

LINK

The magazine for people with
Spina Bifida and Hydrocephalus

**Middle childhood
and adolescence –
research results**

**School phobia and
hydrocephalus**

**Our GREAT North
Runners**

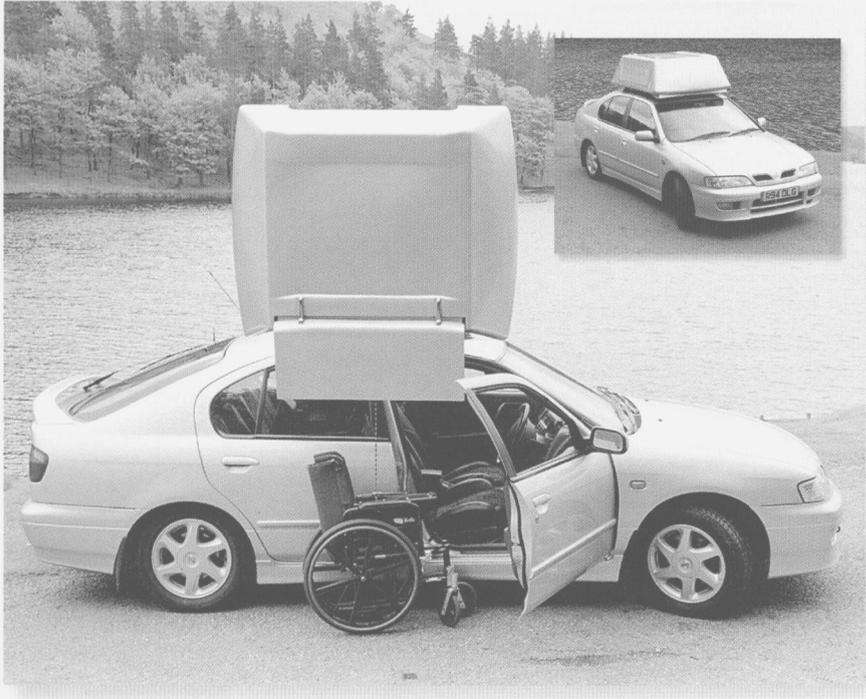


NOVEMBER/DECEMBER 2002

ISSUE 202

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Cover: Annie Huang, Peter Ogden-Smith and Allan Hughes were among 14 ASBAH entries in the Great North Run. Story on page 24.

Editorial

Philip Shad's invention (on page 4) is an example of what a difference technology can make to people with disabilities – in the home, at school, at work, in sport and leisure activities and as parents.

Similarly, a pilot project in Idaho, USA, showed that assistive technology redefines what is possible for parents with disabilities who are striving to protect and care for their children. One parent was concerned about taking her child out. She complained: 'I have been unable to take my child out without worrying about her running off and not being able to catch her because of my health.' This family received a child's harness and mum now feels safe taking her daughter out with her.

It is not only technology but our networks in society that pave the way towards excellence in parenthood. A conference report on page 26 states that most parents can be caring and competent if they live in a caring and competent environment, with adequate social links, networks and resources that can support them in times of difficulty, as well as reinforcing their success in good times.

I think all parents – disabled and non-disabled alike – would agree with that!

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All sewn up ● Page 4



No stopping ● Page 25



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

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

link@asbah.org

www.asbah.org

Registered Charity
Number 249338

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

Invention opens up textile technology



Kim's future could be all sewn up

Photo: Salisbury Newspapers

NATIONAL Curriculum technology subjects have been opened up for one secondary school pupil, thanks to the invention of a remote control device.

The device gives wheelchair-users access to machinery that before could only be operated by a foot pedal.

For 13-year-old Kim Randall, of Salisbury, Wiltshire, it means the option of taking a GCSE and a career in textiles.

A receiver box is activated by a matchbox-sized remote control device, which can be strapped by Velcro on to any part of the operator's body. By lightly pressing the switch at her side, Kim starts and stops the machine at

will. It also has an independent speed controller attached to the machine body so the speed can be selected.

Her teacher, Annette Vinall, said: "This little box is wonderful. To see Kim's face when she first used it was marvellous. She is now joining in with the mainstream textile technology class – the special needs label has been taken away."

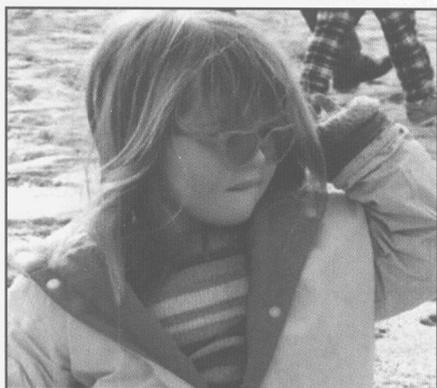
Mrs Vinall, the technology course co-ordinator at Downton School, Salisbury, says there is the potential of applying the invention to other technology subjects with foot operated machines, like pottery and woodwork.

Kim has already been designing and making pieces such as an appliquéd cushion, a pencil case with zip and a soft toy.

Her mum, Mary Randall, said: "It has opened up a whole new life for her. It has increased her range of realistic career options."

The device has also been adopted by Gloucestershire's National Star Centre, London's South Hampstead Junior School, Kingston University and Birmingham's Golden Hillock Community School.

● **Invention details from: Philip Shad on 01895-634848; 07860-764636 (mobile). Demonstrations can be arranged.**



Roll up, roll up!

NOW is the time to apply for ASBAH's Family Weekend 2003 which has something to offer for all members of the family.

Applications are invited from families with a child with spina bifida, hydrocephalus or benign intracranial hypertension who is aged six and under on 1 March 2003. Special programmes are arranged for the disabled children, and their brothers and sisters, aged 16 and under.

The weekend is designed to be a chance for parents to learn more about their child's disability. There will also be opportunities to relax and meet other parents.

For 2003, we are returning to Sands Family Resort in Porth, Cornwall. If it seems a long way to travel by car, you could consider flying. For example, Ryanair flies from Stansted to Newquay – www.ryanair.com. The hotel is just 10 minutes away from the airport.

The weekend takes place from Friday 7 to Sunday 9 March 2003. It costs £65 per family – once again we are grateful to BBC Children In Need Appeal for giving us financial support.

● **Application forms: Rosemary Batchelor 01733-555988; rosemaryb@asbah.org**

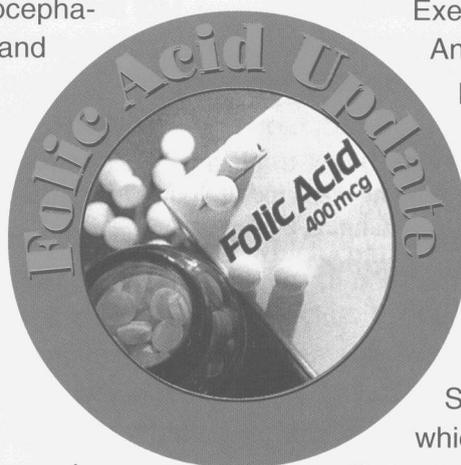
Europe-wide bid to prevent spina bifida through folic acid

ASBAH is proposing a Europe-wide policy by the various national Associations for Spina Bifida and Hydrocephalus on folic acid and promoting the fortification of flour, for the primary prevention of spina bifida and other neural tube anomalies.

This is to try and prevent a Brussels veto of manda-

tory flour fortification on grounds of free trade and standardisation of products.

Executive director, Andrew Russell, proposed a policy initiative at the annual meeting of 'if', The International Federation for Hydrocephalus and Spina Bifida, which was held in Poland.



Reach out to others with benign intracranial hypertension

A MESSAGE board has been set up on ASBAH's website for people with benign intracranial hypertension (BIH).

You can find this conference by going to our main page <http://www.asbah.org> or you can go straight there with <http://cgi.asbah.plus.com/cgi-bin/bbs.pl>

An ASBAH specialist adviser (medical) accesses the site twice a week to answer any medical queries.

At the same time, ASBAH's IT Director, Paul Dobson, has warned about giving out your

address, phone number or even attaching a personal photo to an email you send to anyone that you have got to know on the Internet. People who seem trustworthy at the outset could become a nuisance later on.

However, we are keen to get people to post messages on our own bulletin board. If it proves successful, we could start other conferences for hydrocephalus and spina bifida.

Mr Dobson said: "The more people who post to it, the more people will get out of it."

Pressure ulcer: 'new spray worked wonders'

A SPRAY, derived from natural sources, has been hailed a success for healing pressure sores by a mum in Cornwall.

Sharon Bennetts resorted to buying Youki after a sore at the base of her son's spine refused to heal and a skin graft was considered.

Seventeen-year-old William had just left home to start a GNVQ course in media studies when the sore developed. It could have been caused by a change in bathing routine and increased use of his wheelchair.

A few weeks into the Autumn Term, Mrs Bennetts saw the reddened area but didn't realise it was a pressure sore.

Two weeks later, the college medical centre began treating it as a pressure sore. But the

frequent dressing changes traumatised the skin around the sore edges and it wasn't healing. Various dressings were tried but none of them stayed in place.

Mrs Bennetts said: "We were in a no-win situation because of where it was."

Then a relative read about Youki Wound Spray for cuts, grazes and burns. After checking with their GP, they tried it.

Over the summer, Will's sore shrunk from the size of a 50p piece to a small finger nail. No dressing was needed so the skin could form its own protective layer. Mrs Bennetts said: "It was weeping at first, then it dried and went dark red and the new skin growth came from that."

Other factors thought to have helped included: Will lying face-down on his bed daily with the wound uncovered; using a Ro-Ho cushion; having more vitamin

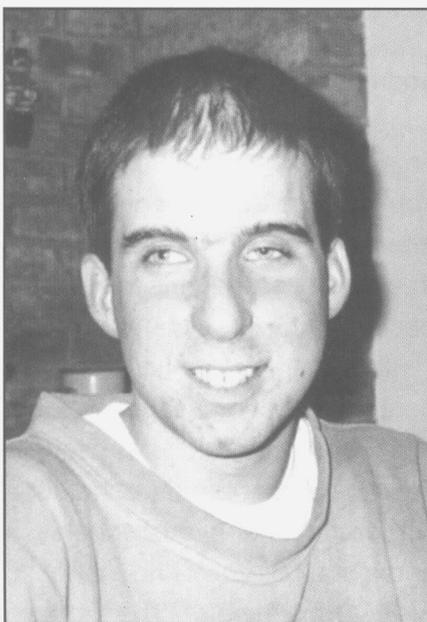
C, zinc and protein in his diet and adding a few drops of tea tree oil into his bath.

Mrs Bennetts said: "We never would have believed that it would have healed in 10 weeks."

When the surrounding skin looked healthier, Youki Skin Repair Cream was applied and once the sore closed, this cream was placed on the sore itself.

The only drawback is the cost – £25 for a 30ml spray. Trial sizes (5ml) are £6. It is available from some chemists or direct from: Depeche Mode Laboratories, PO Box 2365, Maidenhead, Berks SL6 8WJ. Free p&p to *Link* readers. www.depeche-mode.co.uk/youki.htm

Editor's note: This is one reader's experience and is not endorsement of Youki by ASBAH.



Will Bennetts whose pressure sore healed rapidly using Youki

Farewell to a distinguished consultant

A DISTINGUISHED consultant neurodevelopmental paediatrician and member of ASBAH's Medical Advisory Committee, has sadly died after a long illness.

Dr Margaret Borzyskowski MBBS FRCP, a consultant at London's Guy's Hospital, contributed greatly over seven years to our committee's work on

research, practice and policy.

Dr Borzyskowski was also well known to many of our service-users for her kind, clear and supportive medical approach, which combined with her expertise and deep knowledge of our field, made her such a well-liked and respected consultant.

● **A full tribute will be published in the next issue.**

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Pill box that bleeps

DO you sometimes forget to take the pills you've been prescribed on time?

Then a box which carries your pills *and* bleeps when you need to take one could be for you. It could be particularly useful for people with hydrocephalus or benign intracranial hypertension.

The 'Wonder Pillbox Timer', which fits neatly into a shirt pocket, is being sold by retired couple, Roy and Davina Bensusan, who searched worldwide for a supplier after their lives became dominated by Parkinson's Disease.

Mrs Bensusan said: "No more watching the clock. If we want to

go out, all we need is the pill box, a bottle of water and we are away. Our lives have picked up again."

Orders are sent out First Class and the pill box has a year's guarantee. Anyone who finds it difficult to understand how to set the timer, can ring Davina and she will talk them through it. There's also a full money back guarantee if the pillbox is returned within 14 days of purchase.

● **Wonder Pillbox Timer, £17.50 (inc p&p), from: Dept RNB Supplies Ltd, 7 Daleham Gardens, London NW3 5BY. Helpline: 020-7435 2417.**

roy.davina@bens7.freeserve.co.uk



Online view of QMC leaflets

INFORMATION leaflets written by staff at the Queen's Medical Centre, Nottingham, can now be viewed online.

More than 100 leaflets, aimed at parents, can be accessed via a link at QMC's website – www.chic-qmc.org.uk/home.php

The leaflets have been entered on to a searchable

database. Users can either view a complete list of leaflets or select from several disciplines. There is also a word-search on leaflet titles.

Although the leaflets are mainly intended for use by families and parents at QMC, in conjunction with their doctor or nurse, the information can now be used by others as well.

RADAR has the key

5,000 accessible toilets across the UK can be unlocked by a key from RADAR – the Royal Association for Disability and Rehabilitation.

The key costs £3.50 and a directory of toilets is also available for £5.

Please make your cheque payable to 'RADAR', enclose your address and state that you have a disability (to exempt you from VAT).

Send to: RADAR, 12 City Forum, 250 City Road, London, EC1V 8AF.



KIMROY PHOTOGRAPHY, SHEFFIELD

Advertisement promotion

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Back in the saddle

GERAINT Catherall, who has hydrocephalus, is back doing the sport he loves best after a hernia operation put a stop to him competing last year.

Working his way back to fitness last winter, he enjoyed a full cycle race season this year – culminating in the National 24-Hour Championships.

It was the second time Geraint had competed in this event and this year he used the opportunity to raise a wonderful £300 for ASBAH.

Geraint clocked up a distance of 328 miles in 24 hours – slightly less than last time due to the very hot weather and a strong headwind in places.

The race started just outside Chester, with riders setting off at one minute intervals during the Saturday afternoon. After reaching Chester, the competitors turned south and rode through the night towards Shrewsbury. They were directed by marshalls at roundabouts and junctions.

Geraint (29), a Welshman who works in Leicester as a dental technician, said: "During the night riding, I struggled with tiredness. I also found myself getting dehydrated by the early hours of Sunday. Thankfully, helpers from my cycle club and my dad were on hand with fluids and food."

By 9am on Sunday, the riders were heading back towards Chester and on to a 14-mile finishing circuit, with time-keepers every three minutes. The competitors continued around this circuit until their 24 hours had elapsed.

A much-needed massage the next day prepared Geraint for a 100-mile time trial the following Sunday and a fortnight later he covered 206 miles in a 12-hour race. He ended the season with a 50-mile and 25-mile time trial and a hill climb up the Horseshoe Pass, Llangollen.

Brighter horizons

DESPITE a difficult year financially, the mood was buoyant at our Annual General Meeting in September as local Associations joined us in looking to the future with optimism.

The mood was helped by having a powerful and dynamic guest speaker, Richard Howitt MEP, who outlined the role of the European Parliament and its All-Party Disability Group, of which he is president. The Labour MEP for East of England explained the value of the European Year of Disabled People in publicising the messages of access and inclusion across Europe.

ASBAH chairman Peter Cottingham's introductory

speech acknowledged the difficult financial year and paid tribute to the commitment of staff who, he said, focused on the needs of others in spite of many professional pressures.

He stressed the need for national and local Associations to work very closely, particularly on fund generation and approaches to statutory funders.

Honorary Treasurer Mike Allen reported that the financial results for the year to 31 March 2002 had again been poor. He reported an overall deficit of £196,198.

Legacies – a very erratic income stream – had been down from the prior year (£289,446 vs

£494,274). Furthermore, our Telesales operation's income was down because of the foot and mouth crisis plus the September 11 disaster (gross profit £1,068,213 vs £1,166,034).

However, our shops' income continued to show good results and increased significantly over the prior year.

The overall poor results necessitated the regretful decision to reduce staff by redundancies. Mr Allen thanked all the local Associations who contributed to the support of our Advisers, this support reducing the number of redundancies.

● **For a copy of the Accounts and Review, please contact Brian Deffee, tel: 01733-555988; email briand@asbah.org**

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Over to you!

WHAT kind of training would ASBAH service-users in Greater London find useful?

This is the question being asked by ASBAH project workers Judy Hunt and Lucy Hughes. It follows a disappointing response to a training workshop on direct payments in October.

The October workshop, scheduled to take place at the Charity Centre in NW1, had to be cancelled as only three people responded.

Judy Hunt, independent living adviser, said: "If anyone would like us to try and organise a similar or different training day, please get in touch so that we can find out what kind of training people would find most helpful.

"This would help us to make sure we invest resources in the most relevant way."

● ***If you would like to advise Judy on your training needs, please could you leave a message for her at ASBAH's South-East Region Office on 020-8449 0475, with your telephone number, and she will call you back.***

Advertisement promotion

Looking for adventure, a challenge, a holiday or the chance to have some fun!

THE Calvert Trust has been providing outdoor activity holidays and courses for people of all ages and with varying nature of disabilities for over 25 years. Its three centres – Keswick, Kielder and Exmoor – have been developed for groups, individuals, families and friends.

The accommodation is either fully catered or in self-catering chalets or cottages, all being accessible throughout. Each centre has an indoor heated pool and excellent on-site facilities. The centres differ in character, as do some of the activities offered; however, they have a shared philosophy that 'it's not what you can't do ... but what you can do that counts.'

The range of activities is constantly being extended and the centre staff are selected for their professional skills and their experience in working with people with disabilities, and pride themselves on meeting the needs of the visitors within an atmosphere of enjoyment and a framework of safety.

If you would like to know more, either contact each centre for a brochure or visit the website: www.calvert-trust.org.uk – there's something for everyone.

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www.calvert-trust.org.uk

Sporting life

SOME of Britain's leading junior and senior wheelchair athletes have had a busy time of it, with European and World Championships in wheelchair basketball, the World Team Cup of wheelchair tennis and the Great North Run all having been on the international sporting calendar.

After finishing fourth in the Sydney Paralympics two years ago, Great Britain's Men's Wheelchair Basketball team went to Japan for the Gold Cup. Their tournament started with a tremendous 77-72 win over defending Gold Cup champions the USA and was followed by a 64-58 victory over 1996 Paralympic champions Australia. This spectacular form carried on until GB reached the final. However, they were unable to repeat their earlier heroics against the USA and had to settle for silver after a 61-74 defeat.

Among the leading lights in the GB team was Jon Pollock, who was selected for the 'All Star starting 5', a hypothetical team selected after the tournament with votes from all participating nations. Jon (*pictured right*) received more votes than any other player and was one of two GB players in the line-up.

Meanwhile, Ann Wild – a name and face that is probably familiar to regular *Link* readers – again captained the GB Women's team in the Gold Cup. However, in amongst the world's best teams the GB girls struggled, eventually finishing eighth of the eight teams.

Shortly after the Gold Cup, the GB Junior (22 and under)

By
Marshall
Thomas



team won the European Junior Championships in Frankfurt, with Gloucestershire's Dean Smith making a vital contribution to their success.

Dean (22) plays club basketball for the Staffordshire-based RGK Panthers in the National League Premier Division, which means a long distance journey for training sessions and home games, but that's the kind of commitment that has turned Dean into an excellent defender and a European champion.

Mid-September saw the cream of Britain's wheelchair tennis players travel high up in the mountains above Lake Garda in Italy for the Invacare World Team Cup by Camozzi. The World Team Cup is the wheelchair equivalent of the Davis and Fed Cups. British Men's No 1 Jayant Mistry helped the GB Men's wheelchair team to their second best ever performance as they finished fourth.

Meanwhile, the GB Women's tennis squad consisted of three players making their Great Britain debut. The challenge was spearheaded by Debbie Thomas, from the Wirral, who proved she is an ever-improving talent with some very good performances during the week, although GB only finished 14th

in the Women's competition.

The world's biggest half marathon, the Great North Run, took place in October. Britain's best-known wheelchair athlete Tanni Grey-Thompson has yet to regain anything like her full fitness after the birth of daughter Carys. This, coupled with a sickness bug she picked up just before the race, contributed to her finishing fourth in the Women's wheelchair race. *For news of those who ran the Great North Run for ASBAH, turn to page 24.*

In the Men's race Surrey's David Weir, winner of this year's London Marathon, finished second. David (22) is looking forward to becoming a dad in the New Year.

The Junior Great North Run boy's race wheelchair race was won by 16-year-old Brian Alldis.



PHOTO: GRAHAM BOOL

Cool, calm and collected: Jon Pollock, GB basketball squad member

School phobia: questions unanswered

IS IT my imagination or are many teenagers with hydrocephalus suddenly going off attending school?

Could it be hormonal confusion or does an overwhelming feeling that it's 'all too much' come over many of these youngsters?

Have parents anything to do with the condition or can we blame the demands of mainstream school perhaps? Is bullying a factor or just plain old

teenage blues?

Does school phobia slowly creep up on a person or do youngsters wake up one morning shouting 'this is the answer?' Could it be a geographical problem or a need for home tuition? Are any of these youngsters depressed or frightened, or just not

interested and can't see the point? Maybe the gap between peers is more obvious, causing frustration or lack of self-esteem?

But, if so, how do some teenagers with hydrocephalus stay motivated while others just want to stay at home?

By Joanne Grenfell
ASBAH Specialist Adviser
(Education)



● *If you can answer any of these questions or have a comment to make, please let me know. Email: joanneg@asbah.org or write to Joanne Grenfell at ASBAH House North.*

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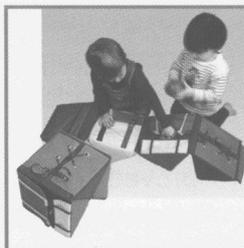
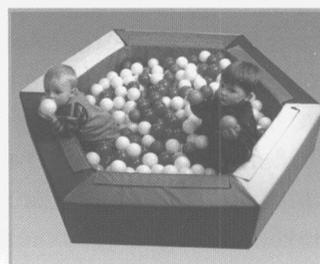
Treloar School and College are supported by the Treloar Trust, registered charity number 307103.

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- Sand and water play
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Buddies not bullies

ONE comprehensive is attempting to ease the difficult transition from small primary to huge secondary by encouraging older pupils to support the younger ones.

Year 10 and 11 pupils at Llanishen High School, Cardiff, are trained by CHIPS (Childline in Partnership With Schools) to become effective listeners.

These buddies go into the registration groups of the younger pupils to get to know them. They offer help in whatever area is needed including homework, difficulties in subjects, bullying, friendship issues, etc.

The buddies also do individual mentoring with pupils who have a particular problem.

They may help a young person resolve the issue of bullying or encourage them to speak to buddies co-ordinator, Sarah Parry, about what has been happening.

If a younger pupil is being bullied, the buddies 'shadow' them at break and lunchtimes to

ensure they are all right. If bullying occurs, they can report this to Mrs Parry and immediate action can be taken. If there is no bullying going on, the buddies provide a sense of security for the younger pupil and help them to break out of the cycle.

Mrs Parry said: "This is a short-term measure which has proved really effective and helps the parents to see that we are taking bullying seriously.

"The buddies and I meet at Friday lunch-time so they can feed back to me and I can help them with any difficulties they are encountering."

The buddies have designed and produced a booklet for each Year 7 and 8 pupil to help them think about friendship in greater detail.

The scheme has won an award for £10,000 for support and development. The money is being used by the buddies to set up a room for themselves and a laptop computer so that they can offer an on-line support network.

Low proportion of disabled people going into higher education

AN 18-year-old with a disability or other health problem, is only 40% as likely to enter higher education as an 18-year-old without a disability or other health problem, according to a National Audit Office report.

With the Government and education sector talking about widening access to higher education for under-represented groups, action must be taken to improve this figure, says Skill – the National Bureau for Students with Disabilities.

To help to encourage more disabled students to apply to university, Skill has published *Into Higher Education 2003*, an informative and practical guide for disabled students thinking about entering higher education.

The guide features advice on applications,

getting support, grants and benefits, as well as profiles written by disabled students about their own experiences in higher education.

There are also listings written by institutions on the arrangements they can make for disabled students. These listings, which include contact details for each institution's disability co-ordinator, can also be accessed as a searchable database on www.skill.org.uk

● **Into Higher Education is £12.50 for professionals; £2.50 for disabled students. It can be ordered from Skill, tel: 0207-450 0620; email:**

skill@skill.org.uk
Skill's information service is open Mon–Thurs, 1.30–4.30pm, on 0800-328 5050 (voice) or 0800-068 2422 (text).

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

Here as long as we're needed

THE second in our series showing what local Associations are about; to share experience and ideas, and help foster feelings of solidarity with each other, ASBAH, and ASBAH in the regions.

LEICESTER ASBAH (LASBAH) is working together with ASBAH Eastern Region so that it can keep its Adviser, who works 10 hours per week in Leicester City. The funding for the Adviser post runs out at the end of this month (November).

LASBAH's secretary, Alison Twomlow, said: "We are prepared to make grant applications to various charities and trusts if it will help us to be successful, as we do realise that in some cases smaller charities are looked upon more favourably than national charities.

"We need to work with ASBAH Fundraising so that we have full information about funding before proceeding with any applications."

She added: "We have, in the past, funded our own adviser but found this to be an enormous financial strain and we, as an association, do not feel able to make this commitment again.

"Fundraising is very difficult – there are so many charities out there all asking for help from the same pot of money and many of our members are in full-time employment and their free time is very limited."

LASBAH has a very hard-working committee of 14 – three of which are wheelchair-users, who give their time and energy to keep LASBAH on the right track. Several committee members are founder members and its president, Mrs Peggy Keeling, was also a founder member of ASBAH.

The biggest fundraising event for LASBAH is the Combined Children's Charity Walk which helps seven charities in Leicestershire. LASBAH also holds an annual raffle, organises a fashion show and attends car boot sales and fetes.

This year, LASBAH was offered the opportunity to organise the catering for an event

held jointly by the RSPB and Severn Trent Water – at the picturesque Old Pumping Station at Cropston. It was the first time the association had attempted anything like this before. Although it was hard work obtaining support from supermarkets and local food and drink companies, it proved a great success. With all the support, LASBAH made more than £1,000. Many of the members made cakes, supplied prizes for stalls and helped on the day.

LASBAH offers discretionary grants,

produces a quarterly newsletter and helps with travel expenses when their members are in hospital for more than three nights. It owns a non-profit making holiday chalet in Norfolk which enables members to have a low cost holiday. At Christmas it holds a children's party and a meal out for the over-16s.

The association was set up by parents more than 30 years ago to improve the lives of their children. Many of these children went to school in Leicester and the friendships made



Committee members Jean Ellis, Malcolm Law, Nic Ellis & Carole Armour at the LASBAH chalet

there are still as strong today. The second generation of children go to both special and mainstream schools all around Leicestershire and Rutland and therefore miss out on the common cause and comradeship that was experienced when LASBAH was first formed.

Alison is usually the first point of call for new members and is able to offer a sympathetic ear and point people in the right direction for the help that they need. She is employed by the association for 10 hours

a week and is also the fundraising co-ordinator.

Alison became involved in LASBAH 14 years ago when her daughter, Lorna, was born with spina bifida. She first contacted national ASBAH from a phone number found in a booklet given to her at her local maternity hospital. To help others in the area, LASBAH has just produced a leaflet highlighting the association, the conditions and contact numbers. The group hopes to make it available at health centres, hospitals and schools in the near

future, and is planning an awareness day at one Leicester hospital later on this year.

Alison said: "We feel that times have changed over the years but as long as there is a need for our help and support, LASBAH will be there. Our aim is to ensure that our members live their lives as comfortably and as fully as possible."

● **LASBAH contact:**
Alison Twomlow,
01858-432967.
ASBAH East Region:
tel: 01733-555988;
marym@asbah.org

FACTfile on LASBAH

Knows of 285 families in Leics and Rutland.

Main aim: To support people with H/SB.

Formed 34 years ago in 1968.

Four out of 14 committee members (including trustees) are founder members.

Membership fee: £5 a year.

Camping for all

THE WORLD of camping and caravanning is opened up to people with special needs in a new, free booklet.

It includes first time advice for those travelling to UK sites or going abroad.

Camping for All is available from: Membership Dept, Camping & Caravanning Club, Greenfields House, Westwood Way, Coventry CV4 8JH or telephone 024-7685 6797.

Easy rider in Leicestershire

GRASS and rough gravel are no longer a problem for Leicester ASBAH member Carole Armour, since she became the owner of a power adaptation to her manual wheelchair.

The PowerTrike – featured in a previous *Link* as a *Tomorrow's World* award winner – is a single wheel with handlebars that attaches to a manual chair, raising the front castors off the ground, so the chair is converted into a powered tricycle.

The trike has a range of 10–12 miles on a fully

charged battery, depending on the terrain.

The only disadvantages Carole has no-

ticed, so far, are the lack of a reverse gear and assembly problems for a completely independent user.



Darren's video on disability gained Millennium funding

WITH acting in the family, Birmingham-based Darren Bill has made a disability awareness video for secondary schools with £8,500 from the Quest Millennium Award Scheme.

Darren and his friend John Robertson, who know each other through a local day centre, employed a professional script-writer and technicians to make the 20-minute video,

Small Steps, Big Achievements.

Darren's parents, Roger and Maureen Bill, are professional actors and Darren attended Birmingham School of Speech and Drama. As the main character of the video, he is thrust into various real-life situations but manages to come out on top.

There are scenes at Darren's flat in Artinghall House, Stirchley; Birmingham's Icon Gallery, Midlands Art Centre and outside Costa Coffee.

Doubling up as actor and director, Darren had an input in what was going on on both sides of the camera.

The video and a teachers' pack is aimed at secondary school pupils and professional training colleges, and 200 copies are available for hire. Sometimes Darren and John go along to a showing of the video to help with discussion.

Darren (31) said: "I think people's eyes have been opened. I'm keen to get the video

widely circulated to show people that this is how people often approach people with disabilities.

"The way some people approach disability is all down to ignorance. They don't know how to cope with it."

● **To hire the video, contact Darren on Tuesdays and Fridays, 10-3pm, at Fairway Day Centre, tel: 0121-459 4994; or John Robertson at the same number on Wednesdays and Fridays.**

10 GCSE line-up for Rachel



Rachel Hickey is delighted with her exam results

RACHEL Hickey achieved a tremendous 10 GCSEs this summer and is now doing an AVCE Level Health and Social Care Double Award at her local sixth form college.

Rachel, who has benign intracranial hypertension (BIH), got through all the revision and exams despite the headaches and tiredness.

She wrote about her experience of BIH in an article published in the May issue of *Link*.

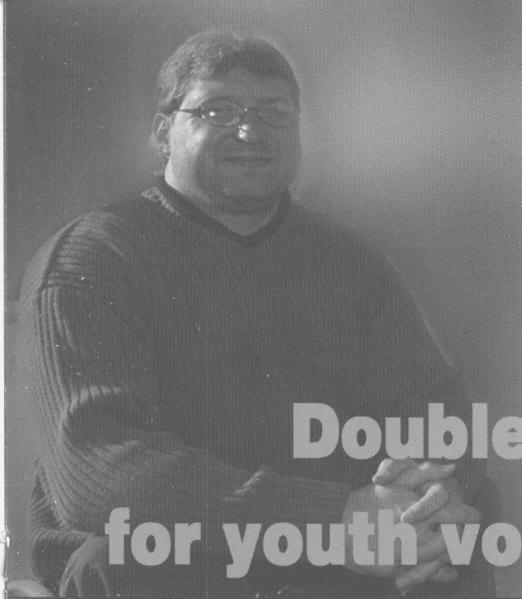
Speaking from her Huddersfield home, she said: "I had a lumbar puncture in May and another in October as my pressure is still rising, so the exams fitted in between the two.

"I know some people in my situation might have dropped subjects

and I was given that option, but I wanted to carry on.

"It's having the will-power and knowing it will be worthwhile, that got me through."

In the long run, Rachel (16) wants to become a social worker for families with children who have problems. And seeing her determination, so far, she will undoubtedly do it.



Double award for youth volunteer

A HARROGATE man, who celebrated the big 40 this year, has been doubly awarded for the time he gives to children.

Alan Shorter (*pictured*) works at a Barnardo's playscheme for disabled and non-disabled children and is personal mentor to two boys.

He was presented with a Golden Jubilee Award by Harrogate Borough Council and is about to go to London for the Unsung Heroes Award from the Celebrity Guild of Great Britain.

Alan, who has spina bifida, said: "These awards were totally unexpected.

"I can't work full-time due to a pressure sore and, three years ago, I was looking for something to get me out of the house. I went to see a guy who was running an outdoor activity centre and he happened to mention the playschemes.

"It's the most enjoyable thing I've ever done."

He is personal mentor to an 11-year-old with learning difficulties and a nine-year-old with Down's Syndrome. "I've got a really good bond with the boys and have got to know if a problem's going to arise before it happens."

But as a playscheme volunteer, he's just as comfortable mixing with non-disabled youngsters and answering any questions they may have about his own disability.

His ASBAH adviser, Geraldine Binstead, said: "Alan gives so much of his time helping others, especially children through Barnardo's. He's a great inspiration; now he's been duly recognised for it."

Alan also plays Division 3 basketball with The Cardinals. He said: "It's a good club because of the 7-55 age-range. It's not just about basketball; any wheelchair-user who wants to try any sport can come along and we'll try and find funding for it."

Photo courtesy of Harrogate Advertiser

Five-star treatment

A LUXURIOUS cruise on a five-star floating hotel was where 19-year-old Robert Pollard spent his holiday this year.

He and his parents boarded the beautiful *Splendour of the Sea* at Barcelona, sailing to the South of France, three ports in Italy and Malta.

When booking, the travel agent found cruises with accessible facilities. Mr Pollard said: "We chose to go with Royal Caribbean because wheelchair access was very good and the time and destinations were right."

Robert, from Cornwall but now a student at Cheltenham's National Star Centre, gave the thumbs-up to life on board.

"Numerous lifts travelled the 11 decks, all the doors were wide, with many being automatic, and there was

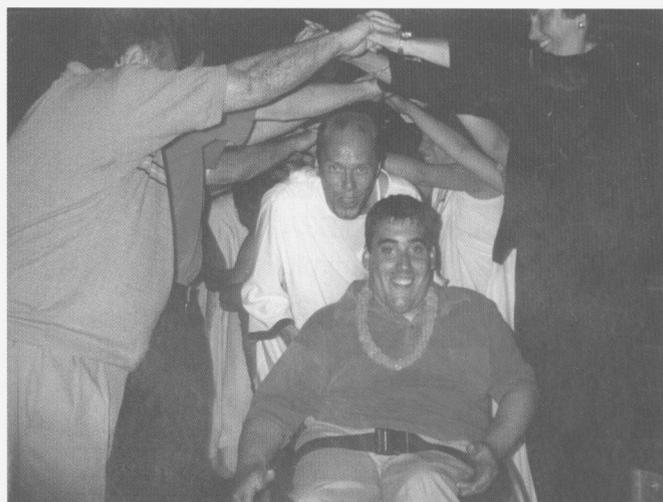
plenty of space throughout the ship.

"Even the pool on deck had a chair lift and ramp."

Food and drink were available all day and most of the night and Robert enjoyed the bingo, discos, evening shows and occasional drink in one of the numerous bars!

He said: "The staff were very friendly and helpful so I didn't depend on mum and dad for much on board. The food was excellent and there was plenty of it. Mum and dad enjoyed the formal dining room but I preferred the self-service restaurant."

A down side was the organised tours which were on inaccessible coaches. Robert and his parents wheeled and walked the shorter distances or took a taxi or train to see some of the sights.



Four new consumer guides

RICABILITY, an independent charity, has launched four new attractive consumer guides:

Car controls is based on a survey of more than 200 users of car controls and looks in depth at the types of adaptations available to help you drive if you have a disability (52 pages A4, cost: 87p in stamps).

Getting a wheelchair into a car gives comprehensive information about devices which help get a wheelchair into a car such as roof-top hoists, interior hoists, racks and trailers. (44 pages, A4, cost: 76p in stamps).

Ins and outs of choosing a car: a guide for older and disabled people is an advice guide on what to look for when choosing a car. It includes features that can help; tips on getting in and out of a car and ways of adapting a car to suit you. (52 pages A4, cost: 87p in stamps).

People lifters gives comprehensive information about the types of devices that help wheelchair-users get into a car. (32 pages A4, cost: 66p in stamps).

All Ricability guides are free except for a stamped addressed envelope to cover postage. Guides are also available in full on www.ricability.org.uk

● **To order a copy, please contact: Ricability, 30 Angel Gate, City Road, London EC1V 2PT. Tel: 020-7427 2460; textphone: 020-7427 2469.**

Family day in the Northern Region

A FAMILY Day in the Northern Region was hailed a success by the 13 families who attended.

Aiming for a wide appeal – parents/carers, disabled children/young people, their brothers and sisters, even grandparents – different programmes running at the same time gave something for everyone.

For the adults, it was a chance to meet with others, talk to ASBAH Advisers, find out more about hydrocephalus and spina bifida, and learn about their local ASBAHs.

There were discussions on medical matters, education, benefits, continence and



Ellie – what no toys!

looking after yourself.

A choice from pottery and food preparation, followed by a session on 'Living with hydrocephalus and/or spina bifida', was offered to the young people over nine years old.



Hannah & Millie – let's colour!



Claire entertaining Samuel with Daniel watching a video in the background.

For the 5–8-year-olds it was a fun day with a little bit of ‘work’ thrown in. There was a creche for the under-fours.

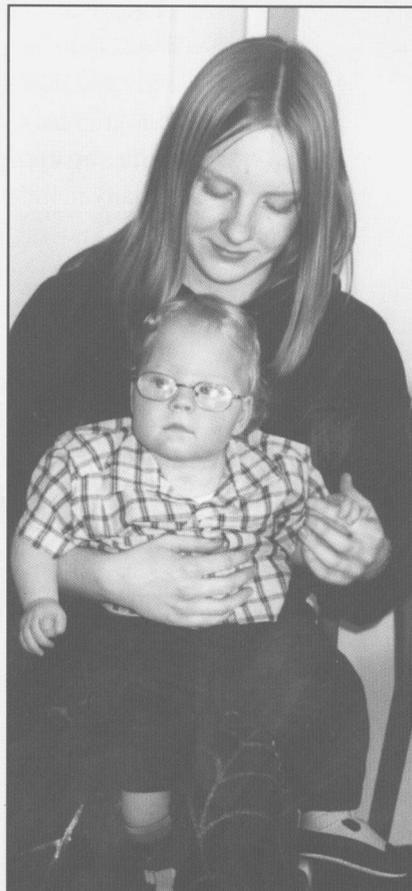
At the close of the day, children proudly displayed their collages, pictures and masks.

Organisers Bernadette Baldwin and Geraldine Binstead were delighted with the excellent service provided by the venue, Harrogate College, not least the donation of two tutors for the pottery and cookery sessions.

Bernadette, our West Yorkshire Adviser, said: “Parents said they found the day enjoyable and useful. There were plenty of questions and discussion during the talks and a good atmosphere during breaks. Some were keen to attend a future ASBAH Family Weekend. We’d like to run a similar day in another part of the Northern Region.”

Thanks to Leeds & Bradford ASBAH, Yorkshire North ASBAH, Harrogate College, the Benefits Centre in Leeds, The

Family Fund Trust, Bumbles Ltd and all the volunteers for their support.



Helen & Joshua watching the world go by!

DLA – does it support your needs?

ASBAH, in partnership with Headway, is carrying out a survey on the benefits system – focusing on Disability Living Allowance (DLA) to determine whether people affected by a brain injury, eg a traumatic brain injury or hydrocephalus, are receiving adequate support through DLA awards.

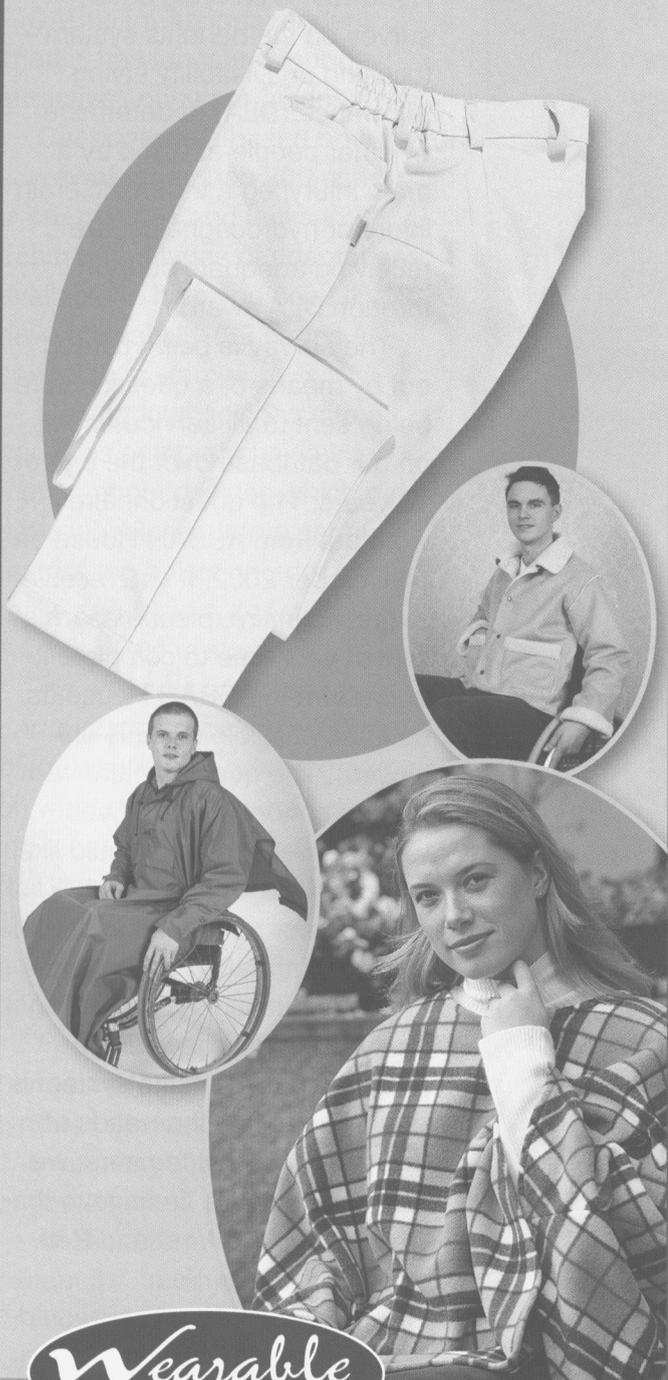
The survey is being carried out by means of a questionnaire being sent to all service-users on our database over the age of 18 years. The questionnaire went out from ASBAH House on 14 October 2002. If you receive a questionnaire, please spare a little of your time to complete it and return to ASBAH House as soon as possible (SAE is enclosed). The questionnaire can be done anonymously if you wish. However, if you would like a copy of the findings, we will require your name and address.

The information we obtain from this questionnaire will be analysed and if the findings prove that the benefits system is not fully meeting the needs of this group of service-users, we will present these findings to the Department for Work and Pensions in the New Year.

ASBAH and Headway would like to thank you for assisting in this survey and will keep you informed in future issues of *Link* of any progress made.

● **Contact: Mary Malcolm on 01733-555988 or email marym@asbah.org**

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Wearable recognises that people who require a shorter leg length also need a proportionate narrowing of the trouser leg, and the good news for readers of *Link* is that anyone ordering before **31 December** and quoting *Link 11/02* on the order form will receive this special cut at no extra charge.

Phone *Wearable* now for your free catalogue on 0141-774-9000.

BENDRIGG Trust is a residential activity centre, specialising in working with disabled people, located in 15 acres of grounds between the Lakes and Dales. There are two buildings, *Bendrigg Lodge*, fully accessible to wheelchair users (40 beds) and *Oakwood*, a self-contained annexe (20 beds).

Everyone welcomed, for a week or weekend, from schools, colleges, homes, hostels, clubs, hospitals, community and disability organisations. There is no age limit.

Programmes 'tailor-made' with a wide variety of activities eg climbing, abseiling, canoeing, caving, sailing and many more!

A team of qualified and experienced tutors are employed throughout the year to deliver the activities. *Bendrigg* is registered by the Adventure Activities Licensing Authority.

Contact: Jo Jolly, Bendrigg Trust, Old Hutton, Kendal, LA8 0NR. Tel: 01539-723 766, email: bendrigg@msn.com

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The inner self

Results of an ASBAH study into the psychological development and behaviour in middle childhood and adolescence

ASBAH funded a research team at the University of Southampton to find out the psychological development and behaviour associated with hydrocephalus and spina bifida in middle childhood and in adolescence.

The team were asked to investigate aspects of development that were known to be creating problems (for example, education) for young people and their families.

The work started in 1999 with a first phase study based on a questionnaire that was sent to families known to ASBAH. A total of 553 families with a child aged 6–12 years returned the forms and this has provided a large and rich set of data to start to examine the development of these children and the difficulties faced by parents.

The second phase of the work was to study in more depth a smaller group of children and their families. These were recruited mainly from Southampton and the surrounding areas but families as far away as Kent and Oxford were brought into the study. A total of 202 families took part. The age-range of participants was 6–18 years and they were given a variety of assessment tests (eg of their reading ability, of memory and of language development).

The parents were also interviewed about their child's development. We are enormously grateful to the families for making themselves available to us and for giving us their time. The

By
**Professor
Jim Stevenson
& Ineke Pit-ten Cate**
Dept of Psychology
University of
Southampton

second phase of the study included, for comparison purposes, children without either hydrocephalus or spina bifida.

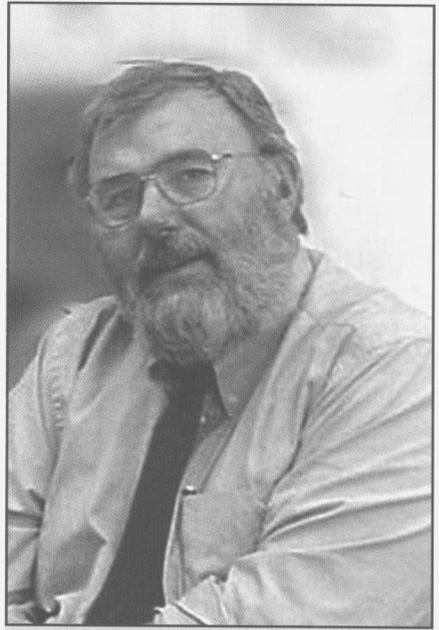
Some of these children were born prematurely (before 32 weeks gestation). Their inclusion allows us to separate the effect of hydrocephalus from premature birth in influencing the children's subsequent development. This is necessary since hydrocephalus is associated with premature birth (37% of our hydrocephalus children were premature – substantially more than in the general population).

The analysis of the data has started and the following provides some of the initial findings from the study. An overall picture is emerging that those children with hydrocephalus have more behavioural and educational difficulties than young people with spina bifida. Those with both spina bifida and hydrocephalus usually fell between the other groups in their level of difficulties. For example, in the questionnaire study we found that children with hydro



The Child Health and Development Study (CHADS) team, left to right: Teresa Rivers, Ineke Pit-ten Cate, Jane Wilkinson, Gemma Buckle, Jim Stevenson (Aine Fulcher not pictured)

Advertisement for
WEARABLE
wheelchair



Professor Jim Stevenson

The research team at the Centre for Research into Psychological Development, Department of Psychology, University of Southampton, was headed by Professor Jim Stevenson and the study was co-ordinated by Ineke Pit-ten Cate. The research team included Gemma Buckle, Jane Wilkinson and Aíne Fulcher with Teresa Rivers providing administrative support.

cephalus had more reading difficulties reported than children with spina bifida or with a combination of spina bifida and hydrocephalus. Difficulties with mathematics at school showed an even stronger association with hydrocephalus. These results are given in Table 1.

In the second phase study we

hydrocephalus children are higher than for the prematurely born children.

More extensive analysis found that the other most important feature of the behaviour of children with hydrocephalus is the extent of problems with peer relationships. One of the factors contributing to problems with

Table 1 – Parent reported educational difficulties by type of disability and sex of child

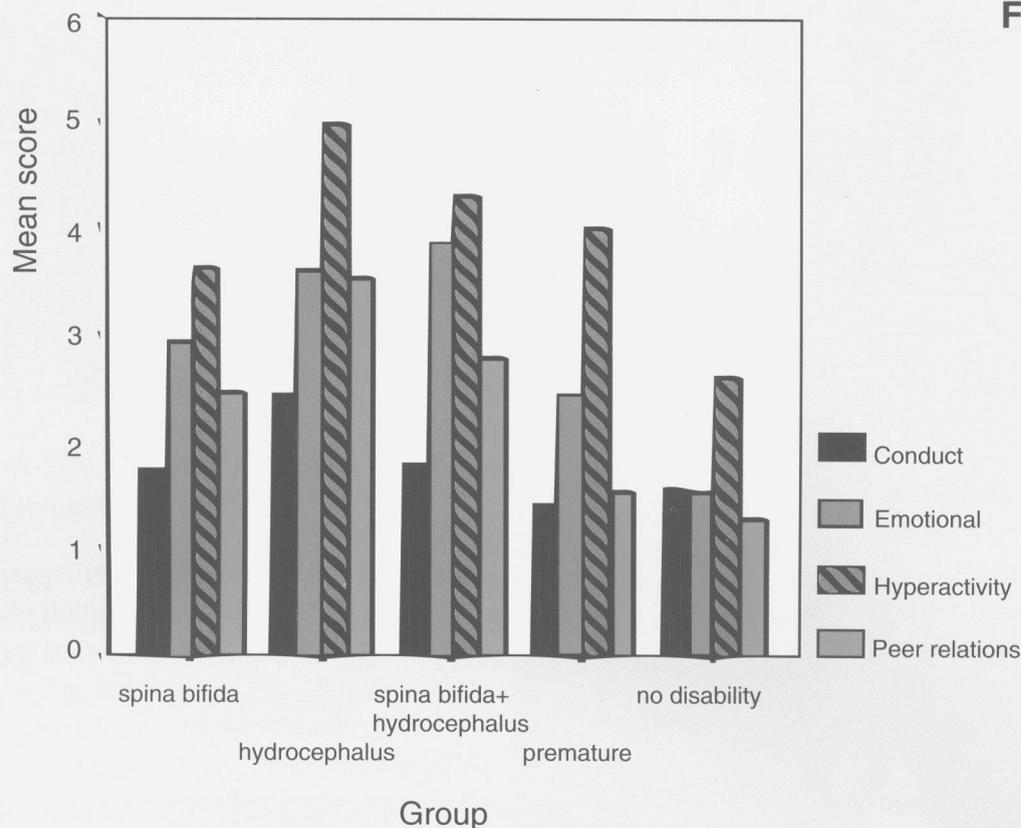
	Percentage with difficulties:			
	in reading		in mathematics	
	Boys	Girls	Boys	Girls
Spina bifida (n = 61)	36	9	30	23
Hydrocephalus (n = 345)	49	46	67	66
SB and H (n = 127)	27	28	61	62

were able to use information from teachers and parents to see how many children had problems of sufficient severity to warrant a diagnosis of a mental health problem. Most children with hydrocephalus do not have such a severe problem, however the rate (33%) is about twice that in the group without a disability (18%). The type of problem experienced is illustrated in Figure 1. This graph presents behaviour scores which are based on parents' reports and show that on average the children with hydrocephalus showed higher levels of hyperactivity (a behaviour style that includes inattention, impulsivity and overactivity). This was not just a result of prematurity since the hyperactivity scores for the

peer relations was that children with hydrocephalus often failed to understand how other people were feeling or that other people may have views and beliefs that were different from those of the child itself. We found that behaviour problems were one of the main burdens on the families.

Although the emphasis in this article is on the problems faced by the children and their families, our research also investigated positive aspects. We were struck by the number of families that readily identified positive gains arising from parenting a child with a disability. Ineke Pit-ten Cate is taking this issue further in her doctoral research in families with children with chronic illnesses as well as disabilities.

Figure 1



Scores on four aspects of behaviour group (high score indicates more problems):

Conduct – aggression, lying, disobedience.

Emotional – fears, anxiety, depression.

Hyperactivity – inattention, impulsiveness, overactivity.

Peer relations – being bullied, no friends, bullies others.

Guidelines for parents

THE researchers came up with the following guidelines for parents after examining the results of their studies:

- Hydrocephalus is associated with an increased rate of hyperactivity and peer problems.

- These children may need to be helped in their relationships with other children especially close friendships. They need to learn to understand that other children may have different wishes, beliefs and attitudes from themselves.

- Both the difficulties they have in schoolwork and their hyperactive behaviour may result from problems in sustaining attention and in retaining information. Help with these problems would include strategies such as breaking tasks down into smaller parts and writing down information at intermediate steps.

- Bear in mind that the difficulties these

children have may stem from the impact of hydrocephalus on brain development and is not just the child being naughty or their psychological reaction to having a disability. Bring this to the attention of others such as teachers.

- There is no indication that any of the four behaviours in **Figure 1** become more or less marked with age. Children with hydrocephalus show less of a decline with age in the level of hyperactivity than children in the general population. These are not problems that go away as the children get older.

- There are effective treatments for both hyperactivity and peer relationship problems. If you think either of these aspects of behaviour is creating important difficulties for your child, then seek help from an educational psychologist, for example via the education service, or from a clinical psychologist or child psychiatrist via your GP.

fundraising

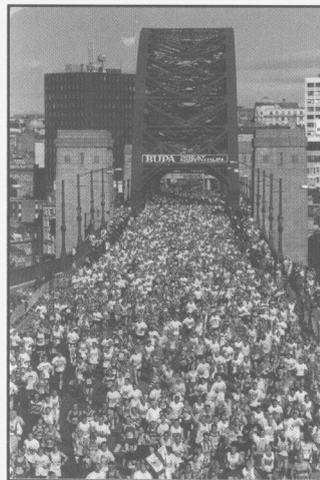
The Great North – we were in the running

THE largest half-marathon in the world – and perhaps one of the most challenging – got off to a slightly breezy but bright start as 42,000 competitors prepared for the off.

In its 21st year, the BUPA Great North Run, from Newcastle-upon-Tyne to the coast at South Shields, was bigger than ever. There was a great atmosphere and plenty of support along the 13-mile route.

The 14 entrants who ran for ASBAH were joined by Sir Jimmy Savile, Frank Bruno, the cast of Emmerdale and chef Gordon Ramsay.

Some competitors chose to run in fancy dress which very much



enlivened the day for spectators. There were bunny girls, fairies, Batman, Elvis, pirates, cheeses, a house, a giraffe, a tap, a dog, a cavewoman and a camel.

All successful competitors received a goody bag, the very important medal and

t-shirt, plus small can of footspray.

It all ended with a wonderful aerobatics display by the Red Arrows at the end of the race, which followed their fly-past at the start in Newcastle.

Congratulations to ASBAH runners:

- Bernadette Baldwin, ASBAH Adviser, ASBAH North.
- Paul Gerrard, Northendon, Cheshire.
- George and Terry Sixsmith, Cramlington, Northumberland.
- Wendy Winterbottom, Keighley, West Yorkshire.
- Annie Huang, Stockport, Cheshire.
- Allan Hughes, Manchester.
- Peter Ogden-Smith, Stockport, Cheshire.
- Dianna Capstick, Clapham, Lancaster.
- Joanna Mitcham, Kendal, Cumbria.
- Sue Hotton, Lancaster.
- Ross West, March, Cambridgeshire.
- Anthony Ng, Peterborough.
- Brian Baker, Chippenham, Wiltshire.
- Andrew Wright, Stilton, Cambridgeshire.



Annie Huang, Peter Ogden-Smith and Allan Hughes were among 14 ASBAH entries in the Great North Run



Luke's reward is shared all round

NINE-year-old Luke Bartlett shared his reward for good behaviour with all the children at his village school when he suggested a non-uniform day for ASBAH.

On gaining five merit marks for good behaviour, Luke didn't go for the usual treats – use of a computer for the afternoon, pretending to be the teacher, or a bike ride with a teacher. He wanted to do something for ASBAH.

The 170 or so pupils of Ysgol Felinheli paid 50p for the privilege of wearing their own choice of clothes, and a marvellous £74 was raised for ASBAH in Wales.

Luke's mum, Jill, who is an ASBAH Adviser, said: "It was at the time when the redundancies were hanging over us all."

Luke was delighted with the certificate and t-shirt which he received as a thank-you.

There's no stopping her!

HAVING an arm in plaster didn't stop young Carly Williams completing a half-mile run for ASBAH.

Carly, who has hydrocephalus ran with her dad, Wayne, in Southsea, two weeks before her eighth birthday. And she raised a wonderful £135 for ASBAH.

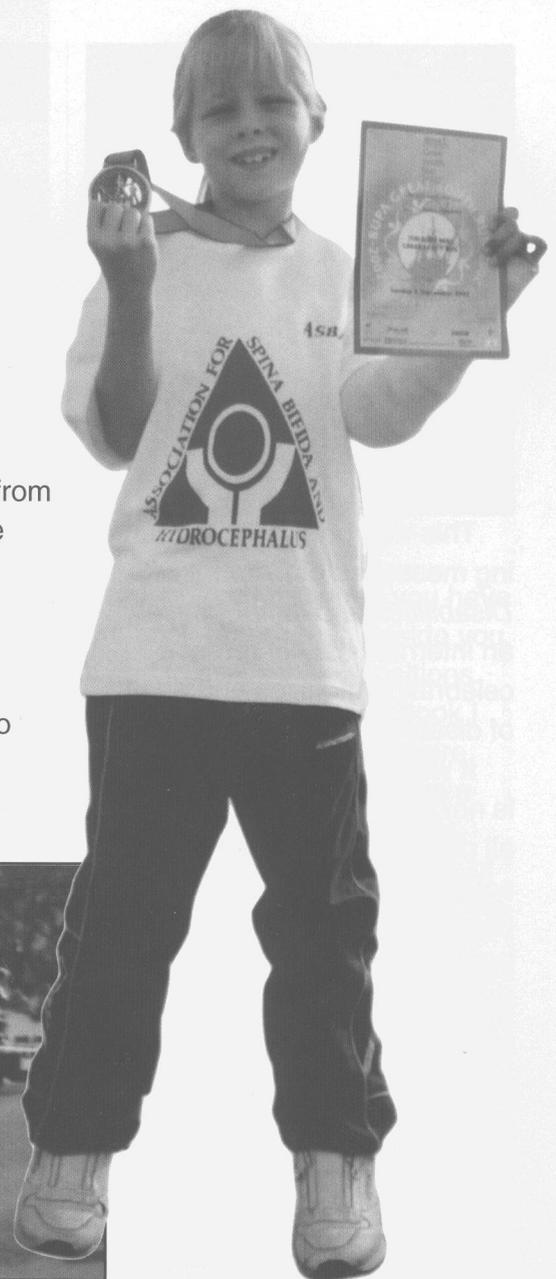
Although her knees hurt towards the end, Carly, of Portsmouth, enjoyed the challenge as she has a keen competitive spirit.

Her mum, Jayne Archer, said: "Carly likes sport and we wanted to

give something back to ASBAH as we have received great support and help from your Advisers Liz Clayton and Caroline Cashman.

"Carly was really pleased with the certificate she received from ASBAH's fundraising department. She was so excited, she took it to school to show to everyone there."

Carly with her dad Wayne Williams



Lycra boys do it again!

A CYCLING trio, led by ASBAH events fundraiser, Ian Morley, did us proud when they completed a 75-mile sponsored cycle ride.

Ian was joined by Brian Campbell and his neighbour Austin Goldsmith. It was the third time Ian had organised a sponsored cycle ride for ASBAH.

The boys pedalled

north of Peterborough, did a circuit of Rutland Water, before heading home. Their 'megacycle' lasted six hours and 50 minutes.

Collecting armfuls of sponsors before they left, the trio are now on course to raising £1,000 for ASBAH.

Congratulations and a big thank-you to all three.



As parents, we need others

MOST parents can be caring and competent if they live in a caring and competent environment, with adequate social links, networks and resources that can support them in times of difficulty as well as reinforcing their success in good times.

This was one of the resounding messages of *Parents with Disabilities and their Families*, an international conference celebrating the lives and rights of disabled parents.

It was stressed that parenting is not an independent function – all parents depend heavily on sources of support, and parenting is characterised not by independence, but by interdependence. Disabled parents may be judged 'incompetent' when these structures are not present, with the perceived 'failure' being put down to their particular characteristics rather than the lack of social supports, financial disadvantage, system discrimination, etc.

As traditional networks of family and community support for parenting become weaker whilst bioethics confronts us with new questions about what a parent is and does, the disability community needs to share what it knows about accepting a whole range of experiences and valuing interdependence.

The conference, in California, was organised by Through the Looking Glass (TLG), www.lookingglass.org

● *Based on an article from Disability, Pregnancy & Parenthood interational (DPPI), www.dppei.org.uk*

Upcoming events

Well Away, Again, N Ireland

16–17 November

An ASBAH residential with a creative challenge for 11–16-year-olds. Transport provided from Londonderry to the venue at Ballinran, Kilkeel. Funded by Right Fit – a Barnardo's/Glaxo/Smith-Kline initiative – the cost will be £10. **Tel: ASBAH Northern Ireland, 028-9079 8878 or email: niro@asbah.org**

ASBAH Feel-Good Weekend, Llandudno

22–24 November

If you're 18 or over and have SB or H, brighten up your November and get in the mood for Christmas at West Shore Hotel. Shopping, makeovers, bowling, nightlife, alternative therapies, cinema, relaxation. £50 for the weekend. Accessible transport may be possible from some areas. **Details: Marcia Conroy 01928-779784; Angela Lansley 0151-733 8392 or Elizabeth Miers 01490-450360.**

NHS conference, London Friday 29 November

Involving Patients and the Public in the NHS, organised by the Socialist Health Association, at London Voluntary Sector Resource Centre, 356 Holloway Road, London

dates for y

N7 6PA. Opportunity to consider the implications of the establishment of patients' forums, overview and scrutiny committees, the commission for patient and public involvement in health and patients advocacy and liaison services. Speakers include: Pam Ashton, Health for All; David Gilbert, head of patient and public involvement at the Commission for Health Improvement. Cost: £20 concessions. **Details: Martin Rathfelder, Socialist Health Association, 0870-013 0065 or email: admin@sochealth.co.uk**

Truro basketball Sunday 1 December

Basketball session on the first Sunday of the month for teenagers with SB/H run by ASBAH's Cornwall Adviser, Lynne Young. 11am–1pm, Truro Sports Hall. **Details: 01726-861 062.**

Carers' awareness day, London

Wednesday 3 December
Carers' Rights Day to raise awareness of the benefits carers can claim. Organised by Carers UK and co-ordinated under the umbrella of the Fair Deal for Carers campaign. **Details: Carers UK, 20-25 Glasshouse Yard, London EC1A 4JT or email policy@ukcarers.org**

Northern Region drop-in, Leeds

Wednesday 11 December
Regular drop-in at ASBAH's Northern Regional Office from 10–12. **Details: 0113-255 6767.**

2003

**Northern Region drop-in
Wednesday 8 January 2003**
Regular drop-in at ASBAH's
Northern Regional Office from
10–12. **Details: 0113-255
6767.**

**Wheelie Club, Belfast
Saturday 18 January**
Opportunity for young people
to improve their wheelchair
skills at McKinney Hall,
Musgrave Park Hospital,
Belfast. Three groups: Wheelie
Kids (10–11.30am); Speedy
Wheelers (11.30–1pm) and
Wheelie Power (2–3.30pm).
Free maintenance by Gerald
Simonds Healthcare Ltd.
**Details: ASBAH Northern
Ireland, tel: 028-9079 8878;
email: niro@asbah.org**

**Northern Region drop-in
Wednesday 5 February**
Regular drop-in at ASBAH's
Northern Regional Office from
10–12. **Tel: 0113-255 6767.**

**ASBAH Family Weekend,
Cornwall
Fri 7 – Sun 9 March 2003**
A residential weekend for
families with a child aged six
and under with hydrocephalus
and/or spina bifida and their
brothers and sisters. Cost: £65
per family; sponsored by BBC
Children In Need Appeal.
Deadline for receipt of applica-
tions: 13 January. **Further
details and application forms
from: Rosemary Batchelor,
ASBAH, 01733-555988;
rosemaryb@asbah.org**

Book review

Yoga for energy

By Valerie Bottoms

AS a complementary therapist, I had been intrigued for some time by the principles of yoga and fascinated by the benefits it could bring. Unfortunately, any efforts I have made to join a class and find out more had always been thwarted.

September arrived and I finally found a yoga class that was being held locally and on a day I could attend!

Just before the first class, ASBAH contacted me and asked if I was interested in reviewing a book called *Yoga for Energy* by Alistair Livingstone. This was definitely the right time for my introduction to yoga.

The book is relatively small in size and consists of only 72 pages but don't be put off by this.

Yoga for Energy gives a good clear introduction to the principles of yoga and although subjects such as the chakras are covered only briefly it gives sufficient information to introduce a newcomer to yoga.

The information the book contains is clear and concise. The pages that show the asanas (exercises) have clear sequential pictures demonstrating how to do each one.

One thing very different about this publication is the large size of the print that accompanies each exercise. At first it is rather reminiscent of reading a young child's book. You soon, however, appreciate the clear, easily read font and the easy to follow bullet



point instructions when you have the book propped up beside you trying to practise the positions.

The only parts of the book I found slightly frustrating were the small sections of text on a few pages that are printed at right angles to the main body of text. This looks very good for the layout of a page but is not so easy to read.

Alistair does say in his introduction that the best way to learn yoga is from an experienced teacher or yoga therapist and having now attended my first few classes I would agree. I can, however, highly recommend this book as both an introduction and an aid to refresh your memory when you practise your yoga at home as you cannot possibly remember all the details of each exercise after a class.

The title of the book, *Yoga for Energy*, is very accurate. You really do feel energised after doing yoga and I would recommend that everyone should give it a try, as it is something that can be adapted to suit any age and any ability. This book is a very good introduction to yoga.

● **Yoga for Energy by
Alistair Livingstone, £7.99,
Duncan Baird Publishers,
ISBN 1-900131-74-9.**



DAVE'S DIARY

david.fulford-brown@ntlworld.com

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PPRIDE goes before a fall. So apparently does smugness. Last issue I wrote that nothing different ever happens when I go to the opticians or to Sheffield for check-ups. *This* time around I was told that there's a small 'something' in my eye, my wee is more alkaline than a Duracell battery and my blood pressure is 'up'. What does any of that mean? I don't know. But it's definitely time for a break. Being a dedicated worker is one thing. But you are no use to anyone if you end up leaving work in an ambulance.

I go on holiday five days and six hours from now – or as my boss worked out, a week just before our annual conference. Telling my boss I needed that week off didn't do much for *his* blood pressure!

This year, my friends Tan and Stu invited me to go on holiday with them, but I'd just booked my ticket to fly to France with my family.

Going on holiday with my friends would have been interesting because apart from a

few outward bound courses as a kid, almost every holiday I've ever taken has been with the family. Which is good, but it would be interesting to do my own thing some time, without the family. I'm not saying I'd go on a wild fortnight of sex, booze and loud music in Ibiza. Well, mostly not. But being in a family holiday *does* rather squash the chance of holiday romance.

Then again, holidaying with a disability can end up raising your blood pressure. Travelling with the family means they help sort the problems. They've had a fair bit of practice dealing with idiot officials and generally organising all the stuff that needs thinking about. Like, if I need my EU-wide Blue Badge to park in the disabled section at the airport, what do I use in France? How do I get around the airports? Will the airline let me sit with my family?

(Do a few drinks on the plane really make me a 'fire hazard'?) Can we rent a wheelchair/scooter there? Is the hotel accessible? What about a hatch-backed hire car? The list goes on!

These days I try to sort some of this stuff for myself. I get more of a say in how we do things, but it also means doing stuff I've never done before, like organising wheels.

I was surprised to learn that the big companies will now rent cars with right or left hand controls. I thought I'd do the driving in France but Mum wasn't keen on the idea. It may have been the five years since I last drove, the way I used to drive, or the thought of her spending the whole holiday screaming 'Right, David. Drive on the right!' but Mum went very pale. Perhaps she needs her blood pressure checking?

No charge for disabled people

BLUE Badge holders will be exempt from congestion charging in central London – but will have to register in advance.

When the toll comes into effect, in early 2003, all other motorists entering the heart of London will have to pay a £5 daily charge.

However, if you are a Badge holder, you do need to register in advance. Transport for London is encouraging disabled drivers to register early. You will be asked to make a one-off payment of £10 to cover administration.

Disabled passenger-carrying vehicles and vehicles used by disabled people, which are automatically exempt from Road Tax, are exempt from Congestion Charging and do not need to register.

● **To receive a registration pack, write your name, address and Blue Badge serial number on a postcard and send it to: Blue Badge Congestion Charge, Dept TR121, FREEPOST SWC 1539, PO Box 35, Leominster HR6 0ZZ.**

Advert rates

- 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* (January) should be submitted by Friday, 29 November.

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

- Display advertising:
Tracey Coe
Park Lane Publishing
Tel: 0113-281 9900

FOR SALE

- **MOBILITY** scooter with roof, excellent condition, £400 ono.

Contact: Martyn, tel: 01733 555988 (Peterborough).

RGK Titan – high performance, ultra lightweight, titanium wheelchair. 14 x 14" seat. Cost around £1,600 (1994). Upholstery needs replacing. Free. **Inquiries to ASBAH North, tel: 0113-255 6767; email: joanp@asbah.org**

Used equipment advertised in Link must be bought as seen – ASBAH cannot be held responsible for any fault or injury caused after purchase.

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.

Tell Ben more about strata valves

I WOULD like to talk to people who have a strata valve as there is a possibility that I might need one in the near future.

I received some very useful information by email from ASBAH but would like to talk to someone to find out what having a strata valve is like.

I currently have a programmable valve and I'd like to find out if a strata valve is better than the programmable valve.

Please email me or write to me c/o *Link* and your letters will be forwarded to me.

Ben Edwards

benevis200@hotmail.com

Editor's note: *The Strata valve is relatively new. It is a programmable shunt that does not need an x-ray to check the setting, unlike other programmable shunts.*

Calling all North-East London service-users

A NEW support group is on the cards for service-users in North-East London if there is sufficient demand for it.

Jason Clark (36) wants to hear from people with spina bifida and/or hydrocephalus in this part of London to take his plans for a support group forward.

There have been no local ASBAHs in North or East London for some years as both were wound-up.

Jason, of Stratford, hopes the new group will have a social element, as well as having meetings to share experiences and offer mutual support.

He said: "I am aiming the group at everyone – parents and people with the conditions – I don't want to exclude anyone.

"We all feel vulnerable and isolated at times and the group will give people the chance to talk things through with like-minded people."

● **If you are interested, please call Jason on 0208-257 7134.**

Euro day

GET involved in the European Day of Disabled People on 3 December – and the run-up to the European Year of People With Disabilities 2003 – from the comfort of your own home by logging on to www.eddp.org/eddp/index_2.html

The site includes a discussion forum and an art competition for 10–15-year-olds.

holiday lets

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

HERNE, KENT

Self-catering bungalows equipped with electric hoist, overhead tracking, Hi/Lo bed, roll-in shower and full inventory. Centrally heated. Situated in the parkland grounds of Strode Park, Herne, Kent. OPEN ALL YEAR. £105 for a weekend break to £400 per week high season fully inclusive. *Brochure: Dept L, Strode Park Foundation, Herne CT6 7NE. Telephone: 01227-373292; fax: 01227-742805 or email info@strodepark.org.uk*

TRENERRY LODGE, ST AGNES, CORNWALL

New for 2002. Bungalow on farm, centrally situated for visits to all of Cornwall. Fully equipped and designed for wheelchair access. Large patio and garden, 2-bedroom, WC and shower room. Sleeps 4-6. Open all year. Home from Home. Green fields and Areas of Outstanding Natural Beauty. *Phone or fax for details: 01872-553755 (Mrs A Parsons).*

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*

NAISH HOLIDAY VILLAGE, NEW MILTON –

Clifftop park with “excellent” status at New Milton, Hampshire. Excellent site facilities within 100 yards, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible log cabin accommodation. Sleeps six, well-furnished. Free club membership.

GRANGE COURT HOLIDAY VILLAGE –

Park with “good” status at Goodrington Sands, Devon. Excellent site facilities within short walk, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible,

mobile home. Sleeps 4-6, well-appointed. Free club membership. (Purchased with funds from the National Lottery).

MILLENDREATH HOLIDAY VILLAGE –

Excellent seaside site with good facilities, just outside Looe in Cornwall. Restaurant, clubhouse, indoor pool. Fully-equipped, and fully wheelchair accessible, two bedroom chalet accommodation. Sleeps six – well-furnished and comfortable.

Details: Mr P Cash, tel: 01425-672055, email:

petercash1@compuserve.com

Bournemouth Spina Bifida Association, registered charity number 261914.

holiday lets abroad

TORREVIEJA, SPAIN

Fully furnished wheelchair accessible 3-bed 2-bathroom apartment. Will sleep up to 8 people. Shops, town centre, medical unit, beach etc all within 10-minute walk. Quiet family location. Ideal for group holidays. Available all year. Rates are £250-£400 per week. October til March £550 per calendar month. *For further details/bookings, contact Julie on 0775-3684708 or Pete on 0780-3614770.*

ORLANDO, FLORIDA

3, 4 & 5 bedroom luxury villas, all wheelchair accessible. All villas are within 20 minutes of Disney and all have private screened pools. Flights and specialist car hire can be

arranged. *For more information contact David or Elaine Foley, tel: 0191-488 6845 or check out our website on www.florida-dream.co.uk*

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

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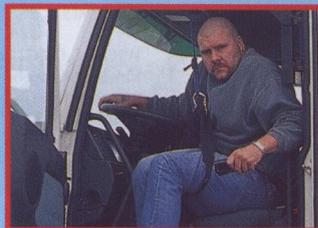
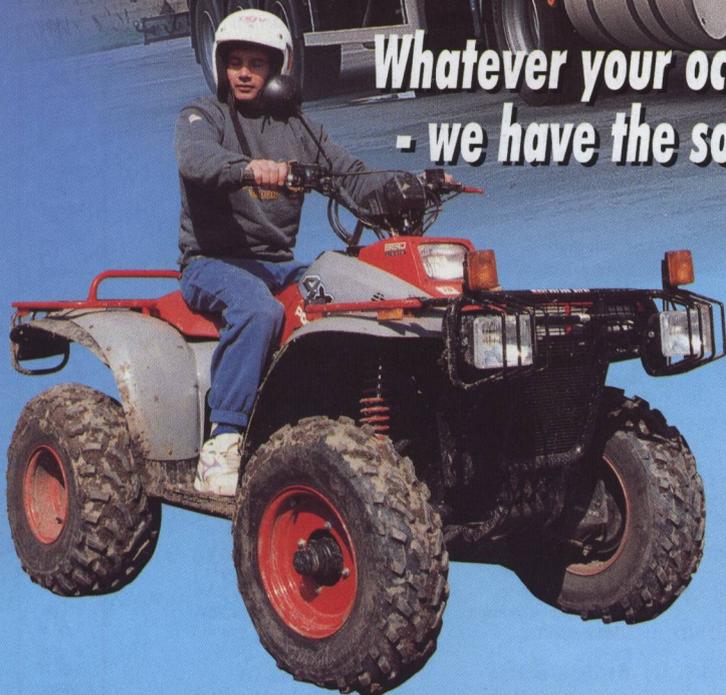
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Association secretaries requiring changes to this list should contact: **LINK EDITOR, ASBAH, 42 PARK ROAD, PETERBOROUGH PE1 2UQ Tel: 01733-555988 Fax: 01733-555985.**

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Our workshop has converted everything - from a lawnmower, through all types of cars, vans and commercial transport, up to the largest heavy plant machinery. KC Mobility Services Limited are a UK market leader in special vehicle conversions for disabled people. We work on a huge, ever-expanding range of vehicles and equipment and no request is outside our range of experience. Call us now for full details about our **Working Vehicle Conversions** and the latest price list. Assessments and demonstrations here at KC House are free.

KC MOBILITY SERVICES LIMITED



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The Complete Conversion Specialists - Creating Independence for Disabled People