AUTUMN 2005 ISSUE 214

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LiNK

The magazine for people with hydrocephalus and spina bifida

Rupert steps back into the past

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

Allied Vehicles advert to follow
(Warners to insert)

Peter Farrall writes

This issue of *Link* – the last for 2005 – is a real mixed bag and we hope that there's something of interest for you all.

Teenagers will pick up some useful information about what to consider when applying to university from our interview with third year student Joanna Clyne, page 18.

For sporty types we've two mammoth cycle ride experiences, plus Ste Hunt's foray into Europe with the Mencap and Gateway England squad.

Local association news comes in the shape of a feature about the hard working Surrey association, plus an interview with Sharon Lapsley, the new part-time adviser for Northamptonshire.

As well as news of some of ASBAH's fundraisers, we've a full medical section, with the Research Society's visit to Barcelona (page 26) and a look at Dandy Walker Syndrome.

Carsten Wikkelsø, Professor of Neurology, Göteborg University in Sweden, reviews the new Normal Pressure Hydrocephalus CD rom, which was launched at the UK Clinical Neurosciences conference in Torquay recently.

So all in all it's a packed issue.

As always, please do keep sending in your stories, pictures and letters, we do value your contributions and comments.

Best wishes,
Peter

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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

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2. How quickly was the Hydrocephalus diagnosed?
3. Had you heard of the condition before diagnosis?
4. How was the hydrocephalus treated?
5. Did you recover from the operation quite quickly?
6. Was a programmable/adjustable shunt fitted?
7. Do you understand how the pressure can be changed?
8. Did anyone talk about taking care around magnets?
9. Can you tell if the shunt isn't working properly?
10. Do you have "open door" access to a neurosurgeon or neurosurgical unit?
11. Do you have a shunt alert card?

Please select a question to be answered from above and then select a highlighted person from the right to answer it.

Profile - Bob Simons from Burgh Le Marsh, Skegness.
Bob's wife Wendy was diagnosed with NPH in 2001.

Gymnast Gareth

As any mother knows to her cost, if she wants a quieter home life the children need to burn off their excess energy.

But in many areas of the country the range of sports activities for young disabled children can be very limited.

So ASBAH trustee Nici Picken breathed a sigh of relief when she saw a gymnastics club offering a new class for disabled children opening in her area.

Her 6 year old son Gareth, who has spina bifida and hydrocephalus, was already swimming every week , but Nici was keen to see him take up other forms of exercise to develop his muscles and keep his joints supple.

Two years on, Gareth, who is a wheelchair user, is in the mainstream class and is taking part in a national "Gymstrada" event in Brentwood, Essex. He is working with 38 able bodied gymnasts to produce a routine to "War of the Worlds".

Since his time with the Rowan Gymnastics Club in his home town of Cheltenham, Gareth has worked to perfect his forward and back rolls, balance work on the beam and rhythmic gymnastics.

> **It has given Gareth a real sense of purpose and a chance to channel his energy.**

Nici said: "The club has been fantastic for him. It has given Gareth a real sense of purpose and a chance to channel his energy. At the moment he is more confident at gym than many of the other children in his class at the mainstream school he attends.

"The club coaches, Dave Powell and Dawn Ellis have made the classes and apparatus accessible whilst not compromising their high expectations of achievement. The class is very structured and forces Gareth to be more disciplined as he learns to work as part of a team."

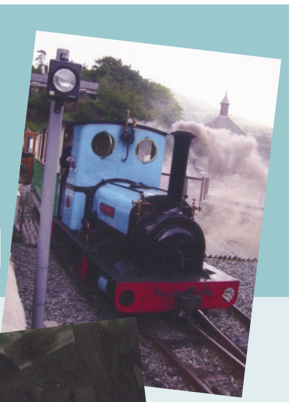
Nici added that Gareth loves his food, and although he eats healthily, he needs to do a lot of exercise to prevent the pounds piling on.

"I'm also a firm believer that all children should have the opportunity to enjoy different forms of exercise to keep their muscles working," she said. "If muscles aren't used, they eventually turn into fibrous tissue."

Now the family are eagerly awaiting the "Gymstrada" to see Gareth show off his talents.

"We're all very proud of Gareth and the coaches." Nici added, "They have all been brave enough to have a go when many haven't dared.

FUN FOR ALL



Even bad weather couldn't stop the third annual North Wales Summer Day Out from taking place this summer at Llanberis Lake Railway, Gwynedd.

The group enjoyed a trip on the narrow gauge steam train, which took them along the 2 and a half mile route along the shore of Llyn (Lake) Padarn, through Padarn Country Park, with some spectacular scenery to admire along the way.

The day was entirely funded by the North Wales ASBAH local association, and area adviser Jill Bartlett, said, "We were expecting about 22 people on the day, but due to a bad storm on the morning, only 8 of us went! Even so we all had a good day and the rain cleared up".

Jess, you shall go to the ball

A fairy godmother came to the rescue when teenager Jessica Hackney needed a dress to go to the ball.

Jessica, 16, had just finished her GCSEs at Heanor Gate Science College and couldn't wait for the school ball at Pride Park in nearby Derby.

But Jessica, who has spina bifida and hydrocephalus, had problems finding a suitable dress for the big occasion.

Her mother Kay Hallam, contacted ASBAH's Derbyshire local association to see if they could recommend any local dressmakers.

Kay explained: "It is very difficult to find a dress for Jess because they don't fit very well and it is difficult for Jess to try them on. Having fittings also takes a lot of time because Jess isn't able to stand, so it takes a lot of manoeuvring. She also knew exactly what style she wanted too."

Luckily committee member Jane Bridges is a talented seamstress so she created the dress of Jess's dreams in time for the ball.

Derbyshire ASBAH generously paid for the fabric and Jane's time, and also gave Jess £25 to buy accessories to match.

Kay said: "Jane was wonderful with Jess, very patient and sensitive to her needs. We are very grateful to her and ASBAH for all their help. The dress was beautiful and Jess had a lovely time at the ball."

Jane Bridges, whose daughter Amy, 12, has hydrocephalus, said she was delighted to be able to help.

"I was really pleased with the way the dress turned out," she said. "I'm just glad I could use my skills to help."

Model role for Sam

A young *Link* reader has starred in a book designed to help primary age children learn more about wheelchair users.

Photograph courtesy of Gareth Boden

Sam Lawton, 13, who has spina bifida, was photographed in a series of real life situations for the *Sam Uses a Wheelchair* book published by Evans Brothers.

The 32-page book by Jillian Powell is on the shelves of many schools and libraries across the UK, and is also available in many other parts of Europe, New Zealand, Canada and America.

It is part of the *Like You, Like Me* series, which focuses on various disabilities and medical conditions. The series aims to help 6-10 year old children understand that although their friends may be restricted by their disability or condition, they live active lives.

Sam, from Tamworth, was pictured with best friend Hannah and sister Kathryn, 11, in a variety of everyday situations, from wheelchair racing and making pizzas, to playing together at home.

Mum Therese said: "We were approached by the publishers through the Association of Wheelchair Children, which has run several courses which Sam has attended.

Rupert the Roman

Cover story

Rupert Jones stepped back into the past when the *Time Team* descended on his home town.

Rupert, along with dozens of other locals in Ffrith, near Wrexham, was enthralled as the archaeologists began their three-day mission to find Roman remains.

Local schools were given guided tours and learned about the equipment used to delve into the town's history.

The visit, due to be screened early next year, saw the *Time Team* – headed by Tony Robinson – poke and prod their way through a playing field, pub car park and residents' gardens.

Six-year-old Rupert, who has spina bifida, even dressed to look the part when the BBC film crew arrived.

Mother Louise told *Link*: "The Time Team were working just a few doors down from us so I took Rupert and my other son Harvey, who is 10, to have a look.

"The dig really captured the boy's imaginations. We live in a quiet village so it was very exciting for them to see film crews too. Everyone was very friendly and chatty, so the boys thoroughly enjoyed themselves."

Photograph courtesy of North Wales Newspapers

Meet Sharon – new adviser for Northamptonshire

Tireless team work by NASBAH and the Eastern Region office was finally rewarded in June when Sharon Lapsley was appointed new part-time regional adviser.

Much-needed funding – worth £50,000 - was agreed by Northamptonshire County Council (NCC) in March and will pay for the position for three years.

Sharon, who joined the ASBAH team in June, has had a busy few months meeting colleagues and families in her area.

She told *Link*: "I spent the first couple of months on induction. I've met all the advisers in the Eastern Region where I'm based and I've been on several training courses."

Sharon, who previously worked at a Mencap residential home, added: "I've already met quite a few individual clients and in the next few weeks I'm meeting groups of nursery and primary school teachers. There's a lot to take in but I'm really enjoying the work."

The Strategic Funding award came as welcome news as the area has been without a permanent adviser since 2001.

NCC did fund a part-time post from March 2004 for 12 months, and the position was shared by Linda Knight and John Richards, who already cover the Hertfordshire, Lincolnshire, Bedfordshire and Milton Keynes areas.

David Isom, manager of the Eastern Region, said: "We are thrilled to have been granted the funding from Northamptonshire County Council and welcome Sharon as our new adviser for the county. She will make a huge difference to the service we can provide."

Maggie Nichols, NASBAH secretary, told *Link*: "The award came as wonderful news and we were delighted to welcome Sharon to the area.

"John and Linda did a fantastic job last year, but it is wonderful to have a dedicated adviser for the county."

ASBAH on show at Eisteddfod

ASBAH's services in Wales were introduced to the hundreds of visitors to the National Eisteddfod festival in Wales.

Welsh singer and comedian Dewi Pws meets adviser Jill Bartlett

The popular event, which dates back to 1176, was held this year in the splendor of the Faenol estate at Felinheli, just half an hour away from the ASBAH office in Bangor.

Wales manager, Elin Ifan and secretary, Maria Morris took the chance to join 350 other exhibitors to have a stand at the eight-day event in August.

The National Eisteddfod is the biggest traveling festival in Europe for drama as well as arts and literature and music, with concerts and competitions held in the pavilions. Outside, the Eisteddfod field buzzed with a variety of activities ranging from food to football.

The ASBAH team, which included advisers Jill Bartlett and Margaret Stanton, manned the stand for four days, providing information and advice, as well as giving out pens to visitors.

Maria said: "As this year's National Eisteddfod was held so close to our office, we thought it would be the perfect place to have a stand.

"We got a good response and gave information to a large number of visitors. The event certainly proved to be very useful for us, in publicising ASBAH."

Two awards for Lizzie

Young Lizzie Price from Newtown, Powys has always been a keen swimmer, but she recently added another sporting triumph to her list of achievements.

Lizzie, 9, picked up Level 5 and 6 certificates in the British Gymnastics Proficiency Awards.

She took up the new hobby last September at a school club, fitting it in between three swimming sessions each week.

Her physiotherapist adapted the exercises so Lizzie, who has spina bifida and hydrocephalus, could stick as closely as possible to the gymnastics curriculum.

Lizzie, who uses a wheelchair, worked hard to master the exercises, and was thrilled to achieve Levels 5 and 6.

Mother Angela said: "Lizzie is always determined to keep up with her classmates.

"She enjoyed gymnastics from the beginning and really stuck with it, even when she found certain exercises hard. We're all very proud of her."

Putting spina bifida and hydrocephalus on the map

The National Service Framework for Long-term Conditions - by Andrew Russell

I don't need to tell you this, but people with spina bifida or hydrocephalus, particularly adults, experience all manner of problems and delays in getting the services they need because of their disability. This applies to many services, right across health and social care. So over the last 3 years or so ASBAH, in partnership with other "neurological" charities, has been pushing for better national policies and higher priority for those with neurological conditions.

The result is the National Service Framework (NSF) for Long-term Conditions, published by the Department of Health in March 2005, concentrating on neurological conditions. Although ASBAH resists the "medical model" of disability, we welcome the NSF because it is the only way to achieve the kind of recognition that, for example, cancer or heart services receive in the pecking order for funding.

> **What is needed now is a bringing-together, at local level, of these interested parties. We in ASBAH must do all we can to be there and make sure that the needs of our members are not forgotten.**

The NSF set out "Quality Requirements" which apply to health and social care services working with local agencies which support people to live independently, such as providers of transport, housing, employment, education and benefits.

These matter greatly to people with spina bifida and hydrocephalus.

In the NSF, neurological conditions are divided into four broad types: sudden onset; progressive diseases; intermittent and unpredictable; stable but with changing needs. Spina bifida fits best into the last ("stable") category, because it is a condition rather than a disease. The kind of services that are vital to ASBAH's service users include things like personal care and family support, equipment and accommodation, early diagnosis of developing symptoms, and sometimes community based or vocational rehabilitation. Hydrocephalus is often stable, but can be unpredictable requiring acute intervention, so families and professionals need to be informed and prepared for this too.

The NSF puts great emphasis on a "user-centred" service, calling for "better co-ordination of services and information - sharing across relevant agencies", including the voluntary sector. What is needed now is a bringing-together, at local level, of these interested parties. We in ASBAH must do all we can to be there and make sure that the needs of our members are not forgotten. These needs are to do with the day-to-day essentials to live a decent life, including equipment, house adaptations, mobility aids, continence management services, correct benefits, training in independence and skills and so on.

Great emphasis will be put on the development of acute neurological disease treatments, and there is a danger that too little attention and resources will go to the day-to-day essentials. Unfortunately, no specific financial resources have yet been allocated by the government to the NSF, but we are assured that money will be made available. We are going to need well-informed people to be advocates for spina bifida and hydrocephalus at local planning level.

Local planners and service commissioners may need to be reminded that people with conditions such as spina bifida and hydrocephalus spend most of their time at home and in the community, not in hospitals and clinics. The social care aspects of the NSF are just as vital as the medical services. We in ASBAH, in Local Associations and the National Association, are going to have to fight our corner.

That's why we're keen to work with someone in every Local Association who is willing to take on the role of champion, with our help and support.

Direct Payments explained

A new guide on direct payments is available for all families with a disabled child.

The information pack has been produced by the charity Scope to help families and young people learn more about direct payments and how to use them.

Direct payments are a relatively new way for disabled people, parents and carers of disabled children to receive the support they need.

This system means that instead of getting social services to arrange the support they need, an equivalent amount of money is paid to families each month so they can buy the help themselves.

The information packs, funded by the Department for Education and Skills, were created in consultation with parents and young people already using the direct payments scheme.

For your copy contact Scope's Library and Information Unit on 020 7619 7342 or ASBAH's information section on 01733 555988.

The Disability and Carers Service has asked Link to publicise the following helpline number.

The Disability Living Allowance/ Attendance Allowance (DLA/AA) Helpline is on:

08457 123456

Positive response to Leicester weekend

Visitors to Leicester ASBAH's first Recreation and Participation event picked up plenty of help and advice about taking up a new hobby.

The two-day special, held at the picturesque Cropston Reservoir, attracted a wide range of organisations including the Uphill Ski Club, the Jubilee Sailing Trust and the National Association of Bikers.

Several smaller, Leicester-based charities such as the Disabled Adventure Club were also on hand to provide information.

The weekend, held in August, was an ambitious project for the Leicester Local Association, and organisers were concerned that turnout was would low.

But Carole Armour, LASBAH's events co-ordinator, said: "To overcome this, members of other local disability associations were also invited. Whilst we would have liked to have seen more of our local members who rarely attend meetings or events, this was a positive start.

"The feedback we received from completed questionnaires was also very encouraging, so I guess we must have been doing something right."

Trio of trustees join Board

Three new faces were voted on to ASBAH's Board of Trustees at the AGM in September.

Judith Hayeem, Louise Iontton and Carole Armour were all welcomed at the meeting held in Peterborough on Saturday 24 September.

Opening the AGM, ASBAH was pleased to welcome its President, Dr Jeffrey Tate CBE. As an acclaimed conductor, Dr Tate travels the world giving concerts but still keeps in contact with ASBAH and is an avid reader of *Link* magazine. Dr Tate spoke of his pleasure in seeing ASBAH become more successful over the last few years, with many new initiatives and a positive outlook for the future.

Guest speaker Judith Kidd, Chief Executive of the Neurological Alliance, gave a presentation about the National Service Framework for Long-term Conditions (see page 7) and Paul Zickel and Lisa Cain of ASBAH's Your Voice group spoke of the Social model of Disability – (featured in the last *Link* magazine)

Peterborough MP, Stewart Jackson, attended along with many Local Association representatives and trustees.

Another key area for discussion was the Local Association Compact. In the past year 19 affiliated Local Associations have signed up to the Compact Agreement, to benefit service users across England, Wales and Northern Ireland.

Chairman Richard Astle paid tribute to the commitment and dedication of two Trustees who retired at the AGM: Alan Twyford from Surrey ASBAH and Mike Booth, Leeds and District ASBAH. Vice Chairman Austin Crowther spoke fondly of fellow Trustee, Janet Waugh, who died earlier this year (see page 24).

Commenting on the AGM, Executive Director, Andrew Russell said,

"This AGM focused on three important strategic themes: the state of Health and Social Services provision; how ASBAH and its Local Associations can work better together and our vision of the future for disabled people."

Endorsing the tribute paid to the two retiring Trustees, Andrew added,

"Though it is always sad to lose valued members of the Trustee Board, it is good to have new people bringing new talents and skills to the Board and we welcome them to the ASBAH team".

New trustees details:

Judith Hayeem

Judith, 34, is a member of ASBAH and has been actively involved in ASBAH activities for several years, both with fundraising and also campaigning for improved rights for our members.

Judith is passionately interested in the issue of disability rights in general and is very involved in political activities at a local level. Another cause close to her heart is improved access to public transport and employment opportunities for all ASBAH members.

She said: "As a Trustee I will use my position to speak up for all our members' interests and to ensure that their rights are recognised and equality is achieved."

Louise Iontton

Louise has been an active member of both her local committee and Your Voice since joining ASBAH two years ago.

Louise, 29, from Ilkley, has also spent some time working, on a voluntary basis, at the Northern Region Office.

Outside of ASBAH Louise works as a classroom assistant at the local primary school. She has also applied to Age Concern to teach older people how to use the internet/e-mail and will shortly be working for an agency that helps people find voluntary work.

Carole Armour

Carole is a familiar face within ASBAH, having been involved with the organization for more than 30 years.

She was initially involved with Surrey ASBAH before moving to the Midlands. Since 1994 Carole has been an active committee member of Leicester ASBAH.

Carole, who has been on the Steering Group of Your Voice since April 1993, told Link: "My hope is to broaden the involvement of members of all ability within both Your Voice and ASBAH."

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

LINK

the lifestyle magazine for people with hydrocephalus and spina bifida

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THE ROALD DAHL FOUNDATION

Generous donation funds information days

ASBAH is planning a series of family workshops after receiving a £8,210 grant from the Roald Dahl Foundation.

The five workshops, which will be held across England, Northern Ireland and Wales, will provide much-needed information about caring for children with hydrocephalus.

The generous donation, made under the Foundation's neurology programme, came as welcome news to ASBAH's fundraising department.

Helen Dow, Project Co-ordinator (fundraising) said "ASBAH are delighted with this support from The Roald Dahl Foundation. These workshops ensure that information on the care of children with hydrocephalus is available to those who need it."

The Roald Dahl Foundation is a grant making trust set up in 1991 in memory of the world famous author, and supports causes important to him during his life.

It provides practical help for children and young people with brain, blood and literacy problems by supporting hospitals, charities and individual children and their families.

A spokesperson for the Foundation told *Link*: "Roald Dahl knew at first hand the terrible impact acquired brain injury and hydrocephalus had on a child and its family. The Foundation is particularly pleased to make this grant to enable ASBAH to give information and support to many of the families of children with hydrocephalus."

Another successful Awareness Day

Arleta Starza-Smith

Darlington was the venue for the latest in ASBAH's series of Hydrocephalus Action Awareness seminars.

The event, funded by the Roald Dahl Foundation, was held at the city's Dolphin Centre. It was well-attended by parents and professionals keen to learn more about helping children with hydrocephalus.

The day-long seminar was a varied mix of presentations and practical workshops, with plenty of time allowed for questions from the audience.

The event, organised by Joan Pheasant, manager of ASBAH's northern region, kicked off at 10am with a talk by Mr Roger Strachan, Consultant Paediatric Neurosurgeon.

Other speakers included Carole Sobkowiak, President of the Society for Research into Hydrocephalus and Spina Bifida, and Arleta Starza-Smith Consultant Clinical Psychologist in Paediatric Neuropsychology - both authors of *Your Child and Hydrocephalus* - and Naomi Boycott, Assistant Psychologist.

Joan Pheasant told *Link*: "The talks were very varied and there was plenty of participation from the audience.

"The feedback forms identified that the parents found the day very helpful and informative. They particularly found the opportunity to have their questions answered by a psychologist very useful."

... and another one!

The Peterborough awareness seminar, held in September was also well-attended by 60 parents and family members.

The day-long seminar included presentations and practical workshops, by neurosurgeon Helen Fernandes from Addenbrooke's Hospital, Sandra John-Charles from Codman and psychologist Hazel Bennett.

Dianna Capstick

(left to right) Steve Naylor, Katherine Winrow, Jon Tibke, Dianna Capstick

Helene Irvine

Karen Feeney

Dash for cash

Miles O'Donnell

Nicole Callaghan

Jonathan Tibke

Henry Trenholm

Malcolm Henderson

A valiant team of 20 donned their running shoes on 18 September to raise funds for ASBAH by taking part in the BUPA Great North Run.

They joined around 50,000 others in the world's most famous half-marathon which stretches from Newcastle to South Shields.

The event, now in its 25th year, saw Jonathan Tibke come home first for ASBAH, with Karen Feeney and Diana Capstick following on.

Malcolm Henderson, who has competed several times for ASBAH, delighted the crowds again by sporting his tartan tam o'shanter & red wig.

Ian Morley, ASBAH's events organiser was at the finishing line with his wife Val, Anne Walton (retired ASBAH adviser), her husband Reg and Regional Manager Joan Pheasant, handing out well earned medals and goodie bags

ASBAH's support continues to grow each year with more and more runners, we are extremely grateful to everyone who took part," said Ian.

"Best ever" total from Megacycle

Megacycle organisers have been counting the cash raised by this year's event and have revealed that the 2005 ride has been the most successful ever.

The 24-hour sponsored cycle ride, held on the first weekend in July, collected more than £3,000 for ASBAH funds.

Ian Morley, who organises the annual event, said: "I am extremely pleased with the success of this year's ride which has proved to be the most successful yet. We were hoping to raise £2,500, so we are more than happy with our final total."

Ian has been organising the event for 13 years and has raised almost £31,000 during that time.

High fliers raise hefty sum

A mother made a 10,000 ft leap from the skies in memory of her daughter Emma Louise and raised £850 for ASBAH.

Elaine Bialkowska from Bradley near Huddersfield, made the fundraising parachute jump to celebrate what would have been her late daughter's 21st birthday.

Emma, who was born with spina bifida, died when she was just four days old from pneumonia.

Elaine explained: "I had no idea that my baby had spina bifida until she was born. It was a complete shock as it wasn't picked up on the scan. I was very young at the time and it wasn't until a couple of hours after the birth that I realised how serious it was.

"I climbed Ben Nevis to mark what would have been her 18th birthday and wanted to do something special for her 21st."

When Elaine, who has a 15-year-old daughter, Olivia, mentioned her plans at work, colleague Ruth Eddie bravely volunteered to join the jump.

The high flying duo did their parachute jump from Bridlington Skydive Centre in the summer.

Elaine said: "The jump was fantastic. I was very scared before hand, but I was determined to do it. I took along a large group of family and friends to watch, so there was really no way I could bottle out anyway.

"A big thank you goes to Ruth and everyone who supported and sponsored me. It was a fantastic way to remember Emma, and being high in the clouds seemed like the best way of being closest to her."

Kind-hearted team donate prize money

A team of health centre co-ordinators from North Eastern Derbyshire Primary Care Trust (PCT) were recently highly commended in the PCT Innovation in Health Care Awards, in the team of the year category.

Instead of going on a spending spree to celebrate their win, the kind hearted team decided to donate their £250 winnings to ASBAH.

Two of the team have family members with Begnign Intracranial Hypertension (BIH), so ASBAH seemed like a fitting choice for the donation.

Our congratulations go to the team for their award, and we extend our thanks to them for donating their prize money.

Christmas Cards

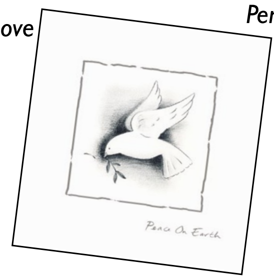
If you would like to order some ASBAH Christmas Cards or Benny Bear Christmas selection packs, please complete the attached form.

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. The back of the Benny Bear cards also have an explanation about the Hydrocephalus Action campaign.

Benny Bear selection of 10 cards and envelopes comprising all three designs

Robin

Wintry Scene



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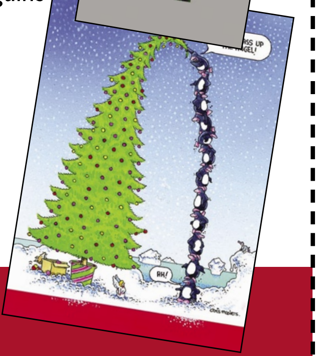

Penguins

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Robin		£2.00 plus p&p	
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Benny Bear		£2.00 plus p&p	
Christmas card (postage and packing) - £0.75p per pack			
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Please send the completed order form together with your payment to:

ASBAH, 42 Park Road, Peterborough PE1 2UQ

Registered charity no. 249338

Shunt info needed – can you help?

Dr Roger Bayston, ASBAH's Honorary Consultant in hydrocephalus, hopes ASBAH members can help provide background data for his medical paper on Ventriculo Atrium (VA) shunts. (These are the shunts that drain cerebrospinal fluid into the heart rather than into the abdomen).

Dr Bayston, who is Senior Lecturer in surgical infection at the University Hospital, Nottingham, says that the Cambridge Shunt Registry has shown that during the past few years, 1.3 per cent of all shunts inserted in the UK were VA shunts.

However, there are probably many more people in the community with VA shunts who have not been entered in the registry because they have not had a shunt operation in the past few years. He wishes to compare the performance of VA shunts with the more common Ventriculo Peritoneal (VP) shunts that drain into the abdomen.

> **We have some evidence that, while most NEW shunts are VP, there are many people in the community with VA shunts who are not currently seeing a neurosurgeon.**

Now he needs information from people who have had a VA shunt fitted to help him with his studies.

A letter and questionnaire was mailed in early October to people who ASBAH believes have or have had in the past, a VA shunt. All information will be treated confidentially and no names will be used in any publication.

Dr Bayston explained: "The first shunts used were VA and they generally worked well. In the past 15 years VP shunts have been used much more commonly, though the reasons are debatable.

"There is now a lack of knowledge and experience among doctors on what to do if a VA shunt goes wrong, and we wish to put this right by publishing an educational paper in a medical journal.

"One of the first questions to be asked by editors will be yes, but they are not used any more, are they? We have some evidence that, while most NEW shunts are VP, there are many people in the community with VA shunts who are not currently seeing a neurosurgeon. It is these people that we wish to reach with the questionnaire."

If you have a VA shunt and have not received a questionnaire, please contact Diane Gardener at ASBAH on 01733 555988 and one will be sent out to you.

Linda's line

This is going to sound like sour grapes, but my friend Albert has much better medical care than I do.

I wouldn't mind, only Albert is a guinea pig and therefore has a lower status in the Corbett household. However, this issue has come to a head because earlier this year both Albert and I fell over (not together!) and both ended up limping.

Sadly, the similarity between our experiences ended there. On phoning my GP surgery, I was told the earliest appointment for my doctor was in 10 days, (and I don't know about you, but experience tells me not to bother seeing anyone else, as the history of my poor beleaguered feet is detailed to say the least!)

Phoning the vet was a somewhat different experience. For a start, you get shovel loads of sympathy – "Oh, poor piggy, is he still eating and drinking? Is he in a lot of pain? Can you wait till this afternoon to see the vet or is it urgent?"

We dutifully hobbled down that same afternoon and saw the hunky looking South African vet after a five minute wait (unlike my GP surgery, where you can usually get a decent way through one of the Harry Potter books before you get summoned).

The vet spent a good 10 minutes looking at Albert, got him to walk around, checked all four legs, reeled off a list of muscles (I didn't realise guinea pigs had so many joints in one furry foot!) and pronounced that he had sprained his hock.

By the time my appointment came around, Albert was back to full fitness and I came home with a card entitling me to another long wait in the local X-ray department.

After it seemed like time had shifted to another dimension, I was informed by the radiographer that I needed to see my doctor, as there was something not quite right. I hobbled back to the doctors, opting for the see-anyone-as-long-as-it's-urgent choice.

I might as well have not bothered as, without even looking at the X-ray, I was told to go home and take paracetomol. No explanation, no nothing. Honestly, if I had been tall enough, I would have hit somebody!

So what have I learned from this experience and what will my New Year's resolution be for next year? Try not to fall over again (obviously!), and in case of further trouble, sign on at Albert's medical practice!

Your Voice presents

KNOW YOUR SHUNT

Everything you every wanted to know about your shunt – but were afraid to ask!!!

Open to all adults – young and old (aged 16 and over)

Topics include:

- **Medical Issues**
- **Epilepsy, Visual Impairments**
- **When is a headache not a headache?**
- **Employment – *disability rights, disability leave***
- **Relationships/ Pregnancy**
- **Coping Strategies**
- **Developing Independence**

SOUTH

Guest speakers include Gill Yaz, ASBAH medical adviser

Sunningdale Park - Berkshire
Saturday 12th November 2005
10.30 - 4.30pm
Cost - £20 including buffet

NORTH

Guest speakers include Rosemary Batchelor, ASBAH senior medical adviser

Moat House Hotel - York
Saturday 19th November 2005
10.30 - 4.30pm
Cost - £20 including buffet lunch

To book your place, please contact:

Barbara Robinson
ASBAH House
42 Park Road
Peterborough PE1 2UQ
Email: barbarar@asbah.org
Telephone: 01733 555988

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

Learning new skills at High Ashurst Activity Centre - archery and rock climbing

The future looks brighter for Surrey

Things are looking up for the Surrey Local Association.

Having been a thriving group in the past, just three years ago it was feared that the association would close through a lack of committee members.

However, Treasurer Steve Wallace kept the group afloat and it is now back on track with an active committee of volunteers.

"There's still a long way to go," Chair Liz Tadd told *Link*, "but we have analysed what we need to do, and how to do it.

"We're currently working hard to increase our membership. There are a lot of people in our area who have spina bifida and hydrocephalus, but in the past we haven't reached them, for whatever reason."

> **Publicity is a key issue for us. The creation of a website was a positive move and, with the help of national ASBAH, we've produced very professional looking leaflets to hand out.**

A new live and active website has pulled in several new faces, and the committee is keen to build on this success.

Liz, who took over as Chair 2 years ago, said: "Publicity is a key issue for us. The creation of a website was a positive move and, with the help of national ASBAH, we've produced very professional looking leaflets to hand out."

The group, which used to cover East Surrey, Kingston upon Thames, Croydon, Merton and Sutton, recently widened its catchment area, taking in the whole county plus the London boroughs of Hounslow and Richmond.

Liz explained: "Hopefully we will soon have more members and that will enable us to organise more events tailored to the interests of the different age groups within the association. But the downside is that it is a big geographical area, so events will need to be arranged at different locations."

Another challenge facing Surrey Local Association is fund-raising to continue their part-funding of area adviser, Angela Bailey, and other ongoing expenses.

"Having a local adviser is the key to a successful association," Liz said. "Angela has been with us for over a year and her work is invaluable.

"All the committee members are volunteers who can only give a certain amount of time to SASBAH because we have other commitments. But Angela can give help and advice on a day to day basis.

"We really need to step up our fund-raising this year, which is always hard work, particularly when there are so many charities asking for donations."

Liz became involved with the association 15 years ago, when her son James, who has spina bifida and hydrocephalus, was 4 years old.

"We heard about ASBAH when James was born," she said, "but we weren't ready to get involved for a while. When we contacted the local association we found everyone very helpful and their support was invaluable."

The group holds a variety of events each year, from visits to the theatre and meals out to bowling trips (for the teenager group) and a summer picnic.

"We have tried to arrange things to suit large groups," Liz explained, "but we accept that not every activity will suit everyone. We'd love more people to get involved with the Surrey Association and for them to tell us how we can help them. New members are very welcome."

For more information about Surrey Local Association check out its website ***www.surreyasbah.org.uk***

Catherine Nichols with mother Maggie, secretary of Northamptonshire ASBAH (NASBAH).

Living independently has been a steep learning curve for Catherine Nichols but although leaving home has been tougher than she imagined, she feels she made the right move.

Forging the way to indepen

Catherine 24, left the family home in Daventry last October, determined to forge a new and more independent life for herself.

With the help of mother Maggie, secretary of Northamptonshire ASBAH, she did a lot of research into suitable properties and areas, as well as checking out the support she may need.

Catherine, who has hydrocephalus, decided to move to Milton Keynes, an area which has a very positive attitude to disabled people and offers plenty of support to find employment.

She initially moved into a supported housing project, but quickly discovered that it didn't meet her needs. She explained: "I was very unhappy there. Most of the other tenants had learning difficulties and the support staff just weren't geared up to deal with anyone with a physical disability. I often felt very patronised.

Luckily Catherine managed to find alternative accommodation through Jephson Housing Association, and after six months moved into a one-bedroomed house.

"It was also so noisy and I felt that I didn't have any privacy, which is important to me. After a few months it really began to get me down."

Luckily Catherine managed to find alternative accommodation through Jephson Housing Association, and after six months moved into a one-bedroomed house, in the Leadenhall area of Milton Keynes.

Mother Maggie explained:" The house is very suitable, but everything had been completely stripped out, so Catherine had to spend quite a lot of her savings on buying carpet, furniture and appliances such as a washing machine. The house was very clean but we still needed to paint some rooms to brighten it up."

Catherine immediately set up direct debits to pay her bills and help her budget more easily, and approached social services for help in the home.

She explained: "I have tunnel vision and I can't grip things in two hands, which means I have problems cleaning certain areas, although I can wash-up and clean the bathroom myself.

"But I have to make sure that floors are kept clean and clear because I can't see anything on the ground in front of me, and I need to leave a light on in the bathroom at night so I can see if I need to get up. Being unable to grip things with both hands means I have problems using the oven. I have to use the microwave to heat food up."

She is also keen to find part-time employment, and has already completed a computer course to help her job prospects.

While things are more or less sorted in the home, Catherine's next challenge is to broaden her social circle, and she's currently looking for groups to join.

She explained: "I need to go out more and make friends, so I'm hoping to join clubs which cater for both able bodied and

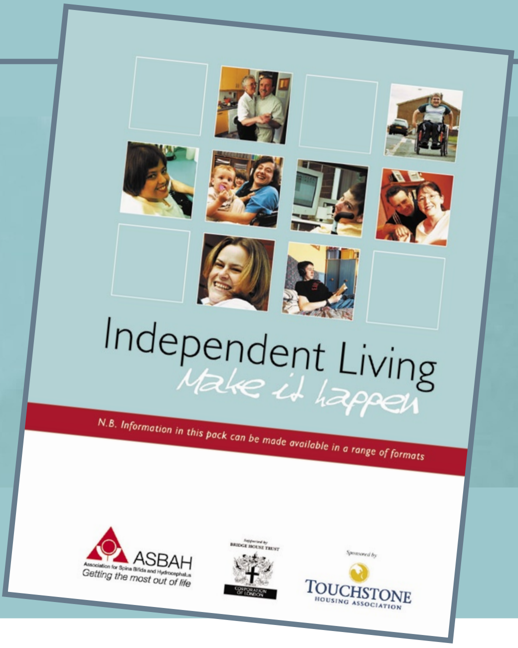
dence

disabled people. The problem is that most groups meet in the evenings, but because I take epilepsy medication in the evening, it makes me drowsy so I never feel like going out then.”

She is also keen to find part-time employment, and has already completed a computer course to help her job prospects. But despite several rejection letters, Catherine is determined that a suitable job will come along.

Catherine told *Link*: “My life has changed a lot in the past few months, and although it was very difficult at first, I now feel very happy and settled. My house is very comfortable and I like the fact that I have my privacy and can relax here.”

More info on independent living



Independent Living

Make it happen

N.B. Information in this pack can be made available in a range of formats

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

TOUCHSTONE HOUSING ASSOCIATION

ASBAH’s comprehensive *Make It Happen* pack published last year is to be expanded with the addition of a new Travel section.

The pack, aimed at helping anyone wishing to become more independent, move home, or manage their life with or without assistance, has already proved its worth.

Produced in a loose-leaf format, its sections include information about preparing for independent living, housing options and direct payments, as well as two questionnaires to help the user decide what they actually want and think about their specific needs.

The new Travel section which will be completed before the end of the year, will give vital pointers to ASBAH service users planning new journeys.

The leaflets were written by members of the “Living in London Forum”, a group of people with spina bifida and/or hydrocephalus, who have first hand experience of living independently.

The new Travel section which will be completed before the end of the year, will give vital pointers to ASBAH service users planning new journeys.

Jo Francis, ASBAH South East regional manager, is one of the people behind the *Make It Happen* pack.

She explained: “When the handbook was written, we were aware that there were more sections that we needed to include. The forum met and discussed the various topics and the area felt to be the most important was travel.

Many disabled people find it difficult to get out and about which adds to their feelings of isolation. Confidence is also an issue and members of the group felt that their own experiences would enable them to write a leaflet, which would provide the basics and signpost people to the appropriate service.”

Jo added: “The handbook is in demand because it is written by people who know what the issues are and know what is needed. Thus with the transport leaflet, there is a checklist of what you need to consider before you set off as well as basic information on various forms of transport.

More information about *Make It Happen* can be viewed on the ASBAH website at **www.asbah.org**

You can obtain a copy from your local advisor or by contacting Gill Winfield, information section, Telephone: 01733 555988, **gillw@asbah.org**

GOING TO UNIVERS

STARTING UNIVERSITY IS A DAUNTING PROSPECT FOR ANYONE. TIMETABLES, STUDYING AND TRAVEL ARRANGEMENTS TO GET TO GRIPS WITH... NOT TO MENTION HUGE, BUSY BUILDINGS TO NEGOTIATE. BUT IF YOU USE A WHEELCHAIR THEN THERE ARE THE ADDITIONAL WORRIES OF ACCESS AND MOBILITY TO FACE.

Joanna Clyne, who is a wheelchair user, says that with a little forward planning, new students should enjoy a smooth transition into university life.

Joanna, who has spina bifida and hydrocephalus, is now in her third and final year at the University of Bolton, where she is studying Human Resource Management.

Halfway through her A Level courses she visited Bolton and the University of Salford to check out their facilities for wheelchair users.

Joanna, 20, whose father David is secretary of the Bolton and Bury ASBAH local association, said: “I finally chose to study at Bolton because I preferred the course, but both universities were very helpful in assessing my needs.

“When I accepted a place at Bolton I went in for a day for a complete assessment, which helped to allay any fears I had. I was given a lap top and my wheelchair was measured to make sure that desks could be adapted so it would fit underneath comfortably.”

Start thinking about universities in the first year of your A Levels, and make visits to talk about what facilities they have.

Joanna lives with her parents, a 20-min car ride away, in Whitefield, Manchester. She travels to university by black cab, paid for by her local education authority. It’s a problem-free way of travel, providing Joanna lets them know her plans in advance.

Extra help has come in the form of a support worker who accompanies Joanna in lifts and carries bags and books.

“Having my support worker means that I can concentrate on my academic studies rather than worrying about how I’m going manage to get around,” Joanna said. “I just let her know when my lecture will finish and where I then need to go.

“But even so it was daunting when I first started because the building is so big. The first time I went to the library

I couldn't find the exit," she laughed. "I spent about ten minutes wheeling round and round before I finally plucked up the courage to ask someone how to get out.

"Again, I think the secret is not being afraid to ask for help. I've always found that if I'm pleasant, people are always very helpful."

Joanna added that if you are in a wheelchair it shouldn't prevent you from achieving your full potential.

"It is all about forward planning, "she said. "Start thinking about universities in the first year of your A Levels, and make visits to talk about what facilities they have.

"My experiences have been very good. I'm enjoying my course and have made some good friends."

Disabled students get new rights

Thousands of disabled students will have new rights to better access on university and further education campuses.

New laws, which came into force on 1 September, mean that colleges and universities must now provide step-free routes into buildings

The Disability Discrimination Act (DDA) now obliges colleges and universities to make 'reasonable' changes to their premises to make them more user-friendly for Britain's disabled students.

Campuses will have to ensure that lecture halls, libraries, ICT suites and halls of residence are more user-friendly.

Such changes could include providing ramps into buildings, lifts, improved lighting and dropping kerbs.

No matter how accessible the teaching is, it's not much use if you can't get in the door.

The Disability Rights Commission says too many disabled students do not apply for places because access is poor.

Last year more than 22,000 disabled students applied through the University and College Admissions System.

However, research by the Disability Rights Commission (DRC) in 2002 among young disabled people found that of those who had not gone on to further or higher education, 30% felt they were prevented from doing so for a reason relating to their impairment.

Bert Massie, Chairman of the DRC, said: "Going on to further and higher education is key for disabled people to get the skills they need to fulfil their ambitions. Access to the sites of learning is fundamental to this.

"No matter how accessible the teaching is, it's not much use if you can't get in the door. This term will see the final piece of the jigsaw going into place giving disabled people the rights they need to ensure they get the education to which they are entitled."

These new laws are the latest part of the process of applying disability legislation to further and higher education.

In 2002 a fairer admissions procedure was introduced, and in 2003 institutions had a duty to provide extra services and equipment like large print and sign language interpreters.

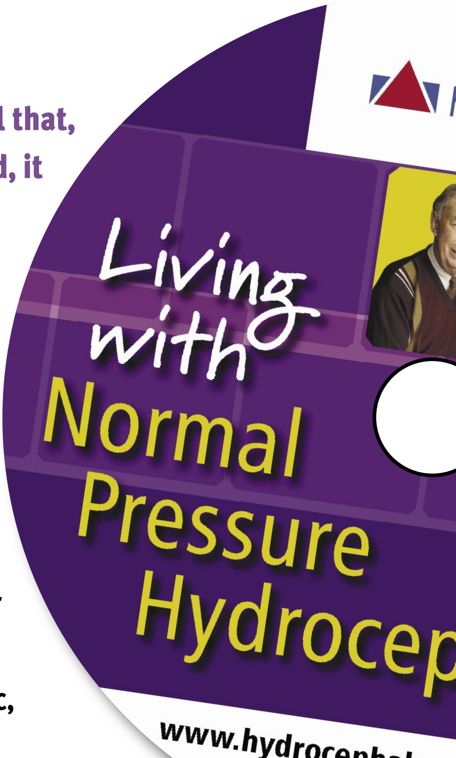
Large sums of money have been made available specifically to improve disabled access - for example the Higher Education Funding Council for England has spent more that £170m over the last four years.

Barbra Waters, chief executive of Skill - the National Bureau of Students with Disabilities, said: "I hope this will be a smooth transmission because providers have had plenty of warning that this was coming."

Further and higher education institutions have been supported by substantial capital investment by post-16 funding bodies.

The Higher Education Funding Council for England, for example, had two capital projects allocating £56 million in 2001 and £117 million in 2003 to higher education institutions, specifically targeted at improving provision for disabled students.

> **"This new CD ROM is a great idea and I feel that, had it been available when I was diagnosed, it would have made adjusting to having NPH much easier and less frightening."**
>
> *Wendy Simons*



New
Normal Pressure Hydrocephalus CD ROM

An informative new CD ROM publication entitled *Living with Normal Pressure Hydrocephalus* (NPH) has been launched by Codman and ASBAH as part of their ongoing commitment to jointly promote Hydrocephalus Action, the campaign aimed at improving the awareness of hydrocephalus amongst the general public, healthcare professionals and public policy decision makers throughout the UK.

The new multi media publication is aimed at a wide cross section of people, from patients and their families to GP's, neurologists and geriatricians, and is presented in a clear, understandable format that makes it accessible to all.

The information is delivered in a realistic way, with video clips from a number of experts explaining different aspects of NPH – these include Professor John Pickard, Professor of Neurosciences at Addenbrooke's Hospital, Cambridge, Mr Laurence Watkins, Consultant Neurosurgeon at the National Hospital for Neurology and Neurosurgery, London and Dr Joanna Iddon, Neuropsychologist at the Department of Neurosurgery, Cambridge. In addition to the wealth of advice and opinions of the experts, viewers are able to see NPH from a patients' perspective in two "My Story" sections, as told by Wendy Simons and Bart Bainbridge, plus Susan Dobson's account of her mother's experience of NPH.

Wendy Simons explains: "The new CD ROM is a great idea and I feel that, had it been available when I was diagnosed, it would have made adjusting to having NPH much easier and less frightening."

Details of how people can support ASBAH are also included on the CD ROM.

CD ROM review

Professor Carsten Wikkelsø

***Link* caught up with Carsten Wikkelsø, Professor of Neurology, Göteborg University in Sweden, at the recent Clinical Neurosciences 2005 Conference in Torquay.**

Carsten, who also holds the post of Chairman, The Foundation of Neurological Science, Göteborg, began his career in neurology in 1975, and has since published many research papers.

He told *Link*: "I thoroughly enjoy my work. I meet people with hydrocephalus every week, and it is rewarding to make a diagnosis and see how I can help.

"I would like to see more people having shunts to alleviate their symptoms, and I think that in the future we could be even more precise when we decide on shunt surgery."

Carsten lives in Mölndal, Sweden, with wife Elizabeth, a teacher, and the couple have three daughters. To relax, he enjoys trekking, sailing and gardening in his free time.

Carsten kindly took time out of his hectic schedule to review the new *Living with NPH* CD, produced by ASBAH.

He told *Link*: "The new CD is a clear and concise guide to many aspects of the condition.

Three experts give easy to understand explanations about NPH, its symptoms, how it is diagnosed and treatment.

I found the interactive CD very easy to use, with bright graphics and easy to follow instructions. It is very informative, and the Frequently Asked Questions section should cover everything a patient and their family wants to know about the condition and how it will affect their daily life.

Anyone with a newly-diagnosed medical condition usually finds it helpful to hear or read about other people's experiences, so they should find the Case Study section very helpful. The five people who feature have different experiences, but their tone is positive and reassuring.

The CD will be a helpful tool for a wide cross-section of people, from patients and their families to healthcare professionals."

Codman - Working in partnership with ASBAH

The Experts:

Professor John Pickard, Professor of Neurosciences

Mr Laurence Watkins, Consultant Neurosurgeon

Dr Joanna Iddon, Neuropsychologist

Our three experts talk in simple terms about NPH – the symptoms, how a diagnosis is made and give in-depth explanations about the various tests for NPH.

1. Introduction
2. Walking problems
3. Memory Problems/Dementia
4. Urinary continence
5. Other symptoms to look out for

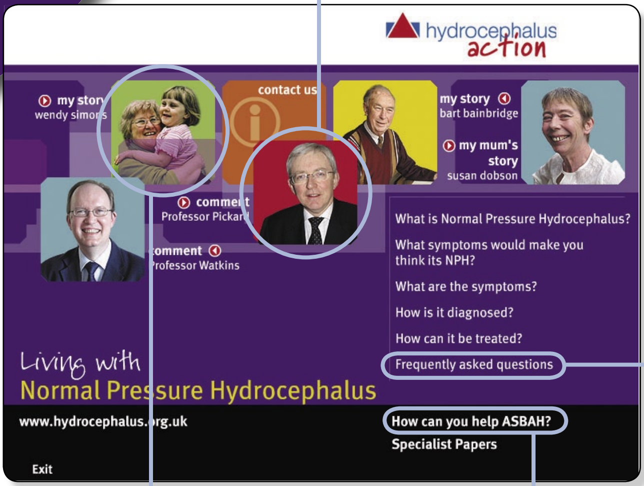
Profile - Dr. Joanna Iddon
BA (Hons), PhD (Cantab), C. Psychol Neuropsychologist
Neuropsychologist at the department of Neurosurgery, Cambridge

Please select a question to be answered from above and then select a highlighted person from the right to answer it.

1. Will I be cured?
2. What is my life expectancy?
3. Will I lead a normal life?
4. How long does a shunt last?
5. How will I know if the shunt goes wrong?
6. How common is it?
7. Is it hereditary - will my children get it?
8. Will I be able to drive?
9. Am I able to play with the grand children?
10. Will I get my memory back?
11. How likely is infection after the shunt operation?
12. What can be done about infection?

Profile - Professor Laurence Watkins
MA FRCS (SN)
Consultant Neurosurgeon at the National Hospital for Neurology and Neurosurgery, London

Please select a question to be answered from above and then select a highlighted person from the right to answer it.



What is Normal Pressure Hydrocephalus?
What symptoms would make you think its NPH?
What are the symptoms?
How is it diagnosed?
How can it be treated?
Frequently asked questions
How can you help ASBAH?
Specialist Papers

Frequently Asked Questions

Patients often return home from hospital and realise there are lots of questions they had wished they'd asked their consultant.

In this section our team of experts answer 12 of the most frequently asked questions from Will I be cured? to What can be done about infection?

How can you help ASBAH?

Here viewers will find plenty of background information about ASBAH, the work it does and how they can support their valuable work.

My Story:

Wendy Simons and husband Bob

Bart Bainbridge and wife Gwen

Susan Dobson, who's mother Rosary Morley has NPH

They all give honest accounts of their experiences of NPH, from the initial frightening symptoms through to their successful treatment.

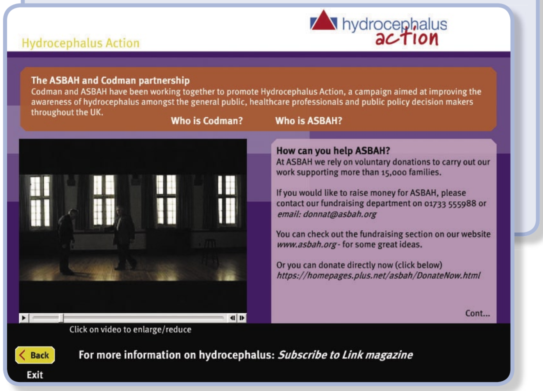
Click on the relevant question and then which of the five people you would like to answer it.

Profile - Bob Simons from Burgh Le Marsh, Skegness.
Bob's wife Wendy was diagnosed with NPH in 2001.

1. What early symptoms did you notice?
2. How quickly was the Hydrocephalus diagnosed?
3. Had you heard of the condition before diagnosis?
4. How was the hydrocephalus treated?
5. Did you recover from the operation quite quickly?
6. Was a programmable/adjustable shunt fitted?
7. Do you understand how the pressure can be changed?
8. Did anyone talk about taking care around magnets?
9. Can you tell if the shunt isn't working properly?
10. Do you have "open door" access to a neurosurgeon or neurosurgical unit?
11. Do you have a shunt alert card?

Profile - Susan Dobson from Wilsthorpe, Peterborough.
Susan's mother, Rosary Morley has NPH.

Please select a question to be answered from above and then select a highlighted person from the right to answer it.



The ASBAH and Codman partnership
Codman and ASBAH have been working together to promote Hydrocephalus Action, a campaign aimed at improving the awareness of hydrocephalus amongst the general public, healthcare professionals and public policy decision makers throughout the UK.

How can you help ASBAH?
At ASBAH we rely on voluntary donations to carry out our work supporting more than 15,000 families.

If you would like to raise money for ASBAH, please contact our fundraising department on 01733 555988 or *email: donnat@asbah.org*

You can check out the fundraising section on our website *www.asbah.org* - for some great ideas.

Or you can donate directly now (click below)
https://homepages.plus.net/asbah/DonateNow.html

For more information on hydrocephalus: ***Subscribe to Link magazine***

The *Living with Normal Pressure Hydrocephalus CD rom will be available from the ASBAH Information Section in the near future. To order your copy please contact* ***gillw@asbah.org****, telephone 01733 555988.*

Codman - Working in partnership with ASBAH

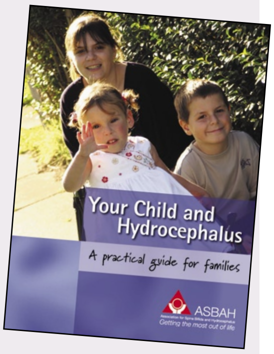
Hydrocephalus book reaches new audience

***Your** Child and Hydrocephalus*, which has received an excellent response worldwide, is to be translated into German.

ASBAH has provided the text and layouts of the book, published last year, to ASbH, the equivalent charity in Germany.

Once the translation has been completed, ASbH hopes to win public funding to have the book published next year.

Wilhelm Langenhorst from ASbH said: “We are very grateful to ASBAH for its continuing help and support. It is our aim to offer the book as cheaply as possible so it reaches a lot of people. It will also be made available to people in Austria and Switzerland.



“A few years ago there was little useful information about hydrocephalus. There has been a high demand for *Your Child and Hydrocephalus*, and we are sure that the German translation will make a huge contribution to improving the lives of children with hydrocephalus in Germany.”

ASBAH’s Peter Farrall said “We are delighted to be able to help ASbH and pleased that they have found the book to be a valuable help for their families with hydrocephalus.”

Peter added, “The praise and support for the book has been truly world wide – Australia, Brazil, USA and South Africa Associations have all been kind in praising the “*Your Child and Hydrocephalus* book”.

Turning Japanese

Benny Bear is set to reach a new audience after the first book in the series was translated into Japanese.

The popular books, produced by Codman and ASBAH, are a valuable resource in helping to teach children and their parents about hydrocephalus.

Mark Attenborough, Codman’s Training Manager explained: “Colleagues who work with me from different countries have taken Benny and some of the books back home with them.

”My friend Mariko Tachiiwa now has Benny visiting children in Japan. They liked him and the first book, *Benny Gets Better*, so much they asked if they could copy it and write the story in Japanese. We were delighted to agree and hear that the book is a great success in Japan. “

It just shows that a good story with good pictures can be appreciated by children no matter where they live.

“Benny Bear is becoming a favourite for children with hydrocephalus all over the world. After his introduction in the UK in co-operation with ASBAH, we have shown him at a number of important meetings.”

Benny Bear has legions of friends around the world since his books have been translated into French, Afrikaans, Spanish and Dutch.

Mark added: “It is nice to see the familiar pictures of Benny and his family but with Japanese writing that I can’t read.

“It just shows that a good story with good pictures can be appreciated by children no matter where they live. I am sure some of the pictures will be familiar to Japanese children such as Benny in hospital - but I wonder if Benny’s street looks the same as ones in Tokyo.”

Japanese children can also look forward to receiving books two and three in the series. Mariko has recently received the pictures from *Benny Goes to School* and *Benny Goes on Holiday* ready for the text translation.

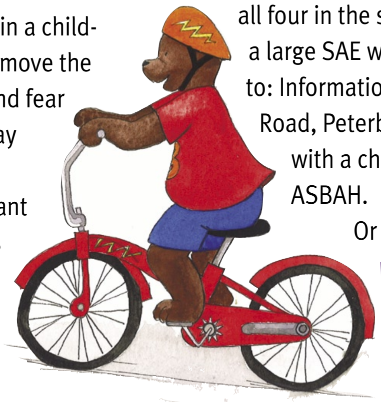
New Benny Bear book

Young fans of Benny Bear will be thrilled to hear that the latest instalment in the teddy’s life is now available.

Benny’s New Shunt is the fourth book in the series and deals with the clinical processes parents may see in their child with a blocked shunt.

The book is written in a child-friendly way, to help remove the mystery, uncertainty and fear of what the process may involve.

Sanj Bassi, Consultant Neurosurgeon at Kings College Hospital, said: “This latest book will educate patients, parents and health professional, while providing reassurance to the child.



Sanj Bassi

“The book is an enjoyable children’s story, for all children, yet it tackles the potentially serious issues which may occur with shunt malformation. It will provide a lot of useful information for all those affected by hydrocephalus.”

Benny’s New Shunt is available at £2.00 each from your ASBAH adviser or £6.50 for all four in the series. Alternatively, send a large SAE with two first class stamps to: Information Section, ASBAH, 42 Park Road, Peterborough. PE1 2UQ, together with a cheque made payable to ASBAH.

Or order online at **www.asbah.org**

ENGLAND CALL-UP FOR STEPHEN

Soccer star Stephen Hunt beat dozens of hopefuls to win a coveted place on the Mencap and Gateway England squad

Stephen Hunt

Stephen, better known as Ste, battled 59 others to gain a place in the 15-strong squad for the annual European Football tournament competition in May.

Ste, who plays for Liverpool FC Disability B Team, was thrilled to hear he'd been selected to play in the competition in Bernex, Switzerland.

He told *Link:* "I was very surprised to have been selected because I have spina bifida and the majority of the other players have learning difficulties."

But his skills on the pitch had impressed selectors and in May Ste, and his team mates, flew out to Bernex, a small town near Geneva.

He said: "Switzerland hotel accommodation is very expensive, so the team – along with the Welsh, Irish, Spanish, French and German sides - stayed in an old Nuclear Bunker, owned by the Swiss Army. It seemed very strange at first but we soon found our way to our bunk beds."

> **"Everyone had a great time. It was a fantastic experience playing for England in such a wonderful country."**

The England team had mixed fortunes, losing to France, Italy and Hungary. But spirits were lifted with victories over Switzerland and Germany, in which striker Ste was voted Man of the Match.

Ste, who has worked in disability sport on Merseyside for the last three years, added: "The England side won a cup and medals at the closing award ceremony and exchanged gifts with their opposing teams.

"Everyone had a great time. It was a fantastic experience playing for England in such a wonderful country."

Stephen Hunt biography

A life-long Liverpool supporter, Steven has had a season ticket in the Paddock for 15 years. He has worked in disability sport on Merseyside for three years and has coaching experience in football and boccia.

Stephen also runs his own sports club for disabled people in the Kensington Sports Centre.

A keen member of the LFC Adult Disability Football Team, Stephen is also on the Liverpool Disabled Supporters Association (LDSA) committee.

Liverpool Disabled Supporters Association (LDSA)

The LDSA works in partnership with Liverpool Football Club to promote inclusiveness for the disabled fans of the club, the disabled fans of visiting clubs as well as those individuals who support disabled people and those with impairments. It recognises that all fans should have an equal opportunity to participate in an enjoyable match day experience.

Obituary

Janet Waugh

Janet Waugh was a committed and hard working member of ASBAH at both local and national level.

She joined the Leeds and Bradford ASBAH Committee in April 1988 and spent a short time patiently developing her committee skills before becoming actively involved with the wider range of adult activity groups.

During Janet's time with the committee she worked as a volunteer at the "Saturday Morning Club" for the youngest children and for several years organised the local association's fund-raising collections.

In addition to her work as Deputy Chair from 1998 to March 2003, Janet devoted time to national association work, becoming Trustee and Director in September 1997.

Michael Booth, an ASBAH trustee and fellow committee member of the Leeds and Bradford local association recalled: "Initially Janet seemed to be a rather quiet, shy and reserved young lady. We remember she even asked some of the senior Leeds and Bradford committee members whether it be appropriate for her to stand for Your Voice Steering Group. Of course it was and what a success she proved to be."

Her role at national association included involvement in the production of 5-year Strategic Plan and membership of the Policy and Resources Committee. She also played an active part with the Your Voice steering group, at various times holding the position of Secretary, Vice Chair and Chair.

Janet's confidence grew to the extent that she did a presentation to an International Federation of Hydrocephalus and Spina Bifida Conference in Sept 2000 about the Your Voice Steering Group.

Michael added: "Janet was a good friend to many people. She was so good at ringing me or other members of the Committee and saying things had gone well, or asking how did something go. Her support will be sorely missed.

"Janet was modest, gentle, dignified, committed, supportive, caring and kind and we will miss her. "

Obituary

Helena Payne

Helena Payne, one of the founders of the South Wales branch of ASBAH, has died at the age of 90.

Helena, known as Helly, was known to many, served on the South Wales executive committee until her retirement, and for many years was a member of the ASBAH grants committee.

Helly worked at Llandough Hospital and assisted Professor K Laurence on a research project looking at diseases prevalent in South Wales.

Here she became involved working with children with spina bifida and hydrocephalus, and was co-author on several papers relating to effect of spina bifida on a family.

Soon after a baby was born with spina bifida, Helly would visit the family. It soon became clear to her that many of the families felt isolated and bewildered, needing reassurance and support.

Helly moved to a retirement home near her son Ceri, in Pershore. There she lived contentedly and died peacefully on 8 May 2005.

On hearing of her death, Professor Laurence, who now lives in Switzerland, said: "The thing I remember about Helly, above all else, was her humanity."

Disabled Parents Network Consultation Events

The Disabled Parents Network has organised four events during the coming months. They are aimed at giving people the chance to meet other disabled parents or disabled people planning to become parents. Guests will also have the opportunity to influence Disabled Parents Network's future development.

The consultation events are free, and financial help may be available for the cost of travel, accommodation and personal assistance. Child care will be provided.

Event dates:

5 November 2005 - Essex
Marriott Hotel, Shire Lane,
Waltham Abbey.

26 November 2005 - Coventry
Village Hotel, Dolomite Avenue,
Coventry Business Park, Coventry.

1 April 2006 - Bristol
Novotel Bristol, Victoria Street,
Bristol.

6th May - Leeds
Novotel Leeds, 4 Whitehall Quay,
Leeds

For further details or to book a place contact Laura Bowey on 0115 9194565 or email:
consult@disabledparentsnetwork.org.uk

Wish you were here?

Disabled people's holiday experiences

A recent survey has revealed that much work is still needed to make holidays accessible to disabled people.

The survey, by the Leonard Cheshire charity, found that too often successful trips were the product of an individual's sheer determination rather than the efforts by the travel industry.

A spokesman for the charity, which supports thousands of disabled people across 57 countries, said: "Ensuring that holidays are accessible to disabled travellers is not only a moral imperative but also makes economic sense.

"It is estimated that the UK's 10 million disabled people have a combined annual spending power of around £80 billion."

The overriding message from those surveyed was that disabled travellers cannot take anything for granted.

Regular travellers said that it is essential to double check arrangements for all aspects of the trip. Many felt frustrated that information tends to be fragmented and they are forced to search extensively to find out whether their requirements can be met.

Key findings:

- *25 per cent said they had not taken a holiday in the past year because of problems with accessibility;*
- *Nearly half of those who had taken a recent holiday felt their travel agent or tour operator lacked basic disability awareness.*
- *57 per cent of those who had taken a holiday in the past twelve months highlighted inaccessible transport as a problem.*
- *Almost a quarter of those who had taken a recent holiday (22 per cent) said that they had difficulty in obtaining travel insurance*
- *Almost one in three (29 per cent) of the disabled travellers had experienced problems with the accessibility of holiday accommodation*
- *Despite frequent difficulties, 80 per cent of those who had taken a holiday said that it had ultimately proved a positive experience.*

The vast majority of those surveyed found UK airports to be fully accessible, with only 6 per cent reporting any kind of problem in accessing airport facilities.

On board the plane, however, 32 per cent of those surveyed had found that the aircraft toilet was inaccessible.

The spokesman for Leonard Cheshire said: "Accessible travel should not be the preserve of those with a budget which allows them to use specialist agencies. Tour operators should work to improve standards so that they are able to provide disabled travellers with packages that meet their requirements.

"They will have reached an acceptable standard of service for disabled customers only when disabled people are able to visit their local high street tour operator and book a trip with the confidence that every aspect will be accessible and meet their requirements."

About Leonard Cheshire

In the UK, Leonard Cheshire works with thousands of disabled people, helping them to live independently whether that means a few hours of care at home, or more intensive support at one of our residential and nursing homes.

The charity also provides independent and supported living, respite care and day services The full report, Travel Industry Discriminates against Disabled People, can be viewed online at ***www.leonard-cheshire.org***

49th conference for Research Society

ASBAH representatives and leading international experts gathered in Barcelona at the annual meeting of the Society for Research into Hydrocephalus and Spina Bifida, (SRHSB).

The four-day conference, held at the city's Vall d'Hebron Hospital, brought together experts from different fields who have a common interest in the conditions.

The Society was formed in 1957 to advance education and promote research into spina bifida and hydrocephalus. Today it is made up of 265 members from 30 different counties and has Carole Sobkowiak, one of the authors of the Your Child and Hydrocephalus book, as President.

ASBAH's Rosemary Bachelor told *Link*: "Papers were of a high standard and covered all aspects of spina bifida and hydrocephalus – from pre- birth with Professor Paul Griffiths report on antenatal MR scanning, to later years with a paper and poster from Dr Gill Hunt and Dr Pippa Oakeshott.

"As well as psychological papers and urology, a large project on childhood obesity was discussed together with an update on animal researchers work into the causation of hydrocephalus."

This years Casey Holter Lecture was presented by Dr John Mazor from the USA. For more than 30 years, Dr Mazor has run a spina bifida clinic, and he drew on his extensive specialist orthopaedic knowledge to give a stimulating talk.

Rosemary added: "The conference also gave us the opportunity to catch up with those people only seen annually and to meet new faces attending for the first time. Inevitably as time passes there are a few faces missing – we will particularly miss John Holter and Duncan Forrest who were connected with both ASBAH and SRHSB for many years. "

Gill Yaz, specialist medical adviser for the south east region, said: " The conference was very successful. The research papers covered a wide range of topics, from cell biology to independence, and were fascinating. Barcelona is a stunning city, I feel very fortunate to have been able to attend."

Dandy Walker Syndrome

Dandy Walker Syndrome causes 2-4 per cent of all cases of hydrocephalus. Dandy-Walker cysts block the fourth ventricle at the base of the brain. In these cases, hydrocephalus is often due to pressure on the surrounding tissues by the enlarging cyst.

Here Neil Buxton, Consultant Paediatric Neurosurgeon at the Royal Liverpool Children's Hospital, talks about Dandy Walker Syndrome and resulting brain abnormalities

Dandy Walker is a condition whereby there is abnormal development of the foraminae (holes) through which the cerebrospinal fluid (CSF) exits from inside the brain to the outside surface.

The foraminae, which failed to open during foetal development cause a blockage of the flow of the CSF.

This produces an abnormal enlargement of the fourth ventricle (fluid cavity between the brainstem and the cerebellum) resulting in failure of parts of the cerebellum to develop correctly.

A large cyst is then visible on scans of the back of the brain. These are severe abnormalities with hydrocephalus being present in 90 per cent of cases. Dandy-Walker causes 2-4 per cent of all hydrocephalus cases.

There are often many associated brain abnormalities. These include:

- Agenesis of the corpus callosum – (a rare neurological condition) in 17 per cent of cases
- Occipital encephalocoele (failure of fusion of the bones at the back of the head) - in 7 per cent of cases
- Spina bifida, syringomyelia (cysts in the spinal cord)
- Klippel-Feil syndrome (small heads and bone abnormalities of the neck)
- Other associated abnormalities include facial, ocular and cardiac.

Prognosis

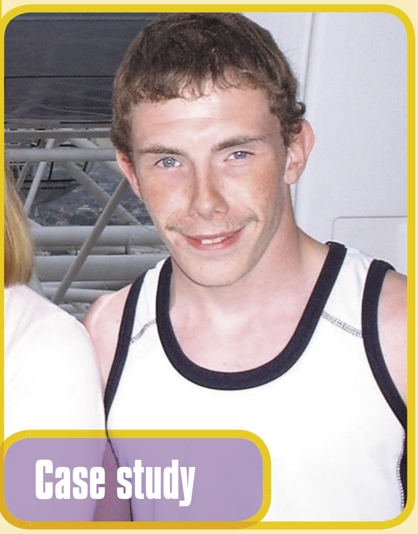
With treatment, prognosis is generally good with a 75-100 per cent chance of survival, but only 50 per cent of cases will develop a normal IQ. Balance, co-ordination and mobility problems are common, reflecting problems with the cerebellum and brain stem. Up to 15 per cent of cases will have seizures.

Inheritance patterns

Most cases are sporadic but there is a 1 per cent chance of recurrence in further pregnancies.

Prenatal diagnosis

Ultra sound scanning may detect the Dandy-Walker syndrome cysts.



Case study

Paul Bunce *(see story to the right)* and his wife Christine have 17 years experience of living with Dandy Walker Syndrome. They discovered that their son, James, now 17 *(pictured above)*, had the condition during a scan, 37 weeks into the pregnancy.

Here Christine talks about Dandy Walker and how it has affected James.

"I was scanned when I was 37 weeks pregnant because my midwife thought I was small for my dates. I barely looked pregnant really. They found a large cyst on the base of James's brain, and also found that his heart wasn't functioning properly either.

We had to wait a few days before there was anyone available to talk to us and explain what exactly was wrong. The cyst was very large and the prognosis wasn't good.

We were told – quite brutally - that James would most likely have difficulty with balance, walking and talking. It was also thought likely that he would have continence problems too. Thankfully he's proved the doctors wrong on all these counts.

James was born at 38 weeks, by normal delivery, weighing 5 pounds. Two of the four valves in his heart weren't working properly, but we were told just to keep an eye on him and were able to take him home ten days later.

Heart problems can be associated with Dandy Walker, but because the condition is quite rare, very little research seems to have ever been carried out. The neurologist we first saw had heard of the

condition, but knew very little about it.

James was a very irritable baby. He hardly slept and spent most of the day and night screaming. Nothing I could do would calm him down. He was a terrible feeder too. It would take two hours to get him to drink a couple of ounces of milk.

He's a hyperactive child, and always was, managing to roll over at six weeks old. But he was much later than other children in sitting and standing, and didn't walk until 21 months.

We were even told that the school would never be able to educate him, but again, James has proved everyone wrong by passing his GCSE's and is now at college.

James' shunt was fitted when he was six months old. We had been told that it was likely that he would develop hydrocephalus and we had begun to notice that he lay with his head to one side, and his forehead began to look very puffy.

When he was ten we were told by a cardiologist that his heart was so weak because of several holes in his heart we had to be very careful when he did exercise. Again, because of a lack of research and knowledge of Dandy Walker, we never knew if the two conditions were related.

James had major open heart surgery in 1999. His heart still isn't perfect, but it functions well enough.

Dandy Walker and hydrocephalus have affected James quite a lot. He's hyperactive and had a lot of behavioural problems at school. He would often get up from his chair and start walking around the classroom, being disruptive, and even though he was finally statemented, his school found him hard to deal with.

We were even told that the school would never be able to educate him, but again, James has proved everyone wrong by passing his GCSE's and is now at college, studying Health and Social Care.

Of course now he's older James goes off on his own, or with friends, but we still feel quite protective and keep a closer eye on him than perhaps we normally would.

He's also had problems with name calling at school. Some children found out that he had hydrocephalus, and through ignorance, started calling him "Half Brain." It did knock his confidence, but James has dealt with it all very well considering. In hindsight we should have asked someone from ASBAH to go into the school to talk to the children."

Paul Bunce cycle ride

Cyclist Paul Bunce tackled a gruelling John O'Groats to Land's End ride to raise more than £500 for ASBAH.

He said farewell to his family - wife Christine, son James, 17, who has Dandy Walker Syndrome, and daughters Catherine, 14, and Chloe, 3, - before saddling up on 20 July for the 950-mile journey... despite a painful shoulder injury.

Misfortune struck on day six, when, Paul, from Saltash in Cornwall, was knocked off his bike as he cycled alongside Loch Ness.

He explained: "My knee ballooned to twice the size and was so painful that I was forced to see a doctor in Fort Augusta who gave me some pills and a support bandage. He suggested rest to allow it to heal, but rest wasn't an option."

The strong-willed cyclist was determined that it would take more than two injuries to prevent him continuing his long-planned epic journey.

He rose to the challenge and relished the experience, enjoying the countryside and meeting many warm-hearted people keen to help him on his mission to boost ASBAH's funds.

After 18 long days in the saddle Paul, an IT instructor, crossed the finish line on 6th August at 2pm, tired but triumphant.

”It was wonderful to finally finish the journey. I got a great buzz to see so many people had turned out to welcome me," he said. "It was a great experience and I've promised myself I'll tackle it again... in ten years time."

Remembering Stevie

***Link* reader Helen Wilson is commemorating the life of her son Stevie by writing a book about his life.**

Stevie Smart, who had hydrocephalus, died on 3 April this year, age 46.

Now Helen is putting her memories of her son on to paper, and hopes to have the book published when it is completed.

Helen, from Amesbury in Wiltshire, told *Link*: “Stevie was born in 1958, just as the Spitzer Holt shunt was being introduced. Stevie didn’t ever have one fitted and travelled through life full of painful problems and severe epilepsy with such amazing courage and humility.

“Through the eyes of my son I have gained a greater understanding of life in every way. For almost 47 years we walked together through a maze of human misconceptions, misguided fears and sometimes heartbreaking rejection.

“Stevie was gregarious and faced the world with all its problems with a perceptive courage that left all obstacles aside.”

To the right is a poem Helen wrote in November 2004, expressing the sadness her son felt when others failed to give him the time to express himself.

I am me
Listening to your words
Hearing all you are saying
Taking it all in
Looking at you
Wanting to respond
In words the same as yours.
Bubbling up inside knowing
How I want to express
My answer.
The words will not move
From inside of me.
Instead you see, you hear
Nothing!

I have heard you
Understood the meaning
Of the words you have spoken.
I cannot reach you
In the same manner.
I see the look in your eyes
And I find it all so painful.
You will not understand me.
The pain is deep as I watch you
Turn away.

If you stayed to look in my eyes
You might see that I am hurting.
You might give me time
To reach you in a different way
And you would know
I am not ‘away with the fairies’,
Two farthings short of a penny
Or the ‘village idiot’.

You will find that I am full of love
Full of emotions
Full of understanding.
Sad almost beyond despair
At my inability to reach you
In your way.
You will find me though
I am me!

Stevie Smart

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.

My 12 week old daughter has recently been diagnosed with hydrocephalus and we went straight onto your site for information, we found it very informative and we are definitely ordering the book. Hydrocephalus isn’t nearly as scary when you are armed with the facts.

Emma and baby Kira

Until our latest grandchild was born, I have to admit that I hadn’t really heard much about spina bifida or hydrocephalus and if I am honest, just quite simply thanked God for my own healthy babies. Pretty selfish huh? Now we have Beth, and she is a delight. What a giggler! I know of course that she will have to face many trials and tribulations, but I’m sure that with the parents she is blessed with, all her family and friends and the enormous backing from Elizabeth Myers, the staff at Alder Hey and her ‘new family’ of others with spina bifida and hydrocephalus, she will grow into a beautiful, accomplished woman. The day I asked my doctor what I could do to help, he literally threw down his pen, shook his head and told me “just be the best granny you can possibly be”. I aim to be exactly that and more.

Granny Sheen

I recently renewed my subscription to *Link*. It is a lovely magazine… keep up the good work.

I wondered if it would be possible for you to include more input from parents? I wrote an article for the February/March 1994 issue about my daughter, Sophia. She is now 16 years old and we have crossed many bridges and life has been hard at times. She is now recovering from her first bout of pneumonia, and our world has been rocked again.

A page where a parent kicks off a debate, about feeding, incontinence, wheelchairs etc, with other parents responding with their views and experiences might help. It would be good to hear how other people deal with everyday problems as they can get even the most determined families down. Often someone will suggest something and I’ll think, “why didn’t I think of that?”. But I didn’t because I was too busy coping day to day.

Colleen Gardiner
Witham, Essex

We want Link magazine to be relevant and useful for all of our listeners – be they children, adults, parents or carers. We always do try to achieve a balance and most certainly welcome the idea of a regular feature -“the issue” where parents, clinicians ASBAH advisers – in fact everyone can give their ideas and suggestions on a topic.

We plan to start the ball rolling next time. Perhaps readers – including Colleen - could write in with possible topics.

Holiday let

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 facilities, 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*

PAIGNTON, DEVON

Six Berth all electric wheelchair accessible caravan situated within a mile of the beach. Site facilities include indoor and outdoor pools, sauna, steam room, children's play area, hire shop, amusements, licensed club and seasonal entertainment. All electricity & club passes are included at no extra cost. **Tel: Devon ASBAH on 01803 522256,** *(www.dasbah.com)*

PRESTATYN, NORTH WALES

Choice of two adapted caravans for disabled holiday makers. Each sleeps 6 people (2 wheelchair accessible bedrooms), wheel-in shower with seat, open plan lounge, dining, kitchen area. Caravans have ramp access and are overlooking a children's play area in a site adjacent to the beach at Prestatyn – a small market town on the North Wales coast within easy travelling distance of Rhyl, Llandudno, and Snowdonia National Park. Costs are between £95-£275 per week; **for further information contact Leeds & Bradford ASBAH, c/o Jo Baxter, 8 Staveley Court, Shipley, BD18 4HF. Tel. 01274 591850, e-mail** *jo@baxterjo.freeserve.co.uk*

TRENERRY LODGE, CORNWALL

Farm bungalow, mobility level 1 accessible. Sleeps 4, open all year. Short and long breaks.
Details: Angela Parsons tel: 01872 553755
www.babatrenerry.co.uk

BERWICK COTTAGE, EAST HARLING, NORFOLK

Purpose-built, self-catering accommodation for people with disabilities, their families or carers. Sleeps 6 (2 with disabilities). Facilities include Scan 700 beds, Clos-o-Mat toilet, bedroom-to-bathroom hoist, wheelchair shower and much more. Awarded highest National Accessible Scheme ratings. Weekly rates £295 - £645. Open all year. In pretty village with pub, shops and GP. **For bookings tel/fax: 01787 372343 (office hours) or email:** *info@thelinberwicktrust.org.uk*
website: *www.thelinberwicktrust.org.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*

ROPERS WALK BARNS, MOUNT HAWKE, CORNWALL

Opening August 2005, single storey accessible barn converted to a high standard by family of wheelchair user. Sleeps 4/5+cot. Short level walk to village, close north coast, 8 miles Truro.
Details: Liz/Pete Pollard, tel: 01209 891632
www.roperswalkbarns. co.uk

For sale

Powertrike with new batteries and wheelchair good condition - **Telephone: 01308 862614**

Titanium Quickie Wheelchair - only used for 2 months. Excellent condition. Cost £2,335 - will accept £1,500 - **Telephone: 01308 862614**

Diary dates

Contact your regional office for more details on the following dates:

Southern Region

Saturday, 12th November
Sunningdale Park, Berkshire
Your Voice presents - Know Your Shunt
Open to all adults aged 16 and over
(see page 14 for more details)

Northern Region

Saturday, 19th November
Moat House Hotel, York
Your Voice presents - Know Your Shunt
Open to all adults aged 16 and over
(see page 14 for more details)

Wales

Wednesday, 8th March
Hilton Hotel, Newport, South Wales
Hydrocephalus Awareness Parents day
(based on the *Your Child and Hydrocephalus* book)

Disabled Parents Network Consultation Events

5 November 2005 - Essex
Marriott Hotel, Shire Lane, Waltham Abbey.
26 November 2005 - Coventry
Village Hotel, Dolomite Avenue, Coventry Business Park, Coventry.
1 April 2006 - Bristol
Novotel Bristol, Victoria Street, Bristol.
6th May - Leeds
Novotel Leeds, 4 Whitehall Quay, Leeds

For further details or to book a place contact Laura Bowey on 0115 9194565.
Email: consult@disabledparentsnetwork.org.uk
(see page xx for more details)

Please e-mail the editor (link@asbah.org) dates of your events for the next issue of Link by Friday 16 December 2005, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.

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 16th December 2005

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

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Fax: 028 90797071
Email: ***niro@asbah.org***

Land’s End to John o’Groats... and back again

Joe Beal

When Joe Beal sets himself a challenge, he doesn’t do anything by halves.

So when he decided on a cycle ride to raise cash for ASBAH, the well-worn Land’s End to John o’Groats trail – tough by anyone’s standards – wasn’t quite enough.

So Joe, 24, decided to cycle to the isolated Scottish village... and back again.

And on 1 September, 19 days after he set off, Joe completed his mammoth journey and expects to raise more than £2,000 for his efforts.

ASBAH is a cause close to Joe’s heart after seeing his older brother Ben, who has hydrocephalus, undergo several shunt revisions during their childhood.

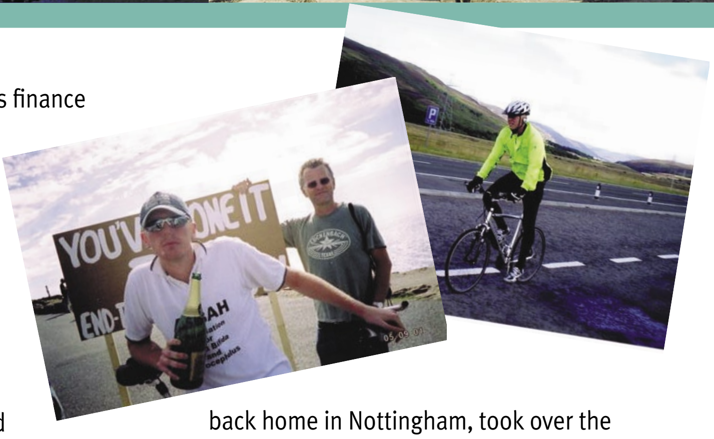
Joe, from Nottingham, said: “When we were younger I suppose I didn’t take much notice. But later on, as we grew closer, it never seemed very fair that I was OK and Ben was the one who always seemed to be in and out of hospital. I often felt that I would give anything to swap places with him.”

When I reached John O’Groats the sun was shining, and for such an isolated spot, it seemed quite welcoming. But I didn’t hang around. I got back on my bike and set off again.

In January Joe decided that he wanted to raise money for ASBAH, and came up with the idea of doing the 1,800-mile ride.

“ASBAH have been very supportive throughout Ben’s life and have given so much to him and the rest of our family,” he explained, “this was my chance to give something back.”

Joe, who works in Ntl’s finance department in Nottingham, had little experience of cycling, although he kept his fitness levels up playing football.



After a one-off 200-mile training ride to Hull and back, he pronounced himself ready and raring to go.

He left Land’s End on 14th August, making his way to the halfway mark on 22August, just 9 days later.

Joe said: “The ride was easier than I expected, but after some bad weather in Inverness, my heart did sink at the thought of going back again.

“When I reached John o’Groats the sun was shining, and for such an isolated spot, it seemed quite welcoming. But I didn’t hang around. I got back on my bike and set off again. Scotland was very beautiful, but I felt very lonely. Thank goodness for my ipod!”

But despite the solitary daily cycling, Joe’s father drove a support van 30 miles ahead, packed with camping gear and food. Joe also kept in touch with family and friends via an online diary. When he was too tired to update it, mum Clare, back home in Nottingham, took over the task.

In front of a 100-strong welcoming committee, Joe arrived back in Land’s End on 2 September.

He told *Link*: “I got quite emotional when I saw everyone gathered at the finish. It was quite a shock. I would like to thank the couple – complete strangers - who donated £50.

“I’d also like to say a HUGE thank you to everyone who has supported and sponsored me especially my support crew.”

When *Link* spoke to Joe, just two weeks after he completed his epic ride, he was already talking about his next challenge.

“Race America, where you have to cycle from coast to coast in 12 days, would be exciting,” he said. “But next time I’ll make sure I take a few friends with me.”

Check out Joe’s daily diary online at ***www.justgiving.com/joebealcycleride2005***

Joe is happy to give help and advice to anyone planning a similar journey. He can be contacted through *Link*.

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