

Link

The magazine for people with
hydrocephalus and spina bifida

**James Nesbitt
speaks out
for ASBAH**

PRICE
80p

AUTUMN 2003 **ISSUE 206**

 **ASBAH**
Association for Spina Bifida and Hydrocephalus
Getting the most out of life

InCare

SO MANY things
WEIGH
on your mind.
BLADDER
MANAGEMENT
SHOULDN'T BE
ONE OF THEM.



That's why there's InCare Advance Intermittent Catheter from Hollister. We have focused the latest advancements in intermittent catheterisation into one solution that gives you every possible advantage.



InCare Advance offers

No-Touch Insertion through a Pliable

Inner Sleeve to maintain catheter sterility and help reduce the risk of infection. Folds like a concertina as the catheter is lubricated and forwarded into the urethra

Unique Self-Contained Gel Reservoir*

Water-soluble gel lubricant requires no water or additional lubrication, and allows you to regulate the amount of gel for maximum comfort. Specifically designed to be easy to hold and manipulate

Protective Ring Cap maintains sterility of the catheter tip and is easy to remove and hold - even for those with limited dexterity

Ultra-Smooth Catheter Eyelets The latest development formed with advanced ultrasonic technology provides maximum comfort on insertion and removal for minimal trauma to the urethra

*Patent Pending

InCare Advance Intermittent Catheter

Technology for Confidence.
Innovation for Life.™



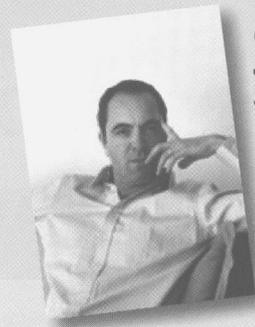
FREEPOST
Hollister Limited
Rectory Court,
42 Broad Street
Wokingham, Berkshire,
RG40 1AB
www.hollister.co.uk
FREEPHONE: 0800 521377

Hollister and logo, Hollister, InCare and InCare Advance, are trademarks of Hollister Incorporated. ©2003 Hollister Incorporated. All rights reserved.

Please send me information and a free sample of InCare Advance.
Mail this form to the Freepost address listed to the right

Mr / Miss / Mrs
Name _____
Address _____
Postcode _____ Tel. No. _____
E-mail _____
Current Brand of Catheter _____
Size (ch) _____ Length (cm). _____

Link



Cover:
James Nesbitt.
See page 4.

Image: © Zed Nelson /
K2 / Katz Pictures Ltd

Peter Farrall writes

Fresh from turning over from the front cover, you'll be wondering why TV star James Nesbitt graces it. Well, on the news page you'll read that he appears in a new ASBAH fundraising video – something the Fundraising Department will be making the most of over the coming months.

Again, it's been great to report on so much ASBAH activity. There was a lot going on this summer and local associations in particular are to be congratulated on their imaginative and attractive events.

You'll see quite a few new faces in this edition – not least that of our new chairman, Richard Castle. We welcome aboard also the new trustees, many of whom have had longstanding and close involvement with ASBAH. Another new face is our new columnist Linda Corbett, who'll be entertaining us regularly with her topical musing. A guest writer this edition is Richard Howitt MEP, who's had a busy year in Brussels with the European Year of Disabled People.

On the medical front, many readers will be interested to read the update on the DNA research. In addition, the cut-out-and-keep information sheet should come in very handy for young mums.

So Link goes from strength-to-strength and our postbag has never been bigger. A happy Christmas to all our readers – made just that little bit easier perhaps by the help we give you with stocking filler ideas, starting on p14!

*Best wishes,
Peter*

Peter Farrall
Assistant Director (Marketing and Communications)
peterf@asbah.org

Editor: Pete Griffiths **Designer:** Tony Nero
Link is published by ASBAH,
National Centre, 42 Park Road, Peterborough PE1 2UQ

All Link enquiries to:
Link, ASBAH, 42 Park Road
Peterborough PE1 2UQ
Tel: 01733 555988 Fax: 01733 555985
link@asbah.org

Subscriptions (six issues per year):
UK £4.80
All European and Air Mail £15.00
Outside Europe, surface mail only £7.50

ISBN 1360-323X

contents

- 4 News
- 9 The issue
- 10 People
- 12 Fundraising
- 14 Lifestyle
- 17 Spotlight on Herts & South Beds
- 18 Linda's line
- 19 Profile - Menai Williams
- 20 Sporting life
- 21 Legislative line-up
- 23 Medical matters
- 30 Days in the life of...



Power of love ● Page 8



New chairman ● Page 10



True hero ● Page 19



Caught on camera ● Page 24

Patron: HRH The Duchess of Gloucester GCVO
President: Jeffrey Tate CBE

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

Registered Charity
Number 249338

 **ASBAH**
Association for Spina Bifida and Hydrocephalus
Getting the most out of life



Nesbitt fronts new ASBAH video

Actor James Nesbitt fronts a new fundraising video from ASBAH which was produced this summer. He kindly agreed to present the video following an introduction through Alan Moneypenny, ASBAH's fundraiser in Northern Ireland.

In the six minute video, which was filmed while he was in Liverpool shooting the new film *Millions*, Nesbitt outlines ASBAH's work in offering support, advice and information on a whole variety of issues - education, medical advice, mobility, benefits and housing - and explains the work of the area advisers. He then goes on to describe both hydrocephalus and

spina bifida and ends appealing for donations by saying that ASBAH has to rely on these to fund its activities. Two versions of the video have been produced, for use in England, and Northern Ireland.

Says Donna Treanor, ASBAH's Fundraising Manager, who was present for the filming: "We're over the moon that someone as high profile as James was willing to take time out of such a busy schedule to help us with our fundraising - and at no cost to ASBAH. We're planning to use the video for a payroll giving campaign next year."

DRC calls for responses

The Disability Rights Commission (DRC) is calling for responses from disabled people, small employers, qualifications bodies, lawyers and others affected by changes to the employment provisions of the Disability Discrimination Act (DDA) which come into force in October 2004.

The changes will affect all disabled

people in employment, as the current definition of discrimination against disabled people will be tightened in the DDA so that employers, qualifications bodies and others cannot justify an act of direct discrimination or the failure to make a reasonable adjustment. The DRC has drawn up two draft codes of practice to support the amended legislation, one aimed at employers,

the other at qualification bodies and trade organisations.

Changes to the DDA will mean disabled people employed by small businesses and non-civilians working in the fire service, police force and the prison service will, for the first time, be protected by the Act.

Qualifying bodies, such as the Law Society and the General Medical Council, will have much broader responsibilities.

DRC Chairman Bert Massie, said: "The DRC's codes of practice will help people understand major changes to disabled people's rights at work. It's important we get the codes right. If you will be affected by the new laws and have a contribution to make, I urge you to take the time to respond to the DRC's consultation."

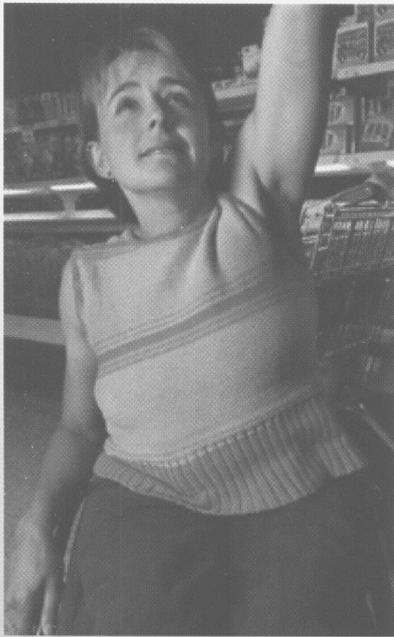
Those affected by the new legislation have until 30 November to respond to the DRC's consultation. Consultation documents are available from the DRC's website, www.drc.org.uk, or from the commission's helpline on 08457 622 633.

London Congestion Charge exemption

If you drive a car with disabled exempt car tax you are automatically exempt from the charge and needn't do anything. If you hold a disabled parking badge (blue or orange) then you need to contact Transport for London with your details and they will send you an information pack. After registering and making a one-off payment of £10, you can enter the zone in nominated vehicles free of charge.

Call 0845 900 1234 or see www.cclondon.com





Tanni Grey Thompson

When Tanni met James

The paths of Tanni Grey Thompson and Kylie Minogue's ex-boyfriend, model James Gooding, crossed recently when James turned photographer and snapped Tanni for the Disability Rights Commission's new campaign Open4All. The campaign is to help business understand the new legislation that requires every business by 1 October 2004 to be more user friendly to disabled people.



James Gooding

Ireland links forge ahead



Brendan Heany, Regional Manager, Northern Ireland ASBAH, greeting the President of Ireland, Mary McAleese, during a visit to the President's official residence in Dublin to celebrate the 35th anniversary of the founding of the Irish Association for Spina Bifida & Hydrocephalus. Also in the photograph: Nick Killian, Chief Executive IASBAH, Mairéad Graham, Administrator, IASBAH, and Andrew Russell.

from Dublin... ...to Peterborough



From left to right: Fiach McDonagh, Chairman of IASBAH, Sarah O' Farrell, Health and Education Adviser, IASBAH, Andrew Russell, Mairéad Graham, Richard Astle, ASBAH Chairman and Nick Killian, Chief Executive of IASBAH, when they met to look at joint fundraising initiatives.



Team challenge

ASBAH Northern Region annual Summer Experience, organised by Regional Manager Joan Pheasant, took place this year in the Lake District. Held at an inclusive

Summer fun

residential centre, the Keppleway Centre in Broughton-in-Furness, 17 teenagers with spina bifida and/or hydrocephalus went on the four day trip. They enjoyed tree climbing, canoeing, archery, local visitor attractions and team building activities, ending with a barbeque and disco on the last night.



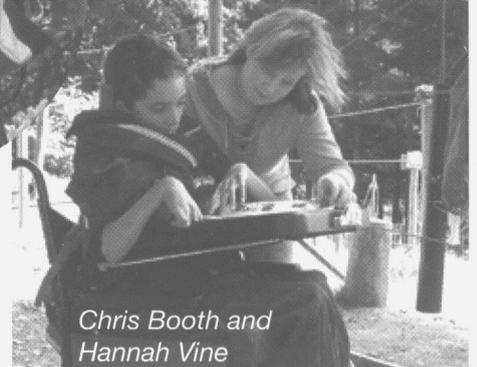
Lewis Brown climbs a 40ft tree



Canoeing on Lake Coniston



Barry Laing, abseiling



Chris Booth and Hannah Vine

Supported by



ASBAH Family Weekend

ASBAH
Association for Spina Bifida and Hydrocephalus
Getting the most out of life
Registered Charity Number 249338

Fri 5 – Sun 7 March 2004 at The Old Park Hotel, St Lawrence Ventnor, Isle of Wight PO38 1XS

A residential weekend specifically for families with a child aged 6 and under with hydrocephalus and/or spina bifida and their brothers and sisters.

- **A chance to learn more about your child's disability**
- **Children's programme – ASBAH staff will look after your children**
- **Time to relax and meet other parents**
- **The cost of this weekend is £75 per family- payable on acceptance. This includes ferry from Portsmouth to Fishbourne.**

APPLICATION FORMS MUST BE IN BY 31 DECEMBER 2003 IF YOU WANT TO BE CONSIDERED FOR A PLACE.

Please note that you will not be eligible if you have attended a previous family weekend. Please contact Mrs Rosemary Batchelor for more information at ASBAH House, 42 Park Road, Peterborough PE1 2UQ , tel: 01733-555988, **email: rosemaryb@asbah.org**

ASBAH is grateful to the BBC Children In Need Appeal for sponsoring this event.

Annual General meeting

ASBAH's annual general meeting was held in Peterborough on 20 September. In a letter read out on his behalf the President, Jeffrey Tate, said ASBAH's advisers, projects and regional offices carry the real burden looking after service users and were doing a fantastic job enabling people to transcend their disability and enter into society with enthusiasm and without fear.

The Chairman, Peter Cottingham, gave a comprehensive address which examined the issues of the UK economy, fundraising and competition from other charities, ASBAH's main strategic aims, its strengths and the challenges ASBAH faces. He thanked the meeting for having him as ASBAH's chairman for the past four years and said that he was passing the chairman's role to Richard Astle knowing that his unique skills and experience will not only steer the ship but also help to get the best out of a dedicated team. He ended by paying tribute to Andrew Russell and the board.

The Honorary Treasurer, Mike Allen, reported that in the financial year ended 31 March 2003 that ASBAH had made a surplus of £92,000 compared with a deficit of £190,000 in the previous year. Total income was up by £196,000 to £2,632,000, mainly due to additional legacy income.

He said that the Charity Commission, following its visit in December 2002, was very complimentary towards the governance and financial record keeping within ASBAH.

Andrew Russell then gave a wideranging report on ASBAH's activities in the year, stating that ASBAH is in good heart, better than the year before. He praised the trustees for their well-informed governance, the motivated staff, the good quality advisory services and the able and committed user forum, Your Voice. He also reported that ASBAH had a valuable and constructive working partnership with the affiliated local associations and was exerting influence on policy matters, such as national service frameworks (NSFs).

He reminded the audience of the main thrust of the five year strategic plan and then went on in depth to talk about the field services. He gave a snapshot report of the communications survey which had been carried out in early 2003 and announced the development of a communications strategy which will improve internal and external communications.

Amongst other issues, he remarked on the growing quality of *Link* in both content and presentations and ended by welcoming the new board members (see p10).



Chairman completes four year term

Peter Cottingham has completed his four year term as chairman and was succeeded by Richard Astle at the AGM (see People, p10). In his report in the new annual review, *agenda 2003*, Peter said:

The last year has been one of welcome stability as we move forward with renewed resolve. Our Strategic Plan 2002-2006 is ensuring that we remain on course in doing what we do and know best: providing support and information to people with hydrocephalus and spina bifida, and to their families.

An endorsement of our efforts came from the Charity Commission which, in a report following a visit to us in November 2002, said that all staff "have high standards and expectations in terms of their interaction with others and service users in particular". It reported that ASBAH "enjoys a dedicated and skilled trustee board and senior management team who are personally and collectively motivated to make a difference to the lives of their clients".

On a personal note, this is the last time I shall be reporting in the annual review, as I relinquish the chairmanship. ASBAH is fortunate to have so many dedicated staff and supporters whose effort and commitment will forever be in my mind.

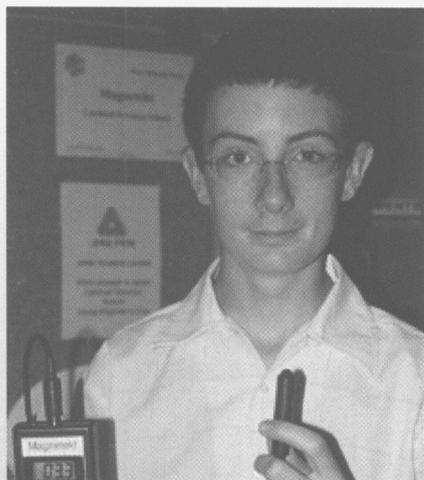
I would like to thank all staff and trustees for their professionalism in offering a growing range of support to service users.

It has not only been a privilege to serve ASBAH but also a real pleasure.

I wish ASBAH every success in the future.

We in turn wish Peter every success in the future too.

Regional finals entry



A device which monitors the adverse effect that magnetic fields (electrical equipment, phone lines etc) can have on programmable shunts made it to the regional finals in July of the Young Engineers of Great Britain competition as the project entered by Joseph Woods from Luton. Joseph, 17, was helped with his entry by information on ASBAH's website, back copies of *Link* and a shunt valve lent by ASBAH. His entry was inspired by problems experienced by Matthew Bottoms, aged 14.

The power of love



Eleri and Colin Edwards-Freeman had a taste of fame when they were featured in the Liverpool Daily Post this spring in a newspaper article celebrating how they have overcome huge difficulties to live happy, busy lives. Eleri, 36, has spina bifida, and Colin, 39, is in a wheelchair as the result of a severe motorbike accident nine years ago. They met at the Stoke Mandeville Games where Colin was managing the Swansea team of disabled athletes

and Eleri was competing in the shotput.

The couple married in 2000, and Eleri moved from her one person flat to a new home in Wrexham that would be more accessible for them both. They both had carers, but now they help each other. Colin says that between them they can manage most things, "except changing light bulbs!"

They both live life to the full: Eleri recently won the carpet bowls at the Rotary Games in Chester; Colin was disabled sailing champion in the Welsh Open Challenger Championships last year, and first runner-up this year.

Colin suffers from bad health, including epilepsy, and so Eleri has to look after him. He is impressed by her strength and positivity: "Through it all she's kept her smile. I think it's a permanent smile!"

Eleri says being married to Colin has increased her self-confidence: "It's made me stronger than I was before."



Leicester ASBAH takes to the water



Leicester ASBAH took to the waterways this summer with two outings on the Grand Union Canal. Both trips (one of which was on the hottest day of the year) ventured from Loughborough to Mount Sorrel, near Leicester. Pictured here is one of the parties boarding and enjoying the ride and the scenery. Organised by committee member Carole Armour, 41 people took part. The boat used was provided by the Peter Le Marchant Trust, which specialises in wheelchair accessible canal boats.



Disabled access

With the Disability Rights Commission new Open4All campaign (News, p5) highlighting the need for all business premises to be accessible to disabled people via ramps and altered doors by October next year, Carole Armour, current chair of Your Voice, has sent in some timely pictures of the problems that councils themselves can create in renewing their highways.

Carole lives in Birstall, a Leicester suburb. Two streets in the neighbourhood have particular problems for wheelchair users: Kingsgate Avenue, where the shops are mainly on a hill; and Sibson Road, which still has problems even after a recent expensive local authority refurbishment.

Here are pictures - some showing Carole - of the problems which wheelchair users and visually impaired people face:



Sibson Road: the steps aren't highlighted and there are no handrails. The bollards on the right are of stainless steel and therefore act like a mirror, making them difficult to pick out. The black band on the top should be yellow or red and the bands should be at the bottom also.



Sibson Road: this is how it can be done. Well done Boots!



Kingsgate Avenue: there are no dropped kerbs for access to the shops; the problem is made worse by the steps for each of the shops.

Follow-up letter

I would like to write about our journey from London King's Cross to Newcastle-upon-Tyne (the issue, Link issue 205). I arranged the travel arrangements a month before we went. The day arrived and we got to King's Cross for the 12.30 to Newcastle; when the train came in on the platform we discovered that my coach had been taken off, so we had to travel on separate trains. My husband Steve went on the 12.30 and I went on the 1.00. Then there was a fire on a local train at Chesterle-Street and both our trains got in 45 minutes late. On the way home they couldn't get me into 1st class as my wheelchair would not go through the door because it's an old style - and Steve got in 20 minutes late.

Kathy Smidmore, Kent
(Both Kathy and her husband Steve are wheelchair users.)



Sibson Road: the stainless steel barriers are again difficult to see and there are no dropped kerbs in front of this stretch of shops.

AGM elects new chairman and six new trustees

Richard Astle was elected ASBAH's new chairman at the AGM in September, in succession to Peter Cottingham who retired at the same meeting.



Richard joins us with wide experience of both the public and private sector. After nine years as a diplomat with the Foreign and Commonwealth Office, including three years as commercial attaché in Moscow, he moved in 1997 to Peterborough as Corporate Affairs Director at AMP Pearl Assurance. He left AMP earlier this year, going on to set up a new Peterborough-based communications and public relations company, Athene Communications.

In announcing the appointment Andrew Russell said: "Business-style management and dynamism are essential to modern charities, so we are delighted that Richard has agreed to our request to become chairman and help us to help disabled people."

New trustees

LISA CAIN

Formerly a member of North East London ASBAH, Lisa is now a member of Essex ASBAH. She has been active with Your Voice and the Disabled Users' Advisory Committee for the last three years and has also been involved in ASBAH's Living in London Forum.



Lisa is as an Administration Officer for the London Borough of Redbridge, where she deals with disabled parking badges and alarm systems for disabled people.

She's a member of the recently formed Redbridge Employees' Forum on Disability.

SARAH COATES

For the last eight years Sarah Coates has been a full-time mother to two boys, but previous jobs have included marketing manager for a tour operator in London and working for the Country Club Hotel

Group, which is part of Whitbread. Four years ago she set up a freelance proofreading business.



Sarah's connection with ASBAH began in 1997 when her son Matthew was born with hydrocephalus. During the past three years she has experienced first hand the tremendous support that ASBAH offers parents and children, through the Northern Region office.

DAVID HALLOWS

David Hallows is a service co-ordinator with the Red Cross. For some years he was a volunteer with them, setting up Red Cross shops in North Wales and helping to develop services. He is also an external speaker for the Red Cross and trains new staff on international law.



David, who has spina bifida, is a disability awareness trainer, and is doing a NVQ in training. He has been on the North Wales ASBAH's executive committee for

ten years and on ASBAH Cymru's committee for three years.

MICHAEL MCKERNAN



Michael McKernan is an engineer/manager with the Northern Ireland Water Service whose 19 year old wheelchair user daughter has spina bifida and hydrocephalus. He has represented his local branch on Northern Ireland ASBAH for a number of years, has served as the Northern Ireland Hon Treasurer and is the current chairman.

NICI PICKEN

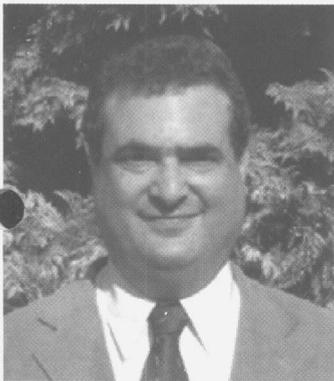


Nici Picken is a qualified teacher with extensive experience of children with SEN. Her son Gareth, aged 4 years, has spina bifida and hydrocephalus and she is a keen advocate of his medical and educational needs. He has been using a wheelchair since he was two-and-a-half and, thanks to ASBAH, he learnt wheelchair use and road safety. Nici and

her husband attended this year's family weekend in Cornwall with Gareth and their other son, Christopher.

PAUL ZICKEL

Paul Zickel has been an active participant on Your Voice for three years, the Education Advisory Committee for the last two years, as well as on the ASBAH/Bridge House Trust Living in London Forum.



Paul works for the Department for Education and Skills, where he chairs the Disability Advisory Network and is vice-chair of the Disability Group.

He has served on the executive committee member of the Civil Service Disability Network, which covers all government agencies, and regularly presents it at meetings of the Cabinet Office's Disability Working Group.



Picture: Delegates with Andrew Russell

ASBAH Residential

by Gill Whitfeld

What's the 'ASBAH Residential' like for a non-adviser? As Information Manager, I've attended quite a few of these intensive training events and one thing is always the same ...not the food, the rooms or the programme, but the respect I feel for the work our advisers do. During the course of the sessions there are always discussions about the difficulties advisers have helped families and individuals to sort out and it really brings to life what ASBAH is all about.

Of course we're about 'information' too, and the residential is fertile ground for this. Expert speakers provide us with information which helps our understanding - such as the latest research on hydrocephalus in rats which suggests that some of the problems hydrocephalus can cause may be to do with the make-up of the CSF and not just increased pressure. Then there are the ideas and feedback generated, both in formal sessions, and amongst staff during 'free time',

which help us plan what new information we need to produce for our service users.

One of the highlights for me at this year's residential, was a talk by ethicist Dr Tom Shakespeare on informed consent and ante-natal screening. This lively session was held one morning, but could just as easily been late in the day as no one would lose concentration during the presentation - which included the difficult area of what parents-to-be are told about the likely impact of their unborn child's disability or the thought provoking discussion which followed. Also of particular interest was a talk by Carole Sobkowiak, in which she emphasised the need for early intervention (literally from birth) in helping children with hydrocephalus to maximise their potential, rather than a 'wait and see' approach.

Delegates enjoy a chat before a session.



fundraising

Great North Run

The Great North Run is the world's largest half-marathon. 47,000 people ran it this September from Newcastle to South Shields, with a record 29 running for ASBAH. To date this has brought in £2,200 for us. Many thanks for this to all those who took part, some of whom we record here to prove they lived to tell the tale!



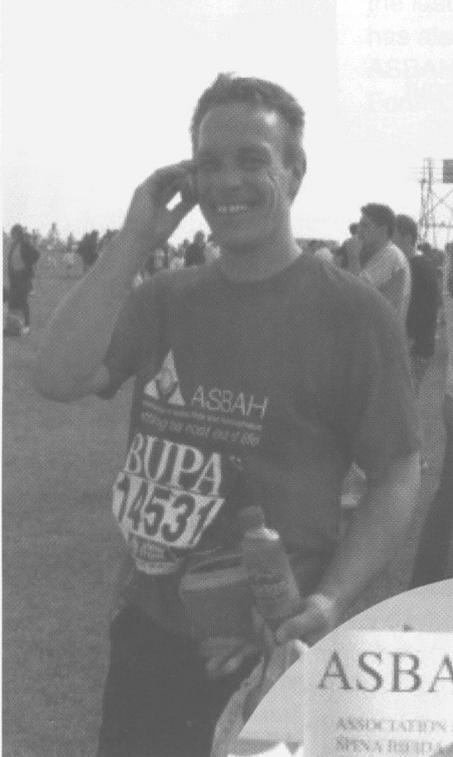
Lynn Markwell and Audrey Johnson from Durham.



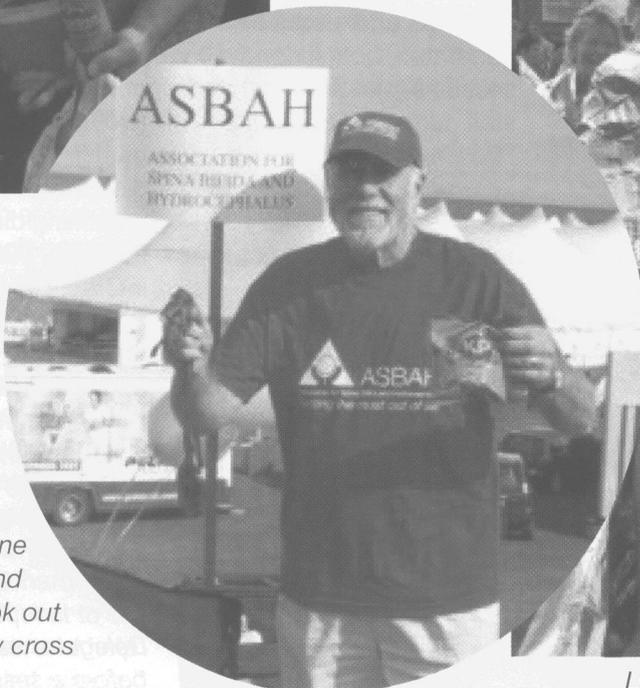
Gary Mockler from Middlesbrough.



Wendy Winterbottom from Keighley.



Jonathan Sharples from Chester.



Area adviser Anne Walton's husband Reg keeps a look out for them as they cross the line.



Lynn Mawdsley and Kathryn Hempel from Blackpool.

In July it was Megacycle time again, organised by ASBAH's fundraiser, Ian Morley. As well as providing a challenge for enthusiastic individuals who wanted to see how far they could ride in the 24 hours allowed, Megacycle was also open to the more leisurely rider wanting to cycle perhaps one lap of the eight mile circuit around Peterborough.

Ian, who is visually impaired, cycled 160 miles in the 24 hrs and raised £1,000 for ASBAH, generating some useful local publicity. Here he is on the right beforehand with Andrew Russell as the Mayor of Peterborough cuts the start tape.

Congratulations also to Ian on his wedding in August to Val Treasure. The day after they tied the knot Ian went into hospital for a major operation and happily is now making a good recovery.

Ian's mega ride



Here's 10 year old Bruce Tull with champion swimmer Duncan Goodhew when he was presented with Southern Water's Learn to Swim Child of the Year Achievement Award – the second award he has won. Bruce has hydrocephalus and started to learn to swim in 2002. He can now swim 400m.



Well done!

Congratulations to Lewis Brown (far left), who has spina bifida, who came second in the Junior Great North Wheelchair Race, which was held on the same day as the Great North Run.

Bryan does the trick

As we mentioned in the last issue, in July Bryan Crick and Ron Johnson successfully completed their walk from Land's End to John O'Groats, raising £2,000 for ASBAH. Bryan's involvement with ASBAH first came about through his daughter Eleanor, who had spina bifida and died aged just two-and-a-half.

When he got back home to Gateshead Bryan said: "It's nice to be able to do something for ASBAH. When Eleanor was alive I was a young man and had to work. Looking back, I don't feel that I was there enough and what we've done here has allowed me to lay that ghost to rest to some extent.

"The walk has been hard because lots of it was on the road, but the warmth and generosity people showed us on the way was unbelievable."

Lifestyle

Top 10 stocking fillers for £5 or under

Christmas is coming and the goose is getting fat! The shopping days are now being counted down and the shops are full of gift ideas.

Aside from the main presents, everyone, including the bigger kids among us, loves a Christmas stocking. It can be hard to find interesting and unusual presents to fill the stockings without spending a fortune, so here are some ideas for exciting new gifts that won't break the bank!

Toni&Guy Secure It Bungees

All girls love to experiment with their hair. Wrap the Toni&Guy Secure It Bungees around your ponytail and hook into your hair to create a funky, modern hair style in less than no time. Design your own stunning, unique new look, or copy the latest fashions, without needing to go near a salon!

Consists of four elastics with hooks. Available from Boots, at £3.75.

Rainbow Pen

Just press the button on the side and it'll glow red or blue or green or purple. Keep pressing and it'll put on a light show for you, flashing and transforming through all those colours. Better than any glow stick, and it will also allow you to write in the dark.

Uses LED that never needs to be replaced, three long-lasting hearing aid batteries and a refill. Available from the Gadget Shop, at £5.00.

Lip Butter

Fantastic for your lips, great fun, and it smells amazing!

Lip butter is the latest, and best, in lip balm. Choose from coconut, mango, shea, pa-paya,



grape seed, melon seed and brazil nut.

Available from The Body Shop, at £4.50.

Hamster Wheel Runner

Watch this rascally rodent bustle around in his exercise wheel. The ultimate low maintenance pet will scurry around and keep you amused for hours.

This cute little guy can keep you company as a desktop accessory. He will keep on running for hours and never get bored.

Requires two AAA batteries (not included). Battery compartment and on/off switch

located on the base of hamster.

Available from the Gadget Shop, at £5.00.

Pink Panther Music Box

Composed by Henry Mancini for the Blake Edwards films, be mystified by the mythic universe of the sinewy and seductive feline.

To enjoy its magical music, place this collectable instrument on a hard

surface and turn the handle.

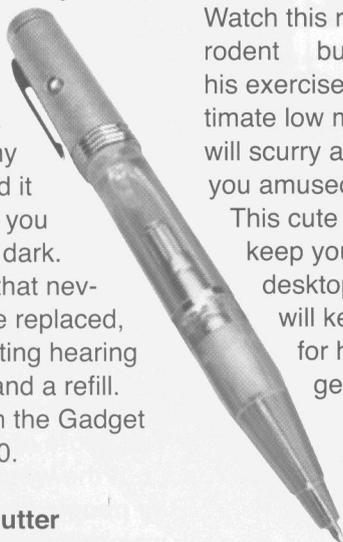
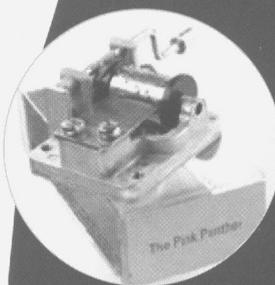
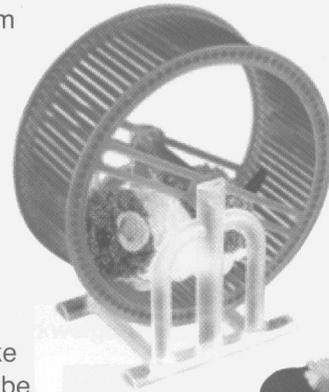
These beautiful music boxes are also available with the tunes 'Love Story', 'Fur Elise', 'Happy Birthday' and 'Imagine'.

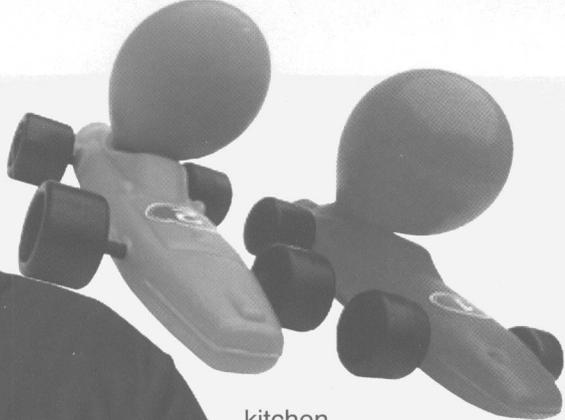
Available from Boots, at £5.00.

Balloon Powered Car

What a blast! Blow up the balloon, attach it to the back of the toy car, and then watch it shoot off as the balloon deflates! If you feel the need for real speed, use a smooth floor such as the

Hamster Wheel Runner





kitchen.

This is such a simple idea, but it makes for hours of fun for all ages.

Available from the Gadget Shop, at £4.00



Rock Star Earrings

Jewellery incorporating words is the hottest new trend, and girls of all ages will love these eye-catching, glamorous earrings. Every star should have a pair!

Available from River Island, at £4.99.



Thong Necklace with Double Rings

It's not just the girls who are into jewellery these days. Men's accessories are becoming a huge trend, and these are the coolest thing in men's jewellery, and a must-have for teens and adults alike.

Available from TopMan, at £3.00 each.



Pig Catapult

When it comes to devices for flinging small plastic farmyard animals, this is definitely in a class of its own. It's bizarrely addictive.

The design is a curious mixture of an

ancient Roman catapult and a toy pistol. All you do is load the trough with one or more porkers, close the top and then pull the trigger. You'll believe that pigs can fly. Maybe. Well, the manufacturers claim a range of up to 15 feet.

It comes with a target and 20 little pigs to fling; not suitable for young children, due to small parts. Available from the Gadget Shop, at £5.00.



Lustre Tea Lights

Set of two gold lustre tealights for only £2.99. With a pale gold glass and tealight inside these will light up any room or try the jewelled tealight holders, £2.29 each. A gold wire holder with beautiful coloured jewels all around with a solid glass insert which will add some Christmas sparkle. Available from Woolworths.



Last issue's winners

Congratulations to the following 10 winners of the Kodak and Fujifilm disposable cameras in the last issue's reader offer:

Margaret Griffith from Anglesey; Gill Pratten, Cleethorpes; Kayley Kilgallon, St Helens; J Bowmar, Rotherham; Robert King, Chippenham; Anne Kenny, Southport; Jordan Jose, Hoddesdon; M Orchard, Droitwich; Laura Gear, Bristol and H Rawlings, Eastleigh.

Reader offer

Link has 10 TONI&GUY accessories to give away



Pictured are two Pretty Things Bows. Available with white or red stitching on faux leather, this perfectly prim and proper bow will easily add a touch of elegance to any ponytail.

For a chance to win one of these or other Toni&Guy accessories simply print your name, address and telephone number on a postcard and send it to: **Link Reader Offer, ASBAH, 42 Park Road, Peterborough, PE1 2UQ.** The closing date for all entries is 19 December.

Happy days

He's behind you!

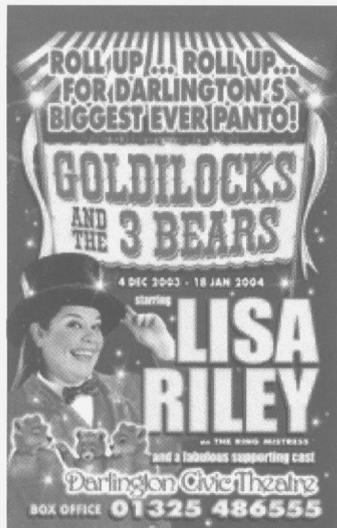
The panto season is coming up on us, and the stars will be out in force, appearing in shows all over the country. Here is just a sample of what you can go and see this Christmas and new year.

Darlington: Goldilocks & the 3 Bears

Darlington Civic Theatre is showing Goldilocks and the 3 Bears, with a circus theme. The ringmaster is You've Been Framed's Lisa Riley.

The theatre has level access into the stalls and the conservatory bar. Unfortunately it has no lift. Wheelchair users may bring a companion free of charge.

Tickets are priced from £9.00 and it runs from 4 December to 18 January. You can contact the box office on 01325 486555, or see www.darlingtonarts.co.uk



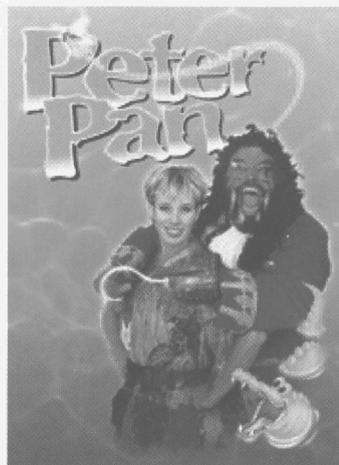
Dartford: Peter Pan

Neverland has come to The Orchard, Dartford, where Brian Blessed is playing Captain Hook, and CBBC's Kirsten O'Brien is Peter Pan.

Wheelchair users have access to the stalls, lower

bar/cafe and toilets. A free ticket is available for an assistant to help with mobility.

Performances run from 5 December to 11 January, and tickets start at £8.50. You can contact the box office on 01322 220000.



Milton Keynes: Aladdin

Milton Keynes Theatre is showing Aladdin, starring ex-Brookside star Claire Sweeney (right), Don Maclean, ventriloquist Paul Zerdin and his dummy Sam and, believe it or not, Spiderman! Glittering sets and spectacular song and dance are promised.

All areas of the theatre are accessible to wheelchair users.

Tickets are priced from £11.00, and the show runs from 11 December to 18 January. You can contact the Box Office on 01908 606090, or see www.theambassadors.com/miltonkeynes



Stoke-on-Trent: Snow White

The Regent Theatre, Stoke-on-Trent has ex-Coronation Street's Ken Morley, Celebrity Big Brother contestant Anne Diamond and Sooty appearing in Snow White and the Seven Dwarfs. The show combines spectacular special effects with traditional storytelling.

There are wheelchair spaces on all auditorium levels, and lift access to all areas of the venue including box office, toilets & bars.

Tickets are priced from £8.00, and performances run from 18 December to 18 January. You can contact the box office on 01782 213800, or see www.theambassadors.com/regent

Southampton: Aladdin – The Adventure

The Mayflower Theatre, Southampton is also staging Aladdin, this time starring comedian Jim Davidson but titled Aladdin – The Adventure. The show features a predominantly Oriental cast, including Masashi Fujimoto from the TV series Banzai.

Also starring are John Lyons, from A Touch of Frost, and Mr Blobby. The Emperor will be

accompanied by eight Ninja bodyguards from the State Circus of China.

There is an adapted entrance which gives access to the rear of the stalls. None of the other areas are accessible to wheelchair users.

The show runs from 21 December to 1 February, and tickets are priced from £12.50. You can contact the box office on 023 80711811, or see www.the-mayflower.com



Herts & South Beds

Pete Griffiths talks to chairman Lorraine Watson

Herts and South Beds? Shorten it to H & SB and, hey presto, what do you have? Hydrocephalus and spina bifida!

So, if ever there was an ASBAH association born to help those with SB/H, then surely this must be the one, nestling north of the M25 in the Hertfordshire commuter belt up to Luton and Dunstable.

And if there was one to represent the importance of new outside blood to an association, then H & SB must lay claim to being a prime example. For chairman Lorraine Watson wasn't born there, didn't have her children there and only moved there in the late 1980s. Lucky old H & SB, you might say, because after just ten years years of living in Hemel Hempstead she'd succeeded Derek Risborough as chairman in 1997, having already been chairman of Cambridge & District.

In fact, Lorraine's contact with ASBAH goes right back to when her son Andrew was born with SB back in 1968. Ever since then she's never forgotten the supporting mechanism that ASBAH provides in getting parents together so they can compare and contrast the issues they face. "Andrew died in 1981. He was a real tryer, even raising £900 for Cambridge & District through a sponsored silence at school. Since his death I've done all I can to put something back."

Fortunately for H & SB Lorraine was a residential social worker for 20 years, so she has the professional expertise that only such experience can bring. This, coupled with her training as a dressmaker with a London couture house in the early 1960s, (she still works as tailoress and dressmaker) means that they also have someone with more than enough creativity to get ideas going.

Of course, she's more than ably abetted by a committee of no fewer than eleven others, three of whom are service users. Some of the committee help with social events; others help fellow committee member Val Bottoms with the support group in Luton, which is open on the second Monday of the month.

H & SB holds two major social events a year: the

annual Christmas disco and the annual summer barbeque, both of which are held in St Albans and have healthy raffle ticket sales. Explains Lorraine: "We don't do any fundraising as such. Our main income comes from donations and these we put to real particular use, such as helping service users with the purchase of washing machines and beds, driving lessons and adapting cars. The association has also benefited from its contacts with other groups. For instance, a fun day organised by a local disabled sports group raised £155. Another benefit, which was certainly more sizeable, were the proceeds of the sale in 1993 of a bungalow in Exmouth that we owned."

With over 100 members, nearly fifty per cent of whom have SB/H, the association is certainly an active one, all kept posted by the biannual newsletter *ASBAH Arrow*. Says Lorraine, who's also ASBAH's lead trustee for the Eastern region: "I see the good that all the members get out of the association. We may only see some of them twice a year, but they all know I'm always on the other end of the phone."

That level of accessibility, when the association already has a disability helpline, proves that that South Beds and Herts is a very lucky association indeed.



Lorraine Watson

LINDA'S LINE

The new diary column by ASBAH member Linda Corbett



I'm having a new bathroom fitted at the moment and you'd be forgiven for thinking that we lived in a war zone, rather than suburbia. However, I'm clinging to a vision of a new and better bathroom, and have been happily daubing paint testers over the walls.

People like the idea of home improvements, and perhaps that's why we are addicted to those house makeover programmes. A quick flick through the television channels reveals a new series of Changing Rooms, plus many more along the same format. You know the sort of thing: friends swap houses, designer comes along with plan, Carol Smiley-type person beams at everybody and owners stare in disbelief at the resulting transformation. I use that word loosely, because if anyone 'transformed' my house like that, they wouldn't be getting any more invitations to dinner!

Let's be honest, the attraction of Changing Rooms is not the excitement of watching someone make strange lampshades out of chicken wire, or turning old ashtrays into candle holders; it's more the voyeuristic pleasure of watching people do things you would never dream of letting anyone do in your own home. (Plus, of course, the cringeworthy bit at the end, where the homeowners have to pretend that they actually quite like having their pine shelves painted up in the same colours as a tube of Smarties).

So why are people stupid enough to let anyone do this? Well, unfortunately I have to make a confession here. You see, I actually did let a good friend of mine decorate my guest bedroom when he lived with us for a while. As the walls were bare and uninteresting, I said he could paint the room to make it a bit more cheerful. Quite safe I thought – blokes normally choose blue, or beige, or pale green...only he didn't. No, my guest room ended up a vivid fuchsia pink and it was hideous!! I reckon it would have certainly wiped the smirk off Carol Smiley's face.

Well, perhaps the lesson here is look after your friends, but keep them away from your paint brushes! Now, where did I put those testers...

Book review

by David Isom

Memory Booster Workout strikes me as a bright, colourful, user friendly book that will engage people to pick up, have a read and use in a practical way, specifically for their own problems with memory.

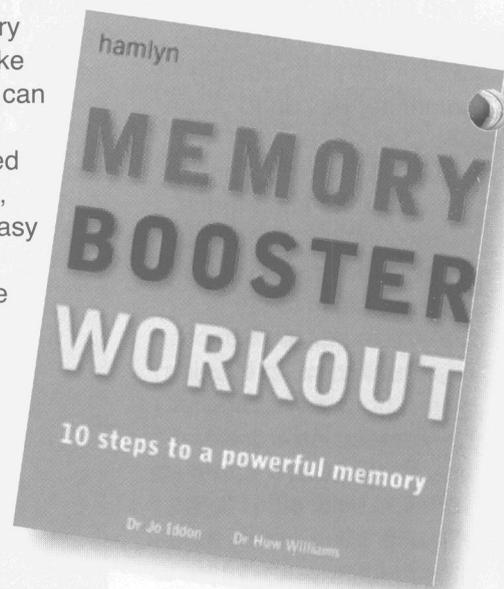
It's the type of book that anyone can dip in and out of with lots of practical advice and tips: for example how dietary habits, alcohol intake and sleep patterns can effect memory.

I particularly liked the layout in step 4, with the answers easy to find. There are situations within the book that all of us can relate to.

The bold statements throughout the book leap of the pages, reinforcing

positive messages and prompts for the reader.

At £12.99 (Hamlyn) the cost of the book would be money well spent and for those who may find the cost too much, but would find a copy very useful, the book would make an ideal affordable sensitive gift.



Travel scholarships for carers

The Lady Allen of Hurtwood Memorial Trust is looking to award travel awards (max. £1,000 each) for 2004. These are made to people working with children, to enable them to travel at home or abroad to

enlarge their experience and enhance the quality of their work. Closing date for applications is 15 January 2004. **Application form and details from Mrs Caroline Richards, 89 Thurleigh Road, London SW12 8TY.**

profile

Caring mother Menai is a true hero

Menai Williams, 47, was voted 'Community Hero 2003' in May by readers of Liverpool's *Daily Post*, but she considers her daughter, Llinos, to be the real hero. Llinos has spina bifida and hydrocephalus, and, at the age of just twenty, has undergone 65 operations.

Llinos nominated her mother for the competition in recognition of the sacrifices she has made for her. Menai won two tickets to see Bryn Terfel and Jose Carreras at

the Walton Centre for Neurology and Neurosurgery in Liverpool, and paying £43 a night to stay in a nearby hotel, meant that money was still tight.

However, they stayed positive, even when they were repeatedly told by doctors that nothing could be done for Llinos. Menai refused to accept this and from their home on Anglesey she travelled to Liverpool, Bristol and Birmingham for second opinions. After a big operation last year Llinos lost the use of her right hand and had to walk

with a tripod, but since then Llinos' condition has dramatically improved. She has mostly regained the use of her hand and legs, and is now able to take care of herself almost completely. She is in her second



Menai and Llinos

the Faenol Fawr Festival. Menai, a modest woman, says that she was embarrassed by winning, but most of her pleasure comes from the fact that people will know how much Llinos herself has accomplished. She says of her daughter: "With all she's been through, she must be very strong."

But life has not been easy for Menai, either. She gave up a career in nursing to look after her daughter, who then required constant care. She received no help from social services, as they told her Llinos did not fall into any category that qualified for support. Menai had to pay for someone to come to her house and help. She was given a donation by ASBAH, but the cost of caring for Llinos, as well as regularly driving the 200 miles to

year at college studying business administration. Menai has been able to return to work, and is running the outpatients clinic at Gwynedd Hospital in Bangor.

Llinos and Menai's partner, Mark, feel that Menai is an amazing woman, but she insists that Llinos is the exceptional one. "To look at her you'd think there was nothing wrong," Menai says of her daughter. She believes Llinos' happy, optimistic attitude is a blessing. They are hoping to arrange some work experience for Llinos at Gwynedd Hospital, and after college Llinos is looking forward to being able to work part-time. Menai urges other parents: "Never give up. Some people think doctors are gods, but that's been proved wrong."

ASBAH offices

● ASBAH

42 Park Road
Peterborough PE1 2UQ
Tel: 01733 555988
Fax: 01733 555985
Email: postmaster@asbah.org

● ASBAH EAST

42 Park Road
Peterborough PE1 2UQ
Tel: 01733 555988
Fax: 01733 555985
Email: ero@asbah.org

● ASBAH NORTH

64 Bagley Lane, Farsley
Leeds LS28 5LY
Tel: 0113 2556767
Fax: 0113 2363747
Email: nro@asbah.org

● ASBAH SOUTH EAST

209 Crescent Road
New Barnet, Herts EN4 8SB
Tel: 020 84490475
Fax: 020 84406168
Email: sero@asbah.org

● ASBAH IN WALES

4 Llys y Fedwen, Parc
Menai, Bangor, Gwynedd
LL57 4BL
Tel: 01248 671 345
Fax: 01248 679 141
Email: wro@asbah.org

● ASBAH N. IRELAND

Graham House
Knockbracken Healthcare
Park, Saintfield Road,
Belfast BT8 8BH
Tel: 028 90798878
Fax: 028 90797071
Email: niro@asbah.org

Sporting life

by Marshall Thomas

So far in Sporting Life we've had plenty on summer sports, but at this time of year it seems a good time to explore the range of winter sport activities available to disabled people.

Ski-ing

Skiing can offer both holiday options and competitive opportunities. Either way, one of the best places to start is with The Uphill Ski Club of Great Britain, a registered charity committed to providing winter sporting activities for disabled people.

Uphill offers a range of skiing activities at their ski school in the Cairngorms and at venues throughout Europe and the USA. It also supports a number of local groups in the UK which meet at various dry ski slopes.

Wheelchair users ski with the aid of 'sit skis', which allow the skier to sit on a 'ski-bob' with either one or two skis underneath them. Balance and manoeuvrability is achieved with ski poles that have mini skis attached on the bottom.

Competitively, ski-ing is divided into Alpine and Nordic disciplines, both of which feature in the winter Paralympic Games. Alpine ski-ing consists of downhill, slalom, giant slalom and super-g (super giant-slalom), while Nordic consists of cross country skiing and biathlon (cross-country skiing combined with shooting).

The Uphill Ski Club has been the starting point for several of Britain's Paralympic skiers and maintains close links with the British Adaptive Ski Team, which consists of elite disabled skiers representing Britain in annual world cup and Europacup ski competitions, world championships and Paralympic Games.

For more information see www.uphillskiclub.co.uk or call 01479 861272.

Sledge Hockey

Sledge hockey is a sitting version of ice hockey and, like ice hockey, is fast and hard hitting.

Players use specially designed sleds, which consist of ice hockey skates bolted to a seat with an extension to support their feet. Players propel themselves over the ice with two metal sticks edged with teeth at one end and shaped into a hockey blade at the other in order to hit the puck.

There are presently four clubs in the UK, competing in a national league - Cardiff Huskies, Nottingham Knights, London Ravens and Kingston Kestrels (from Hull). The clubs cater for all levels and abilities from recreational sport through to elite participants, and anyone is welcome to visit any of the clubs and try the sport. The British Sledge Hockey Association supports all of these teams as well as the national team.

The BSHA has a development officer who can help people with trying to set up a new team in their area if they live too far away from the existing teams.

For more information call Joanna

Coates, BSHA Chairperson, on 029 2030 4747 or 07786 131503 or email j.coates@cardiff.gov.uk

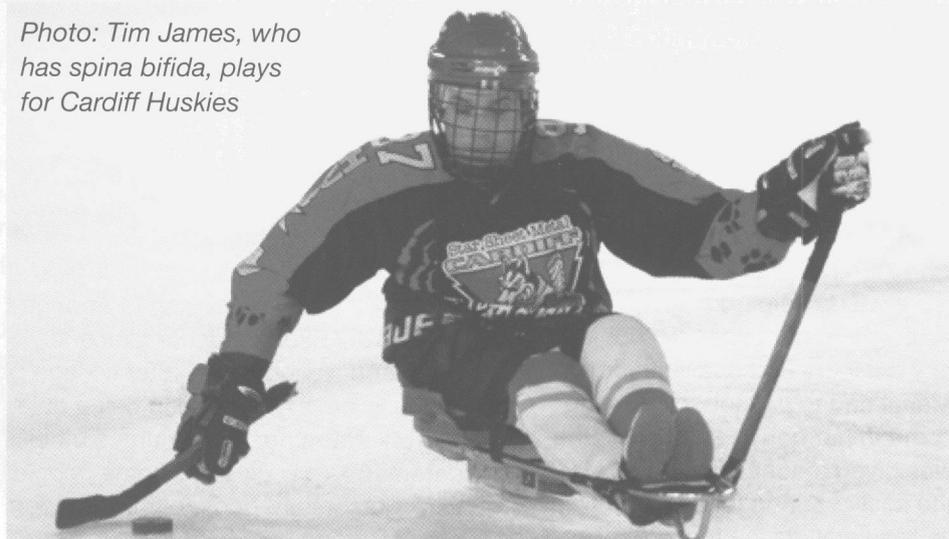
Wheelchair Curling

The gold medal success of Great Britain's curlers at the 2002 Winter Olympics shot the sport into the spotlight like never before. Often described as 'bowls on ice', the sport basically involves delivering specially designed stones into a target area marked out on the ice. Wheelchair curling has also become evermore popular in the last few years, so much so that it will become a full medal sport at the 2006 Paralympic Games in Torino, Italy.

As with the mainstream sport, wheelchair curling in Britain is mainly centred in Scotland, where there are a number of established wheelchair curling clubs affiliated to the Royal Caledonian Curling Club, and where the inaugural Scottish National Wheelchair Curling Championships took place earlier this year.

For further information email ssadsds2@aol.com or call 0131 317 1130.

Photo: Tim James, who has spina bifida, plays for Cardiff Huskies



Legislative line-up



The European Year of People with Disabilities 2003 – the actions and results of the European Parliament

As we draw towards the close of the 2003 European Year of Disabled people, it is time to ask the key question: Has it all made a difference? Yes, thousands of events have taken place all over Europe to raise awareness and generate debate about equality for disabled people.

The European Parliament itself played a key supporting role with the European disability movement in winning the original designation of the Year - which has forced policy makers across Europe to think about the disability dimension to their work.

Our own Disability Rights group is proud of the part we played, as the constant representation within the Parliament to advocate for the interests of Europe's 37million disabled people, and to channel a dialogue with organisations of disabled people.

As ASBAH is itself based in my own East of England constituency, I am delighted that this includes all of you.

Three key objectives for the European Year have been the campaign for a comprehensive, EU non-discrimination directive on disability; the proper implementation of a new EU law combating



By
Richard Howitt MEP

President of the Disability Rights Group of MEPs in the European Parliament

discrimination in employment; and the need to ensure the new EU constitution secures explicit and strong references for non-discrimination and equality of disabled persons to enable strong European action in the future.

Last March our Disability Rights Group provided the platform for the

launch by the European Disability Forum of its proposed Directive on Disability. It would bring the best of Britain's Disability Discrimination Act (DDA) in to European law. It could also extend our own rights here at home by widening the numbers of disabled people able to claim these rights, and in strengthening access for example to manufactured goods and to public office. The European Parliament has already voted in principle for such a law, but we await an initiative from the European Commission who still have cold feet about the proposal. You can help the campaign by ensuring your local MP and MEPs support us.

As far as the new employment law is concerned, in Britain it has already ensured that the small employer exemption to the DDA will be lifted. However, in the European Parliament we have been actively lobbying to key decision-makers at national level throughout Europe to seek rapid and effective transfer of the terms of the Directive into national laws in each of the countries. Some are doing so only reluctantly. Important concepts such as those of reasonable accommodation, direct and indirect discrimination risk being interpreted wrongly in the different national laws.

As far as the EU Constitution is concerned, don't believe everything you read in the press! Putting to one side the wider arguments, it will update the current treaties, which define Europe's powers to act, and our main aim was to ensure there was no going back on the achievements

Continued on p22

of successful campaigns by disabled people in the past. In the European Parliament we successfully improved an initially very weak presentation of non-discrimination in the draft constitution, which will now include combating discrimination as one of the European Union's core values. A charter of fundamental rights is recommended for the draft treaty which provides for positive action on grounds of disability. For the first time a new clause is proposed to allow mainstreaming of non-discrimination actions across all EU policy areas from transport to the environment. We are now fighting to secure Qualified Majority Voting for all of this so that any new laws do not have to pander to the lowest common denominator - another issue on which to lobby your MP and MEP.

At a more basic level, the European Parliament has itself undertaken an independent and comprehensive accessibility audit of our own buildings, facilities, information systems and recruitment practices. The results of this audit are being finalised this month. It should help if you want to come and lobby me!

And on 10-11 November 2003, the European Parliament is also to host a European Parliament of Disabled People in our Parliament chamber in Brussels. This is to be a major event bringing together 200 official representatives of disabled people and parents of disabled people unable to represent themselves from across Europe. They will be in debate with MEPs to draw up proposals for the future priorities for European disability policy and to draft a Disabled People's Manifesto to influence the next European Parliament elections due in June 2004.

These activities illustrate a few of the areas where the European Parliament has been promoting the aims and objectives of the European Year of Disabled People. However, follow-up action is needed to ensure the momentum gained this Year is continued into the next decade. We want to do it but we need your voice to be loud to help us win the arguments.

Your Voice elections: an appeal from Jon Burke

Over the last few years Your Voice has become more and more important in the running of ASBAH and to people with spina bifida and/or hydrocephalus.

We're now involved in the formal decision making process within ASBAH and as such our voice has never been more powerful within the association. We have also put on a range of events for adults with SB/H which have enabled participants to gain new skills, develop greater confidence and get more choice, independence and control in their lives. We are now giving you an opportunity to be involved in the work. There are a number of ways this could happen:

- first, you could put yourself forward for election onto the national steering group of Your Voice. If you do this you would have the opportunity to be involved in the further development of the group and to contribute to all its activities.

- secondly, if you do not feel able to be involved in the group, but you would still like a say in how it is run, you could register to vote in the election. If you do this you will be added to the Your Voice mailing list which means that you will receive advance information about any of our activities in the future. Please note that anyone who is putting themselves forward for the group will also be registered to vote

automatically, whether you have been in touch with us in the past or not.

- thirdly, if you do not want to be involved in the national group but you would like to do something in your own area or you have a particular interest that you think the group should be aware of, please feel free to let us know.

To ask for a nomination form and additional background information about being involved in the group, or to register to vote, you must contact **Lyn Ryland on 01733 555988; email lynr@asbah.org. Nominations close on Friday 14 November.**



Jon Burke

Summer delights

Twenty-one service users converged on a Manchester suburb for the Your Voice Summer Delights weekend and its workshops aimed at self-improvement for the body and soul. These included ones on aromatherapy, tai chi, fashion, make-up, fitness, ski-ing, communication and motivational skills and neuro linguistic programming.

When's the next weekend? "Watch this space," the organisers tell us.

Placement of an Ommaya Reservoir at Endoscopic Third Ventriculostomy (ETV): (A Useful Adjunct in the Diagnosis of Ventriculostomy Failure)

This article is reproduced by kind permission of the *European Journal of Pediatric Surgery*

Introduction: The diagnosis of ETV failure on clinical and radiological grounds can sometimes be difficult. A ventricular access device such as an Ommaya reservoir, connected, via a butterfly needle, to a pressure transducer, allows bedside intracranial pressure (ICP) monitoring to be performed. This simple technique facilitates confirmation of a rise in ICP associated with ETV failure, in the presence of equivocal radiological findings. We have undertaken a study to evaluate the usefulness of an Ommaya reservoir in the diagnosis of ETV failure.

Materials & Methods: A retrospective review of all patients undergoing ETV with Ommaya reservoir insertion over

by
**Kristian Aquilina,
Richard J Edwards,
Ian K Pople**
Dept of Neurosurgery,
Frenchay Hospital

a four-year period was undertaken. Eighty-five patients, 40 male and 45 female, were evaluated. The mean age at ETV was 29.9 years (range 3 weeks to 75 years). The mean follow-up period was 12 months. End points for ETV failure were shunt insertion or revision of ETV. The diagnostic and therapeutic use of the reservoir was quantified.

Results: 75.5% of ETVs were successful. Mean time to failure was 5.4 months. The reservoir was used in 32% of patients (n=27). In

patients with symptoms but equivocal radiological evidence of recurrent hydrocephalus, it allowed assessment of ICP (n=19) and / or a therapeutic trial of CSF aspiration (n=5). Seven of these patients subsequently required revision ETV or shunt insertion (32% of all ETV failures). In the 14 patients who had a normal ICP conservative management was successful. The reservoir also allowed emergency ventricular access in acute recurrent hydrocephalus (n=2) and intrathecal drug administration for post-operative ventriculitis (n=4).

Conclusions: Routine insertion of an Ommaya reservoir at ETV has not been previously described. The technique facilitates diagnosis of ETV failure and enables therapeutic CSF aspiration or intrathecal drug administration to be performed.

Eur J Pediatr Surg 2001; 11: S60.

Anti-epilepsy drugs concern

Epilepsy is the most common serious neurological condition, with at least 1 in 200 people having the condition. Moreover, approximately 40% of people with hydrocephalus are also affected by some form of epilepsy.

There is a growing body of evidence that certain anti-epileptic drugs, in particular some of the 'older generation' anti-epileptic drugs (AEDs) can cause

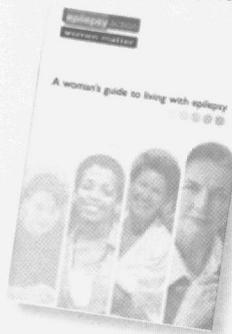
major defects, including spina bifida (by interfering with folic acid metabolism and affecting neural tube development). These are carbamazepine (Tegretol), phenytoin (Epanutin) and sodium valproate (Epilem). Sodium valproate in particular has been associated with a 1-2% risk of spina bifida.

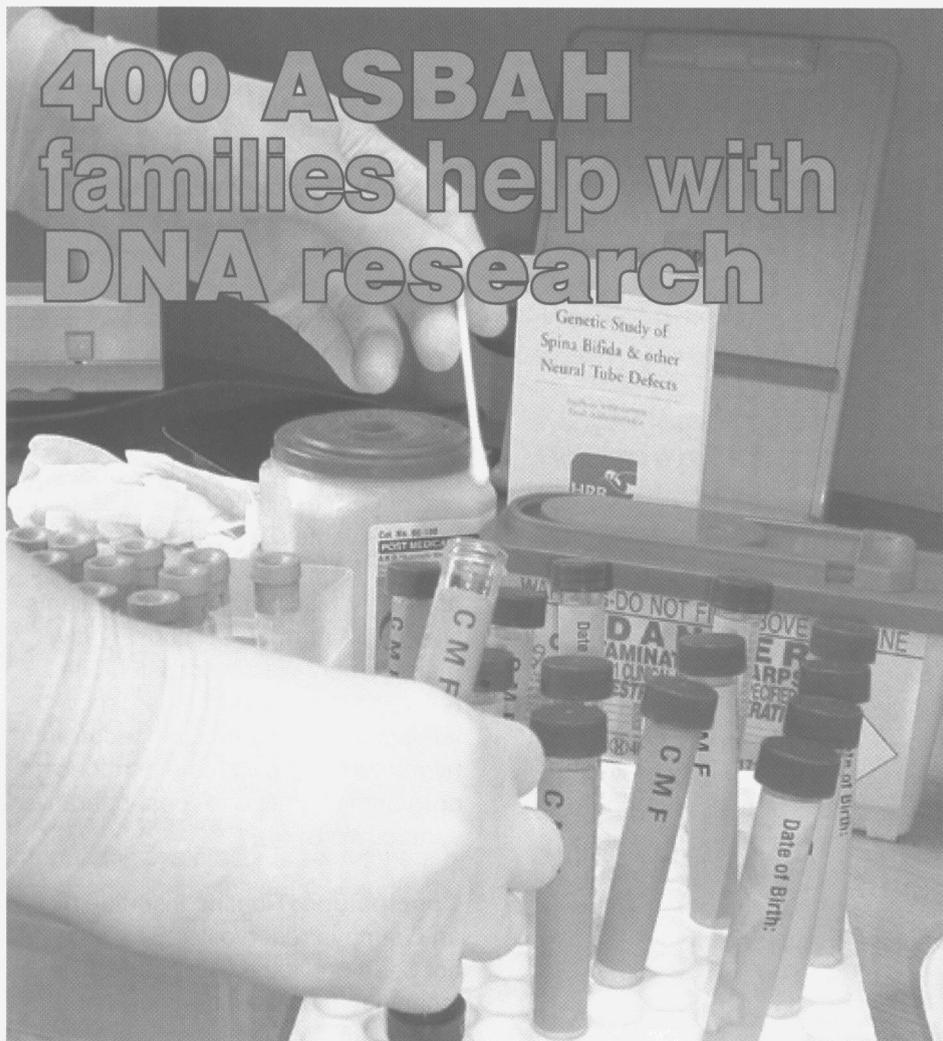
But women should never suddenly stop taking their medication. All women who are on any anti epilepsy medication should seek advice about all possible risks before becoming pregnant. It is important that women taking AEDs should plan ahead and avoid an accidental pregnancy; if a

pregnancy does occur while taking anti-epileptic drugs then doctors should give advice about early antenatal screening. We know that the risk of neural tube defects is reduced by taking folic acid supplements during pregnancy but there is some evidence that folic acid can interact with some AEDs – making them less effective. For this reason it is important to seek advice from the doctor treating the epilepsy before taking folic acid supplements.

ASBAH has worked with Epilepsy Action who have produced a handy new booklet, *A Woman's Guide to Living with Epilepsy*.

To obtain a free copy contact Rosemary Batchelor on 01733 555988 or at rosemaryb@asbah.org





400 ASBAH families help with DNA research

In issues 193 and 203 we reported on the study to find the genes which make some people more prone to spina bifida than others. The research is carried out by people - and preferably whole family groups - collecting their own DNA samples by swabbing the insides of their cheeks and upper lip with cotton buds for at least 10 seconds. This helps scientists to build up a picture of the genes which are implicated in spina bifida and other neural tube defects.

Following the appeal for people to take part in the survey, 600 ASBAH families expressed an interest and eventually around 400 families decided to go ahead. All of them have now returned their completed questionnaires, with their DNA samples, to the Dublin-based Health Research Board (HRB).

The method of obtaining the DNA has proved very effective and the HRB is delighted with the quality that

has been produced. Scientists at the National Institutes of Health and at Trinity College, Dublin, are now in a position to begin the genetic analysis on these UK samples and are also anonymising and coding all the questionnaires, along with the DNA samples.

ASBAH participation means that the researchers will be able to verify if the same genes that were identified in the Irish population as genetic risk factors for spina bifida are involved in the UK. The results in Ireland showed that a genetic variation in a folate-related gene is associated with an increase in the risk that women will have a baby with spina bifida or other neural tube defect.

As the sample will all be anonymised, results won't be available for individual families but a summary of the results will be sent to ASBAH next year, after which we'll report again.

ASBAH brings out new information sheets

The medical team at ASBAH has been busy working on a new and revised range of information sheets. They are:

- *Feeding Problems Associated with Hydrocephalus and/or Spina Bifida.*
- *Behaviour Problems Associated with Hydrocephalus.*
- *Developing Skills through Toys.*
- *Information About Pre- School Children with Hydrocephalus or Spina Bifida.*
- *Shunt Malfunction – A Guide to Symptoms and Suggested Action for Schools.*
- *Benign Intracranial Hypertension and the Child at School.*
- *Shunt Malfunction – A Guide to Symptoms and Suggested Action for Employers.*
- *Going to College or University with Benign Intracranial Hypertension.*
- *A Personal View of What Hydrocephalus Means to a Young Person.*
- *Guide to Organising a Family Weekend.*
- *Unwanted Adjustment.*

While the sheets can be downloaded from www.asbah.org.uk, and can also be obtained from the Information Department at ASBAH House, 42 Park Road, Peterborough, PE1 2UQ, we're going to be reprinting each one in *Link* for you to cut out and keep. On the next page the first, *Feeding Problems Associated with Hydrocephalus and/or Spina Bifida.*

Feeding problems associated with hydrocephalus and/or spina bifida

Some children with hydrocephalus and/or spina bifida do appear to have some associated feeding problems.

Various problems have been described, but six main difficulties emerge as a common factor:

Retching - This usually begins at the weaning stage when "solid" food is introduced. Some babies start to do this irrespective of whether they were breast or bottle fed. Some children have this problem if non food stuffs are in or near their mouths. This usually stops at around 3-4 years of age if not sooner.

Reflux - Many cases start from birth and can continue until 3-4 years of age.

Textures - A lot children with hydrocephalus dislike the texture of certain things eg, sand. This appears to carry through to eating. The problems usually manifest themselves during the transition period between 1st and 2nd stage weaning. These difficulties can continue until 7-9 years, and some adults also express the dislike of certain food textures.

Slow eaters - Some children can take an hour or more to eat one meal. This is particularly distressing if the family are dining out.

Fussy eaters - Once a liking for a certain food has been developed, only these foods will be eaten.

For some of the children this can be limited to only 2 or 3 food stuffs.

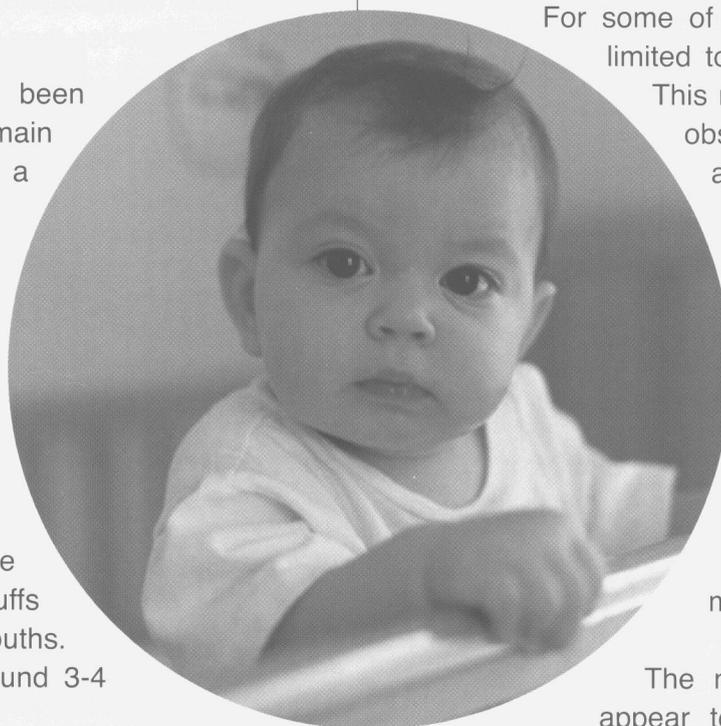
This may be due to the known obsessional behaviour associated with hydrocephalus, and so are not really "fussy eaters".

Small amounts - Many of the children will only eat small amounts of food, showing a total disinterest in any food. Therefore, perhaps only eating one meal a day.

The majority of the problems appear to begin at the weaning stage, when the child progresses to more textured food. The recommended age for this is 7 months, although some children may be ready sooner or later, depending on when they first started a solid diet.

Another peculiarity is that a minority of those children affected will only eat certain colours of food, certain smells, or indeed certain brands - and they can recognise the difference between brands.

Feeding problems appear to peak at around 2 - 3 years of age, and generally start to fade at about 7 - 9 years of age.



Bad Foods?

Junk food is not all bad. The following should ease the guilt pangs of letting your child eat:-

Chocolate - Provides good levels of calcium, copper, iron, magnesium, and phosphorus. Also contains tryptophan, which is believed to increase your serotonin levels, which makes you feel less stressed and happier.

Researchers in Japan have also found out that the cocoa bean contains chemicals that stop harmful bacteria from damaging teeth.

Chicken nuggets - Good source of protein, also contains essential B vitamins.

French fries - Good source of vitamin C. Potatoes in general contain fibre and high doses of vitamin C and potassium.

White bread - Contains calcium, iron, and niacin as well as vitamin B1. It is also low in fat.

Pizza - Cheese is a good source of protein, calcium and conjugated linoleic acid (CLA), which is thought to stop arteries from clogging up.

Tomatoes contain potassium and the vitamins A,C and E. Tinned tomatoes are a good source of lycopene, which is thought to help cut down on cancer and heart disease.

Coping with feeding difficulties

● - RELAX! if your child knows that you are getting upset or "stressed out" about his/her eating habits, they will sense it and problems will be increased.

● - Try to ensure that the child has their meal at the same time as the rest of the family. If this is not always possible, try to ensure that someone sits with the child.

● - Offer them food that you know they will like. If they don't eat it by the time the rest of the family have finished, clear EVERYBODY'S plates away, and don't make a fuss about the child not eating.

● - Remember that you are not the only one having this problem and that it will get better.

● - Don't wait for the child to ask for food - many of the children never feel hungry and so will go all day without food if given the opportunity.

● - Remember that there are no "bad" foods. Trying to persuade a child that has a limited diet that baked potatoes are better than McDonalds' fries, can be a non-starter!

● - If your child is not gaining weight and thriving, talk to you GP or Health Visitor as it may be that a food supplement may need to be introduced.

● - If things get on top of you talk to somebody!

Further information

Link article 'Feeding problems in children with spina bifida and hydrocephalus'. Issue 198.

Help us to help you

This information is provided free but ASBAH needs your help to enable us to go on providing a wide range of specialised information on all aspects of hydrocephalus and spina bifida, for families, professionals and students.

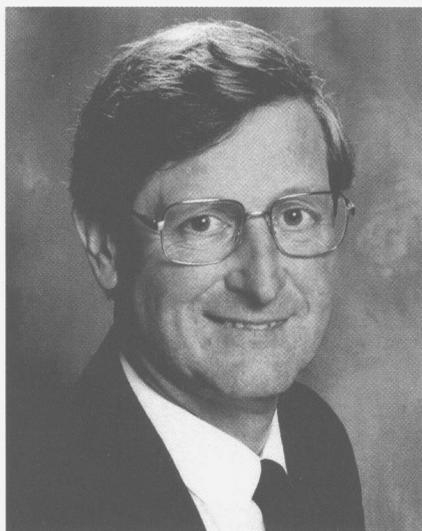
If you would like to help us continue with our information provision, we welcome your donation (cheques made payable to ASBAH). Please send to ASBAH, 42 Park Road, Peterborough PE1 2UQ.

Thank you

tributes

Dame Thora Hird

Project Co-ordinator Michele Savage represented ASBAH at the memorial service to celebrate the life of our long serving patron, Thora Hird, which was held at Westminster Abbey in September. BBC Director General Greg Dyke, comedian Victoria Wood and playwright Alan Bennett paid tribute to her outstanding stage, film and television career, which spanned over 70 years.



Peter Walker

Peter Walker, who was ASBAH's first full time education adviser 1990-98, died in September aged 70.

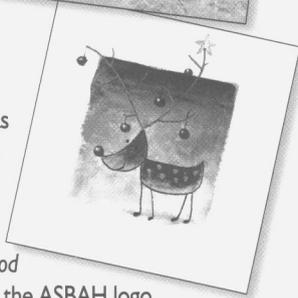
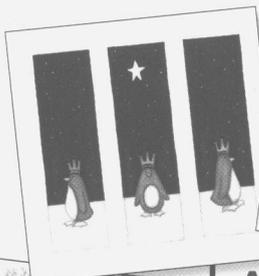
In his time at ASBAH Peter brought education to the forefront of its work, especially for children with hydrocephalus. He wrote our first booklet on statementing, contributed education articles to *Link* and introduced loaned laptops for children (to encourage local authorities to subsequently buy them their own laptops and so give them a permanent chance to express themselves) his standard letters for parents in dealing

with local education authorities are still widely used today.

He always carried a heavy workload: up to 20 files would be on his desk at any one time but, despite this, he found time to serve on the government's Education Tribunal Panel and this he continued after he retired from ASBAH. Peter was a teacher with many years' experience: before coming to ASBAH he spent time as a headteacher in Tanzania and then in Sheffield; he subsequently ran a Christian bookshop in Stamford.

He will be fondly remembered for his "wicked" sense of humour, for his wide breadth of knowledge and for his enthusiasm. Peter was a patient and popular staff member at Lifeskills weeks and family weekends - where his piano playing was a highlight. He moved to Birmingham on his retirement to be nearer to his family. He leaves a widow, Ruth, five children and numerous grandchildren.

Christmas Cards



If you would like to order some ASBAH Christmas Cards from the above selection of festive designs, please complete the attached form.

Each pack of 10 cards and envelopes comes with a greeting inside each card that reads: *With all Good Wishes for Christmas and the New Year.* In addition the ASBAH logo and registered charity number appear on the back of the cards.

Please send the completed order form together with your payment to:
ASBAH, 42 Park Road, Peterborough PE1 2UQ
 Registered charity no. 249338

ASBAH Christmas Card Order Form

Please send me:	Qty (Packs)	Price per pack of 10	Total (£)
Reindeer		£2.95 inc p&p	
Robin		£2.95 inc p&p	
Penguin		£3.45 inc p&p	SOLD OUT
Snowmen		£3.95 inc p&p	SOLD OUT
Wintry Scene		£3.95 inc p&p	
Total order			£

Payment

(please tick/fill in your preferred method of payment and complete your name & address details)

Cheque/PO order enclosed (Cheques made payable to ASBAH)

Or

VISA Mastercard/Access

Card no.

Start date Expiry date

Signature _____

Mr/Mrs/Miss _____

Address _____

Postcode _____

Telephone _____

holiday lets

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

ISLE OF WIGHT ASBAH HOLIDAY BUNGALOW

Fully-furnished and equipped two-bedroomed 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

Home with a heart for disabled travellers! Spacious, luxury, adapted bungalow situated on 18 hole golf course. 3 double bedrooms-sleeps 6, 2 bathrooms (Mangar bathlift installed). Custom furniture, patio & conservatory, cable TV. Telephone. Free Country Club membership. 24 hour 'on-call' management company. 15 minutes from Orlando Airport; 20 mins Disney. For current availability contact paraplegic owner. **Sue Fisher, 5 Park Lane, Broughton Park, Salford M7 4HT. Tel/Fax: 0161-792 3029 or email: rita.sue.fisher@ntlworld.com website: http://homepage.ntlworld.com/susan.fisher33**

For sale

4 year old, portable 'Home and Away' electric wheelshair, with 17 seats, would suit upto 13 stone person. Electric charger included. £350 ono.
Contact tel: 020 8395 1102, Surrey.

letters

We welcome letters for publication, which should be sent to: Editor, Link, 42 Park Road, Peterborough, PE1 2UQ. The editor reserves the right to edit letters, so please keep them short.

Pen Pal Appeal

My name is Sarah, I am 19 and I have spina bifida. I enjoy listening to music, shopping, writing to people and collecting things such as autographs, stamps, stickers, posters, cuttings and CDs of my favourite singers and groups. I'd like to hear from other teenagers worldwide who have spina bifida.

Sarah Jackson Bennett, 199 Flixton Road, Flixton, Manchester M41 5DN

Get in touch

I am 21 years old and have had hydrocephalus since I was born. I would like to hear from any other readers with hydrocephalus who are my age or older.

I also got married last year. David and I met each other in a Scope charity shop three years ago when I started as a volunteer. I'm still doing voluntary work today.

Caroline Finch, 3 Alexandra Road, Parkstone, Poole, Dorset BH14 9ELL

Friendship forging

I'm a 51 year old man with spina bifida and hydrocephalus and have recently had a long stay in hospital. I'm now beginning to pick up threads of my life again and would welcome the opportunity to forge new friendships.

I'm a keen football fan and enthusiastically support Cardiff City, attending as many matches as possible. I'm also very keen on music – in particular Queen and The Eagles. I would very much enjoy being in touch with people and widening my circle of friends. Please ring me on 01633 766487.

Anthony Jones, 24 Greenmeadow Way, St. Dials, Cwmbran, South Wales.

In the same boat

My name is Joseph Perera and I was born with spina bifida in 1955 and went to Chailey Heritage in 1956. I now do re-enacting and horse riding for films. I have just heard about ASBAH and what you do and would like to meet people who are in the same boat.

Joseph Perera. Email grazey@horse80.freeserve.co.uk

Disturbed by TV programme

I enjoyed watching the TV series Born to be Different (Link, issue 205) very much, even though I found some of it very upsetting and also very disturbing. The reason I found the programme that way is because when a mother is expecting a baby and she is carrying him or her for nine months, the last thing she wants to be told by the hospital is that the baby is going to be born "disabled". And to make matters worse, when the father of the baby finds this out, he decides to leave the mother to bring the child up on her own, especially when they have got other children.

Ms CJ Mizzi, Southampton

TV programme praise

I'm sorry it has been awhile in writing, but it is regarding the programme featured on Channel 4 on living with disability (Born to be Different).

Yes we thought it was good - I didn't see all of them but saw a few, I thought they were excellent. I have a disabled daughter – life is getting harder and harder as she gets older. I don't think people realise what it is like to bring up a child with special needs. There should be more programmes like this.

Mrs E Booth (Daughter: Sophie Booth)

dates for your diary

Upcoming events

Saturday 29 November

ASBAH Family Day, Sheffield

An informal day for families with a child with hydrocephalus and/or spina bifida and their brothers and sisters. To be held at The Centre in the Park, Norfolk Heritage Park, Guildford Avenue, Sheffield.

Contact: Julie Turnbull,
tel: 0114 253 0516 or email:
nro@asbah.org

CAN YOU HELP ?

Annette Hames, a consultant clinical psychologist in Newcastle, is completing a research project about the experiences of siblings of children with disabilities and chronic health conditions.

The aim is to produce written material based on siblings' personal accounts. She is interested in hearing from any siblings aged 4-18 years.

If you are interested and would like your children to contribute, then you can contact her directly at: **Sanderson Centre, North Avenue, Gosforth, Newcastle upon Tyne. Annette's telephone number is 0191 2196800 and her email address is annette.hames@nap.nhs.uk.**

Classified rates

£3.75 for 30 words max.
£5.50 for 30-45 words
£6.75 for 45-60 words

- Cheques and postal orders should be made payable to 'ASBAH'
- Classified adverts for the next issue of Link should be submitted by Friday 19 December 2003

Please send to:
Editor, ASBAH
42 Park Road,
Peterborough PE1 2UQ.
Tel: 01733 555988.
Email: link@asbah.org

Link

The ESSENTIAL magazine for people with
hydrocephalus and spina bifida

*ASBAH's magazine,
Link, is an absolute
lifeline!*

Nici Picken
Gloucestershire

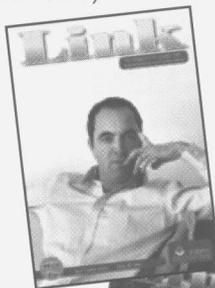


SUBSCRIPTION FORM

Link is published quarterly (Winter, Spring, Summer and Autumn). The cost of an annual subscription is £4.80, Airmail £15, Surface Mail £7.50. To subscribe please complete the form and return it with your cheque/PO (made payable to ASBAH) to:

**Link Subscriptions
ASBAH**

**42 Park Road
Peterborough PE1 2UQ
Tel: 01733 555988
link@asbah.org**



ORDER LINK NOW

*YES, I would like to receive Link
and enclose my cheque/postal
order for £ _____
(made payable to ASBAH)*

Name _____

Address _____

Postcode _____

Tel _____

Email _____



ASBAH

Association for Spina Bifida and Hydrocephalus
Getting the most out of life

Registered charity number 249338



Days in the life of Sarta Kaposowa and son Matthew caught on camera

The ASBAH video camera was dispatched in September to the Hackney, London, home of Sarta Kaposowa and her children Mary,

Matthew and Michael. Matthew has spina bifida and hydrocephalus and here's what Sarta and he had to tell the camera.

Sarta:

“ Matthew has hydrocephalus and spina bifida. He uses a walking stick but for long distances he uses a wheelchair.

We live in a new house in Hackney, which was very difficult to get as it took a long time to be rehoused. Previously we lived in a second floor flat where the lift often broke down.

Matthew runs around happy and healthy. He's got friends at school and he's doing really well there. He likes his scooter and playing outside in the crescent.

He's brought so much joy to us and to everyone he meets. Everyone loves him so much.

He's always been so happy. He's determined and he's overcome so many things. He never gives

up or says 'I don't want to try.' Everything he does he succeeds at.

We've had a lot of help. ASBAH adviser Gill Yazz has been a tower of strength. She helps me with all the benefits and the services. She's been really good and kind and helpful. I'm very thankful to her for everything

Things are hard sometimes. There are services, but they can be hard to get – there's so much form filling and you don't get it straightaway.

Matthew's just like any other child. He jumps in and does everything the other kids do.

All the kids are used to him – they all get on with him. They all know him!

We're happy and everything is going well.”

Matthew:

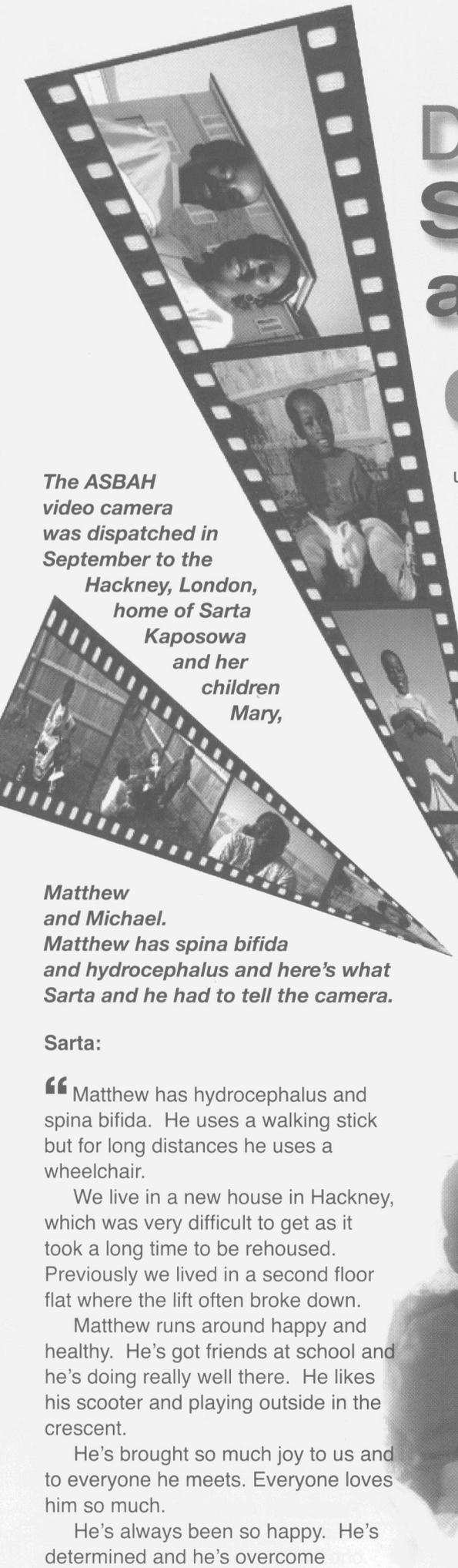
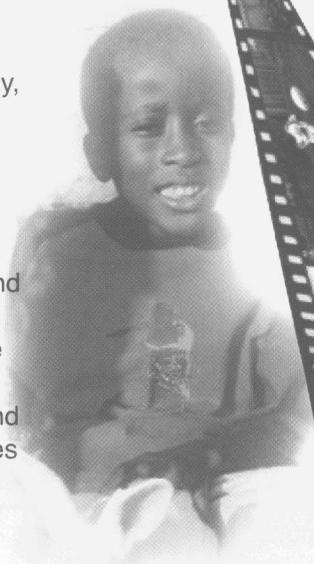
“ My favourite foods are Cheerios and hot dogs. I've got a brother and a sister and I love football, cricket, basketball and tennis.

I play football with my brother Michael every day in the house and in the garden. I can spin the ball on my hand. I support Arsenal and Thierry Henri. I play in shirt number 14!

I like my adviser Gill Yazz. I hugged and cuddled her the whole time when she was last here.

I can count in Spanish from 1-10. I've got an electric bike. Mum helps me to charge the battery.

I've got a rabbit called Sugar. I love my mummy.”



DIRECTORY OF INDEPENDENT LOCAL ASSOCIATIONS

AFFILIATED ASSOCIATIONS

BEDFORD

Mr R C Simmonds
16 Parkstone Close
Bedford MK41 8BD
Tel: 01234-400068

BOURNEMOUTH, CHRISTCHURCH & DISTRICT

Mrs Gill Lanning
43 Rothesay Drive,
Highcliffe
Christchurch, Dorset,
BH23 4LD
Tel: 01425-276820

BRISTOL & DISTRICT

Mr G Egan
64 Rookery Road
Knowle, Bristol BS4 2DT
Tel: 0117-977942

BUCKS & EAST BERKS

Mrs Karen McClean
Sandlemas Mead,
Beaconsfield
Bucks HP9 1AP

BOLTON & BURY

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

CAMBRIDGE & DISTRICT

Pauline Desborough
Summerlin Farm
Boxworth Road, Elsworth,
Cambs, CB3 8LJ

CHESTER & DISTRICT

Mrs P Ithell
34 King Edward Street
Shotton, Deeside
Clwyd CH5 1DW
Tel: 01244-811074

COVENTRY

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

DUDLEY & WOLVERHAMPTON

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

GRANTHAM

Mrs J Hickling
88 Goodliffe Road
Grantham, Lincs
NG31 7QB
Tel: 01476-401643

GREENWICH & DISTRICT

Mrs M Mears
29 Wellmeadow Road
London SE13 65Y
Tel: 0208-244 3526

HERTS AND SOUTH BEDS

Mrs Jennifer Hammond
28 Gladaside
St Albans, Herts AL4 9JA
hamrock@supanet.com

KENT

Office address:
7 The Hive, Northfleet
Kent DA11 9DE
Tel: 01474-536202

LEEDS & BRADFORD

Fiona Bryett
c/o ASBAH North
64 Bagley Lane
Farsley
Leeds LS28 5LY
Tel: 0113-255 6767

LEICESTERSHIRE & RUTLAND

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

LINCOLN & MID LINC'S

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

LINCOLNSHIRE SOUTH

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

LONDON NORTH WEST

Mrs H Prentice
37 Milton Road, Hanwell
London W7 1LQ
Tel: 0208-579 4685

NORTHAMPTONSHIRE

Mrs Maggie Nichols
11A West Street,
Weedon
Northants NN7 4QU
Tel: 01327-340732

PRESTON

Mrs S Thompson
Flat 3,
62 Alexandra Road
Southport
Merseyside PR9 9HH

SHEFFIELD

Mrs Barbara Clark
35 Woodhouse Lane
Beighton,
Sheffield S20 1AA
Tel: 0114-269 9299

SOMERSET

Mr Matthew Jenkings
8 The Gables,
Waterloo Rd, Wellington
Somerset TA21 8JB

SOUTH THAMES

Mr Peter Winterton
35 Paynesfield Road
Tatsfield, near Westerham
Kent TN16 2AT

SOUTHAMPTON & DISTRICT

Mr S J Fitzgerald
32 Ellis Road, Thornhill
Southampton SO19 6GR
Tel: 023 8040 2644

STAFFORDSHIRE

Mr Reay Pearman
2 Spode Grove
Westbury Park, Clayton
Newcastle-under-Lyme
ST5 4HF

STAINES, HOUNSLOW & DISTRICT

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

STOCKPORT & TAMESIDE

Ms Theresa Wild
41 Betley Road, Reddish
Stockport SK5 6SJ
Tel: 0161-443 2430
(after noon).

SUNDERLAND

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

SURREY

Steve Wallace
2 Carlton Crescent
North Cheam
Surrey SM3 9TS
Tel: 0208 641 7866

SUSSEX

5A Grand Avenue
Worthing
West Sussex BN11 5AP
Tel: 01903-507000
sasbah.office@tiscali.co.uk

TRAFFORD & SALFORD

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

WARRINGTON & DISTRICT

Mrs S Lawless
4 Astley Close, Warrington
Cheshire WA4 6RB
Tel: 01925-573708

Whitchurch (Salop)

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

WIGAN, LEIGH & DISTRICTS

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

WIRRAL

Mrs M Appleyard
13 The Row, Market
Street, Hoylake, Wirral
CH47 3BB

WORCESTERSHIRE

Mrs Ann Cotter
49 Brueton Avenue
Fringe Green,
Bromsgrove
Worcs B60 2AW

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
Tel: 01792-428004

Mid Wales

Roger Price
28 Coldridge Drive
Shrewsbury, Shropshire
SY1 3YT
Tel: 07812-130939

North Wales

Mrs V Conway
10 Cae Clyd, Parc
Clarence
Craig y Don, Llandudno,
Conwy
Tel: 01492-878225

South Wales

Mrs Brenda Sharp
4 Lakeside
Barry
South Glamorgan
CF62 6SS
Tel: 01446 735714

NORTHERN IRELAND

Mrs Elizabeth Graham
101 Coolreaghs Road
Cookstown
Co Tyrone BT80 8QN

NON AFFILIATED ASSOCIATIONS

Blackpool & Fylde

Mrs Diane O'Hagan
83 Boothley Road
Blackpool
Lancs FY1 3RR

Calderdale

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

Cannock & Walsall

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

Chesterfield

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

Cornwall

Mrs Liz Pollard
Ropers Walk Farm
Mount Hawke
St Agnes
Cornwall TR4 8DW
Tel: 01209-891632

Derbyshire

Mrs A Hewitt
St Merryin, 20 Burley Hill
Allestree, Derby DE22 2ET
Tel: 01332-841893

Devon

Tony Sprague
52 Lorrimore Avenue
Stoke, Plymouth
PL2 1HZ
Tel: 01752-550430
mailto:info@dasbah.com
www.dasbah.com

East Anglia

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

Essex

Mrs R McCarthy
26 Brixham Gardens
Ilford, Essex IG3 9AX
Tel: 0208-594 1852

Isle of Wight

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

Lancaster, Morecambe & District

Mrs M Dyson
25 Royds Avenue,
Heysham, Morecambe
LA3 1PA

Nottinghamshire

Mr Allan Barratt
127 Limetree Road
Hucknall,
Notts NG15 6AW
Tel: 0115-953 7291
Fax: 0115-953 2081
(8am - 6pm)

Oxfordshire

Mrs Shirley Dale
14 South Row, Chilton,
Didcot, Oxon
OX11 0RT
Tel: 01235 -834785

Wessex

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

OTHER ASSOCIATIONS

SCOTTISH SBA

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

IRISH ASBAH

Mairead Graham
Irish ASBAH
Old Nangor Road
Clondalkin, Dublin 22
Tel: 00 3531 457 2329

JERSEY,

Channel Islands

Mrs Ursula Emmanuel
Priory Gardens
La Grande Route
de St Clement, St Clement
Jersey, JE2 6QQ
Tel: 01534 -853019

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

Readers may reproduce any of the material in *Link* for their own purposes, except where permission has been expressly withheld. This will be indicated clearly when contributors wish to assert their own copyright. Opinions and views expressed in *Link* are not necessarily those of The Association for Spina Bifida and Hydrocephalus. While every care is taken to ensure accuracy of information published in *Link*, the publisher can accept no liability.

WHEELCHAIR ACCESSIBLE



EUROBUS ™



FREEDOM ™

LOW COST ACCESSIBILITY

As one of the country's largest vehicle conversion companies Allied Vehicles have built an excellent reputation over the past 35 years for quality, value and service. Vehicles are converted at our own purpose built facilities - which means valuable savings - savings that are passed onto you, in addition to better build quality and faster delivery times.

To find out how easy and affordable it is to purchase your new vehicle please phone free on **0800 587 9608** and talk to one of our friendly customer service team today.



Motability
The leading car scheme for disabled people

Allied Vehicles
Driving For Perfection