no objection to research into life-threatening diseases such as cancer because I lost a grandmother to bone cancer. Such work should be carried out without hindrance.

Secondly, I maintain that research into spina bifida and hydrocephalus should be focused purely on care management rather than prevention so that, in time, the number of terminations for SB/H is reduced because society's attitudes towards disabled people (and their right to have children who share their genetic inheritance) will have changed for the better. Surely we all want that, don't we? Incidentally, I'd love an 'able-bodied' child as much as I would a child with a 'disability.'

Thank you to those who have written to *Link* in support of my views. Hopefully, I'm in the mainstream, not the minority. I don't see myself as a militant or a radical, just someone who is trying to change a little bit of this wonderful world, one person at a time.

Chris Page, Letchworth, Herts

Readers' offer

AS a special offer to *Link* readers, specially cut trousers for part-time wheelchair-users who don't need all the shaping required for permanent sitting, will be supplied by Wearable Clothing. Their advert appears on page 2 of this issue of *Link*.

Alternatively, the company will supply trousers for either full-time or part-time wheelchair-users with a shorter and narrower trouser leg.

The range has grown since the company started up four years ago and now includes everything from underwear to rainwear – all designed to be worn sitting.

Forget about boring tracksuit trousers – they don't even appear in the Wearable range. Instead there are chinos, denims, cargo pants and smart tailored trousers. For outdoor wear there is a range of bright waterproofs styled like the fashionable garments you would find in any high street store – but the clever cut means that they can go on and off without the wearer having to leave the chair.

Order a copy of the Wearable catalogue on 0141-774 9000 or email:
enquiries@wearableclothing.com

holiday lets

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

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 Julie Parks, tel: 01273-472298.*

BERWICK COTTAGE, EAST HARLING, SOUTH NORFOLK (CATEGORY 1)

Modern, purpose-built, self-catering cottage. Ground floor accommodation for up to 2 people (single beds) with disabilities. Scan 700 beds: Clos-o-Mat; overhead track hoist bedroom-to-bathroom, wheelchair shower and much more. Up to 4 carers/family/friends upstairs. Awarded Grade 1, Holiday Care. Open all year. Low rates Winter/ Spring (£250 to £350 per week) – full central heating. Helpful caretakers demonstrate equipment, but otherwise total privacy in pretty village with accessible pub, GP, shops. *Cottage brochure, Lin Berwick, (tel: 01787-882111). Booking forms and full information, George Tickner, The Lin Berwick Trust, (registered charity), 020-8595 7056.*

ISLE OF WIGHT ASBAH

Fully furnished and equipped, two-bedroom bungalow. Beautiful area. Wheelchair accessible. Site clubhouse, shop. Local indoor heated pool. Transport advisable. Excellent rates: offers early/late season. *Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF, tel: 01983-863658, www.iwasbah.co.uk*

ORLANDO, FLORIDA

Purpose-built vacation homes for the disabled of all ages. 3, 4 & 5 bedroom luxury villas. All villas are wheelchair accessible, with roll-in showers and hydraulic lifts for access to the private pool. Situated 20 minutes from Disney and close to all amenities. Wheelchair accessible transport available. *For further information, contact David & Elaine Foley, tel: 0191-488 6845, email: david_foley@lineone.net www.floridadream.sagenet.co.uk*

ORLANDO, FLORIDA

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

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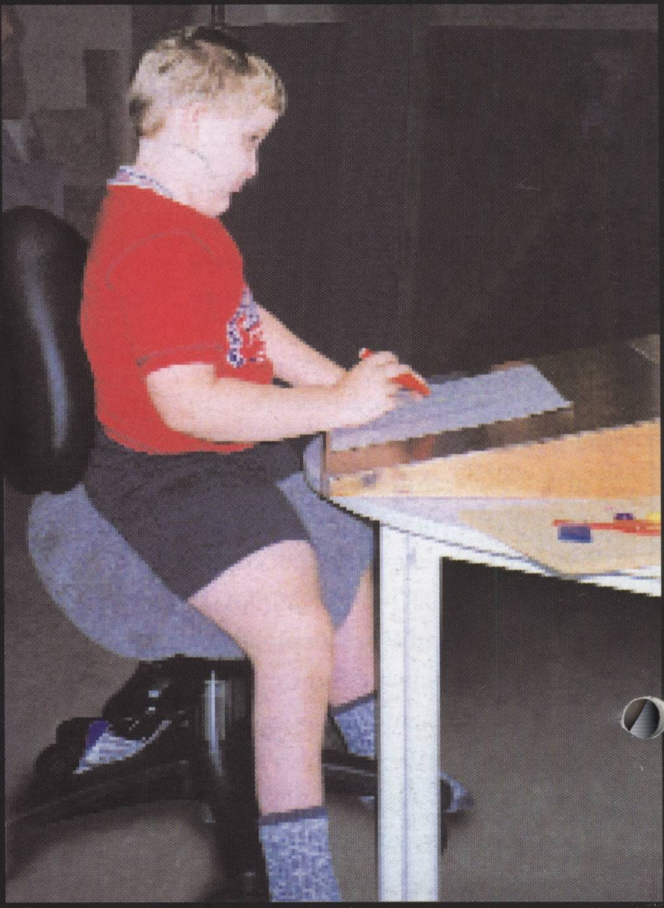

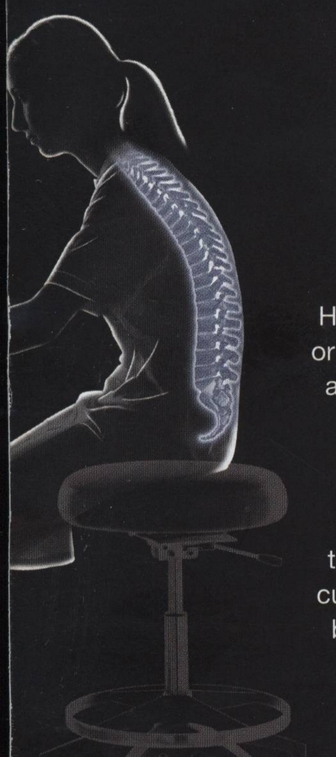

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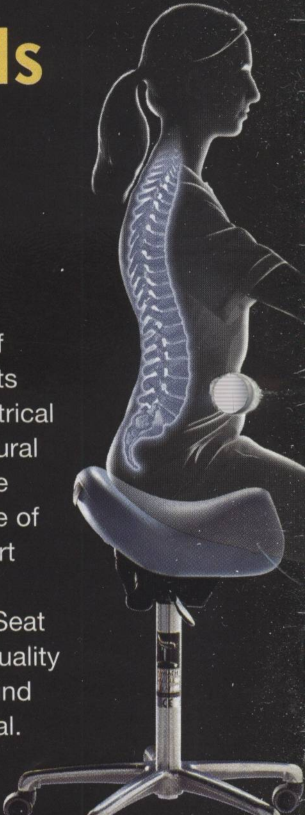

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