WINTER 2008 ISSUE 222

link

The magazine for people with hydrocephalus and spina bifida

Below the Belt tackles teenage issues

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For more information call our telephone fundraising team on 01733 421334

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the lifestyle magazine for people with hydrocephalus and spina bifida

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Gill Winfield writes

I am delighted to be editing this first issue of *Link* for 2008 as part of my new role as Marketing and Communications Manager.

I've been with ASBAH for many years, most recently in the role of Principal Policy Officer, so I'm very familiar with what is happening in the organisation.

As regular readers will know *Link* is running a series of special supplements to take a more in-depth look at some of the many issues which affect ASBAH service users.

This time we're focussing on pregnancy issues, from the diagnosis of spina bifida and hydrocephalus, through to the psychological problems associated with having a child with a disability.

Also in this issue is news about the launch of ASBAH's exciting new book for teenagers. *Below the Belt*, has been published in partnership with Hollister and deals with the subjects of continence and sexual health.

There's an update on the campaign for the mandatory fortification of flour, following Andrew Russell's recent visit to Brussels to take part in a Flour Fortification conference organised by the International Federation for Spina Bifida & Hydrocephalus (IFSBH).

Of course there's the usual round-up of fundraising stories, a humorous write-up by columnist Linda Corbett and the regular Days in the life of … feature.

Which just leaves me to wish you all a happy and healthy 2008.

Gill Winfield
Marketing and Communications Manager
gillw@asbah.org

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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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contents

Helping you to find a better job

A new employment project launched by ASBAH has confirmed that there are still many obstacles facing disabled people trying to find employment.

The project, which is funded by the City Bridge Trust, aims to help people with spina bifida and hydrocephalus in London find suitable work.

The project, which was launched last year, is headed by ASBAH education & employment adviser Naomi Marston.

Naomi told *Link*: "It became apparent early on that many professionals in establishments had little knowledge of spina bifida and knew even less about hydrocephalus.

"This meant that they had no knowledge of strategies such as memory aids and organisational strategies that could be implemented to help with some of the difficulties people with hydrocephalus experience.

"We have since worked closely with a number of organisations and individuals to implement and support strategies such as these."

The project has already held two Employment Information Days in Greenwich and Bromley for service users hoping to find work.

"The feedback has been that these sessions have been very informative and motivating," Naomi added.

Personal profiling with individuals is another key role Naomi has incorporated into the project, to enable service users to examine their skills and interests and find a job to which they might be suited.

Sue Jackson, Senior Lecturer in Disability Support at the London College of Communication, explained: "The DDA expects Higher Education to 'anticipate' the needs of disabled students.

"With ASBAH's extensive knowledge of hydrocephalus, I was able to work with Naomi to evaluate a student's learning using very different assessment processes to overcome his memory problems and depression. That student now has a degree and is looking for employment."

Case study

Gemma, from London, has Hydrocephalus. She was unhappy in her job - it was stressful and caused her to experience Repetitive Strain Injury.

After a two-hour session with Naomi to identify her strengths and weaknesses Gemma had a clearer idea of the sort of job she should be looking for.

Gemma said: "Naomi advised me to look at my skills as a new starting point to find a more suitable job.

"It helped me create a stronger foundation and taught me to work with what I am good at, not at what I think I should be good at. I have now found a job that makes me satisfied in so many ways."

Parents fight school funding cuts

ASBAH is linked to a new website of a small but dynamic action group which is protesting about huge funding cuts for children with Special Educational Needs (SEN).

Action4SEN was formed by parents in Minehead concerned about the latest 40% Level 1 school funding cuts by Somerset County Council for SEN.

The group, led by Siobhan Hutchings and Kate Atkins, is lobbying at all levels in the fight to provide a good education for all children.

Siobhan's son, Joe, age 7, has spina bifida and hydrocephalus with Level 1 special needs. He also receives funding for his medical needs.

The cut in funding means that instead of working alone with a key worker on a one-to-one basis, Joe will now work in a small group of children, which Siobhan says is not sufficient for his needs.

Siobhan said: "Joe has several hydrocephalus-related problems including short-term memory difficulties and poor concentration. He is also easily frustrated and after we had him independently assessed, he was diagnosed with borderline dyslexia.

"This severe cut in funding is a major concern to us and our fear is that Level 1 funding will disappear altogether.

"These children who have less severe needs will not be getting the important one to one support they require to keep up with their peers.

"The budgets are being stretched further and further which means that children of 'normal' ability will be missing out as the classroom Learning Support Assistants are having their hours cut back or are trying to be in two places at once."

Siobhan and fellow campaigner Kate Atkins set up their own action group in Minehead in July as Kate's son, who also receives Level 1 funding for his special needs, was affected by these cuts. Between them they have gained plenty of support from other concerned parents in the area.

They contacted their local MP Ian Liddell-Grainger who has backed their cause; they've raised their concerns with Somerset County Council and have lobbied Lord Andrew Adonis, Parliamentary Under Secretary of State for Schools and Learners.

From left Siobhan Hutchings, Joe and Kate Atkins

ASBAH Education adviser Carol Rubinstein visited Joe's school in May to talk to staff about hydrocephalus and how Joe could be helped.

"Carol gave staff some very practical advice such as suggesting that Joe was given a writing slope because children with hydrocephalus often find it easier to read words if they are on a sloping surface. Also, looking at words in terms of shapes can make them easier to remember."

Siobhan added: "We'd love other parents from around the country who have also experienced funding cuts to get in touch and lend their support."

View Action4SEN's website:
www.action4sen.org.uk

Below the Belt hits the right spot

ASBAH has launched a new book to help address some of the many issues facing teenagers with spina bifida and/or hydrocephalus.

The 32-page *Below the Belt* book was launched on 31 October and has already been praised for its practical advice.

The A4-sized publication is packed with useful information and advice on matters which affect teenagers.

Continence issues form a large section of the book, ranging from easy-to-understand medical explanations, problems which can occur and how they can be rectified.

The Taking Control chapter looks at the challenges of managing your own bladder and bowels and how to plan a thorough hygiene routine.

Relationships and sex is another area – often unmentioned – which is covered in the book. A glossary explains some of the medical terms people with continence issues may come across, plus there are plenty of contact numbers and websites where readers can access more information.

Below the Belt was written by ASBAH advisers Rosemary Batchelor, Lisa Raman, Angela Lansley and Gill Yaz . It was sponsored by Hollister Limited, a healthcare company which provides the Advance range of intermittent catheters.

The book's foreword was written by Frank Lee, Consultant Urological Surgeon at St George's Hospital, London.

He said: "*Below the Belt* is an ideal starting point for children approaching their teenage years, or anyone wanting to know more about spina bifida. The transition from childhood to adolescence is enjoyable, but can also be stressful.

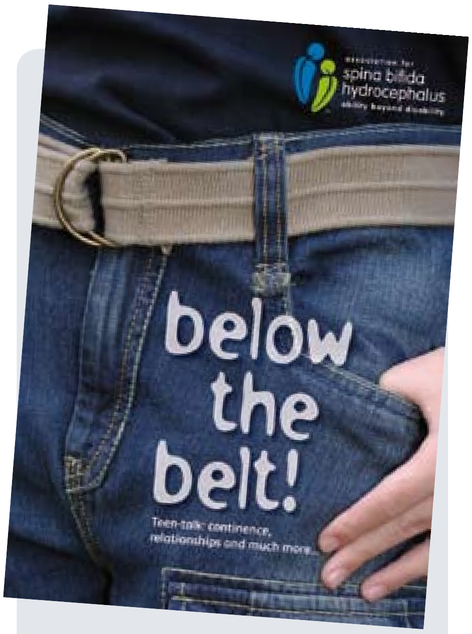
"I hope the topics covered will stimulate further questions and encourage people to talk to ASBAH about any issues which they may feel uncomfortable raising."

One of the models in the book was Karl Goddard, whose mum Michelle is Chair of the Sheffield Local Association.

Michelle said: "I think there was a real need for the book. We have found that any extra information is a great help.

"The teenage years are difficult and unsettling for anyone, and it is doubly hard for anyone with a disability. *Below the Belt* should really help to answer some of their questions."

Phone ASBAH's helpline on 0845 450 7755 for details of how to obtain your copy or order your copy on-line at ***www.asbah.org***



"ASBAH recognises that taking responsibility and control over one's life is the most desirable yet most difficult thing to do during the teenage years.

"Teens with spina bifida and hydrocephalus may feel even less prepared to meet the challenges of growing up; but in fact, the key to success is no different for them than for their peers. That key is knowledge and self-awareness.

"*Below the Belt* provides teens who have SB with honest, straightforward information that they need to navigate the difficult issues and make their transition into a healthy adulthood, so they can fully realise their true potential."

Lisa Raman, National Medical Adviser and co-author of *Below the Belt*.

Below the Belt official launch

***Below the Belt* was launched in style at a special House of Commons reception.**

The event, on 31 October, was attended by 50 guests, including health professionals, representatives from ASBAH and Hollister Inc and several MPs.

Several families who have contributed to the content of the 32-page book were also among the party.

Stewart Jackson, MP for Peterborough and keen supporter of ASBAH, hosted the House of Commons launch.

Mr Jackson said: "ASBAH does tremendous work in helping individuals and families affected by spina bifida and hydrocephalus so I was delighted to be able to help with the launch of this fabulous new book.

"*Below the Belt* is a great new resource for young people who have spina bifida."

ASBAH Chairman Richard Astle welcomed the guests and thanked those who had been involved with the production of the book.

Diane Owen, Global Clinical Marketing Manager at Hollister's Continence Care division told *Link*: "Hollister is committed to the mission of providing quality products and services that help people live with dignity. We are delighted to back education initiatives such as *Below the Belt* which support this mission.

"*Below the Belt* provides teens with information on living with incontinence in a frank and honest way, addressing these issues in a language that teens understand.

"Hollister is delighted to have sponsored such an important education tool which we are certain will have a positive impact on the lives of teens living with Spina Bifida."

Gateway to Opportunity

Young people involved in the Gateway to Opportunity project brushed up their painting skills on an eight-week art course.

Seven people, who have spina bifida and/or hydrocephalus, took up the chance to study under French artist Franck Saucian, who is based at Rossan College in Letterkenny in north west Ireland.

The course ended with an exhibition of their work on 6 December in the town's Create A Link art studio.

The Gateway to Opportunity project is part of the Cross-Border Initiative between the UK and Irish Associations for Spina Bifida and Hydrocephalus and Inishowen Rural Development (IRDL).

It aims to deliver a wide range of opportunities to young disabled adults aged 18-30 through training, signposting and encouragement.

Barbara Wosser, project worker, said: "The participants enjoyed it immensely and got a lot of enjoyment out of it. They are so proud of their achievements and were thrilled to see their work on display.

"When the course started I think they found it quite tiring and they were unsure that what they were creating was going to be judged.

"But Franck made them aware that what they were doing was for themselves and to just enjoy it. As you will see from the photos, they really got stuck in."

Barbara said that the Cross Border Initiative is currently contacting groups such as state agencies, medical professionals and disability organisations within Northern Ireland to share knowledge and experience.

"We hope they will come on board and link up to sustain a model which may be used throughout the Border Regions of Ireland," Barbara added.

The participants enjoyed it immensely and got a lot of enjoyment out of it

"This Project is very worthwhile for this age-group as it offers training with certified courses and enables them to meet people from all backgrounds.

"It encourages participants and their families and peers. It raises awareness of the difficulties faced and generates a greater appreciation of how more support may be provided."

Cathy McKillop, Northern Ireland Regional Manager added, "This project has allowed ASBAH to develop a strong cross border presence and working with the Republic of Ireland partners bodes well for future joint initiatives."

The project has been part funded by the Community Foundation for Northern Ireland through the EU Peace II initiative.

£30,000 for Mum whose GP failed to advise her to take folic acid

A Lincolnshire mother has won an important legal case that highlights how essential it is for women to take folic acid before they try to conceive as well as during pregnancy.

Jill Fox, from Bardney, won compensation totalling £30,000 from a GP in her former home town of Stockport.

He failed to advise her to take folic acid as a dietary supplement even though she had told him of her plans to conceive.

Mrs Fox became pregnant but, during a routine 20-week ultrasound scan in 2001, her baby was discovered to have anencephaly - severe abnormality of the brain.

She felt unable to have the pregnancy terminated but the baby girl, named Rachael, died at birth at 34 weeks. Mrs Fox suffered years of anguish and was later diagnosed as suffering from post traumatic stress.

Experts consulted by Mrs Fox's solicitors later said it was "more likely than not" that the anencephaly would have been prevented if Mrs Fox had taken folic acid supplements.

Mrs Fox, who has five other children, had taken folic acid during previous pregnancies but was not fully made aware of its importance.

She said the death of her baby daughter had led to years of depression and meant she became unable to cope with everyday tasks, despite the strong support of her husband, Kevin.

She said: "After discovering that Rachael had anencephaly at 20 weeks into the pregnancy we had to prepare both for her birth and her death, even making arrangements for her funeral while I could feel her moving and kicking inside me.

"Rachael died just as she was born and I never got to hold her, which was devastating.

"I dropped into a deeper and deeper depression and, partly as therapy, I began to research anencephaly and its causes and I came to realise that Rachael's death could have been avoided.

"Bringing the legal action was horrendous but there was no other way to show that the doctor had not acted properly and, more importantly, to highlight just how important it is to take folic acid, not only in the first few weeks of pregnancy but before conception."

STAR supporters

This issue we take a look at The City Bridge Trust, another of ASBAH's Star Supporters.

The London area has enjoyed the services of an extra ASBAH adviser thanks to generous funding from The City Bridge Trust.

The charity, which changed its name from Bridge House Trust earlier this year, awarded a grant worth £120,000 over three years to ASBAH in 2005.

This specialist adviser provides Educational Transition, Life Skills and Employment Development for young people and adults, in London, who have spina bifida and/or hydrocephalus.

DOMINE DIRIGE NOS
CITY OF LONDON

Helen Dow, Project Co-ordinator at ASBAH, said: "When we applied for the grant in 2005 ASBAH was supporting 335 people with hydrocephalus in Greater London, 209 of which were over 14 years old.

"With an estimated 1,700 young people and adults in Greater London who have hydrocephalus and another 200 being diagnosed each year, there is always great scope for our work to expand.

"ASBAH is very grateful for this grant which enables people in London with spina bifida and/or hydrocephalus to receive appropriate educational support when leaving school for further education and for others to reach their potential in employment.

"Without The City Bridge Trust's support this work would have been unable to take place."

The Trust, which makes grants in excess of £15 million a year to charitable projects in Greater London, has donated a total of £201 million since it was established in 1995.

It was created from the Bridge House Estates charity, which was set up to maintain the first stone bridge across the River Thames - London Bridge.

In more recent years the charity built Blackfriars Bridge and purchased Southwark Bridge and, just over a century ago, constructed Tower Bridge.

The charitable arm enables the Trust to use its surplus money for the benefit of Greater London.

In the past 12 years thousands of people through the 32 London boroughs and the City of London have benefited from grants The City Bridge Trust has made.

Among them are hundreds of people who have been helped by the ASBAH adviser.

Jenny Field, Principal Grants Officer at The City Bridge Trust, told *Link*: "Removing the barriers that prevent disabled people taking part in society is central to the City Bridge Trust's Access for Disabled People programme.

"A key barrier to independent living and participating on equal terms with non-disabled people is access to education, training and employment opportunities which is why we are funding ASBAH to work in this area."

Jenny said that the City Bridge Trust's previous funding of ASBAH which has been put towards its work promoting independent living, has already demonstrated the high quality of ASBAH's work.

In this latest grant application ASBAH had put forward a convincing case about the needs of young people in transition from school and of adults who left school before the introduction of statements of special educational needs.

She said: "Thanks to the new adviser, people with spina bifida and hydrocephalus are at last receiving the specialist advice, information and advocacy they need to transform their lives."

Awareness Day boosts understanding

Service users, carers and professionals in the Midlands gained a wealth of information and a different perspective on spina bifida and hydrocephalus at a recent ASBAH conference in Birmingham.

Advisers Geraldine Long and Jenny Green were aware that an information day was needed in the central area, and worked together to set up the event at the Tally Ho Conference Venue.

The conference attracted plenty of interest with 76 delegates – made up of service users, parents and medical and other professionals.

Colleagues from the Birmingham Children's Hospital were keen to offer their services and talks were given by: Mr Solanki, neurosurgeon; Mr Parashar, urologist; Mr Bache, orthopaedic surgeon and psychologist Dr Blyth.

Jenny said: "Their talks were excellent, but for many the highlights of the day were the presentations of four parents who gave moving accounts of their families' journeys with the condition.

"Two adult service users also gave excellent presentations ending the day on an upbeat note, describing their active lives and offering advice to parents and professionals working with young people today."

"Feedback indicated that even those with experience of the condition gained new learning and new perspectives from the highly informative and accessible lectures."

Geraldine and Jenny thank the many people who helped put on the first class event – from the speakers and the local Hollister representative through to ASBAH colleagues Rosemary Batchelor and Lisa Ramon and the many volunteers who helped to run the day.

Nursery gives It some welly

Thorne Manor Day Nursery in Holsworthy, Devon, has raised £400 for ASBAH by holding a rather unusual event where staff and children took part in a sponsored welly and slipper throwing competition!

The event took place over the course of the nursery's Holiday Club Week and every child had the opportunity to take part and receive a certificate. The toddlers had a go at throwing slippers into a box or through a hoop, whilst the older children aimed to throw their wellies over a line 20ft away.

Three year-old Kerenza Downes who attends the nursery has spina bifida. Kerenza's mum, Jo Downes, is an ASBAH service user and both her and Kerenza receive help and support from ASBAH advisers. Jo thought this year's fundraising event would be a great opportunity to give something back to ASBAH.

Emma Gibson, team leader at the nursery said: "We are delighted to have raised this money for ASBAH. It always feels good to be able to help a charity but, as we have a personal connection with ASBAH, this is even more satisfying. Kerenza's friends at Thorne Manor enjoyed taking part in the event."

Pictured right: Emma Gibson, Team Leader and Kerenza Downes

Pounding the streets of Peterborough for ASBAH

A local firefighter took to the streets of Peterborough in October to take part in the Great Eastern Run raising a fantastic £350 for ASBAH.

Andy Wright and his wife Paula, from Huntingdon, Cambridgeshire, were among 3,000 runners tackling the tough 13.1mile course.

Andy, 36, wanted to raise cash for ASBAH as a thank you for the tremendous amount of support that the family has received for their daughter Katie.

Katie, now six, was born with hydrocephalus and the family has received support from ASBAH from the outset. Andy said: "ASBAH has been a great source of information and support for us over the last six years."

See more on the Great Eastern Run in Link 223

Cycling holiday raises £3,000

Shaun Gilliam and Rob Wallace spent their two week summer holiday a little differently this year, by cycling the length of Great Britain to raise cash for ASBAH.

Shaun and Rob cycled 951 miles from John O'Groats to Lands End in only 75 hours and 36 minutes by riding for six hours a day at an average speed of 11.9 miles per hour…. raising £3,000 in the process.

Shaun said: "It was really hard to begin with, both mentally and physically, but after about three days we adapted to the challenge."

It has always been an ambition to tackle the gruelling ride and when Shaun's daughter, Angel, was born with hydrocephalus in June 2006 they thought it would be a great way to raise some money for ASBAH.

"Before Angel was born I had no idea what hydrocephalus was, but in the early months of Angel's life ASBAH gave so much support to me and my wife Debbie. I want to raise the profile of ASBAH so they can keep helping others," said Shaun.

A huge thank you to Shaun and Rob for the fantastic amount of money they raised and for raising the profile of ASBAH throughout the length of the country – literally!

Ready… Steady… Wheel!

Jake Norris raised £250 for ASBAH after challenging Steve Knight, Entertainment Manager at the Beachcomber holiday resort in Cleethorpes, to a sponsored wheelchair race which was held at the resort.

The event was organised as Jake wanted other people to gain an idea of what it's like to be a wheelchair user.

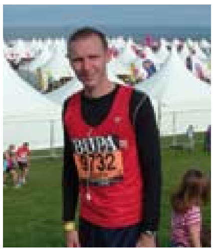
Onlookers were also offered the chance to join in. For those who were brave enough, a £1 donation gave them the chance to race Jake.

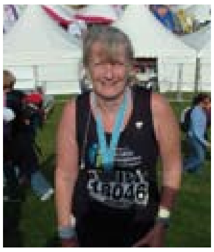
Collette Torrance from ASBAH was at the event to receive the money raised from Jake.

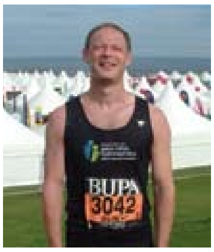
She said: "Jake is a wheelchair user but wanted to surprise some of his friends at the Beachcomber by walking across to hand me the cash using calipers which he has recently had fitted."

"Jake is a remarkable young man with an incredible outlook on life. He recognises that even though he has a disability, other people are even less fortunate than himself and he makes a tremendous effort to help them."



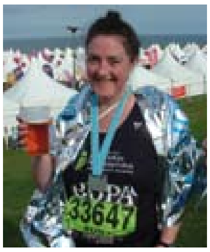





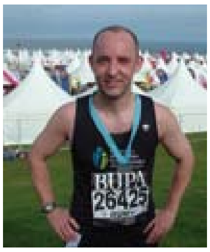













ASBAH's Great North Runners

An army of runners battled their way round the world's most popular half marathon road running event, the 2007 BUPA Great North Run, to raise money for ASBAH.

All the money raised through the race, held on September 30th, will help ASBAH to continue to provide the best care, advice and support to its service users.

Participants covered the 13.1 miles between Newcastle upon Tyne and South Shields, alongside leading athletes and celebrities including Charlie Brooks, Carol Vorderman and BBC Breakfast host Bill Turnbull.

"The race was a lot of fun but it was extremely tough going. Both me and my cousin took part. I found the whole event very enjoyable so hope to do it again. I'll just make sure that next time I do a bit more training."

Michael Ackroyd, Ilkley

"The Great North Run was the best thing I've ever done. After deciding to do the race to lend a bit of moral support to a friend I ended up surprising my friends, family and even myself by achieving the goal I set myself of running all the way. The nine months of training I did before the race really paid off."

Jane Halpin, Carnforth

"My husband ran the race last year and really enjoyed it so this year I thought I'd give it a go and it was a great experience. After 6 months of training and running the whole way round the route I raised £535 for ASBAH which I believe is a really worthy cause. I'm already thinking about next year's race."

Rachel Lindley, Yorkshire

"I'm a bit of an amateur runner and took part in the London marathon earlier in the year so I chose to do the Great North Run as I was already quite fit. I ran for ASBAH because my niece, Ruth, has spina bifida and hydrocephalus. The race was fantastic and I raised over £200."

Lydia Warren, Swindon

The Great South Run

A huge thank you to everyone who took to the streets for ASBAH in this year's Great South Run.

The runners braved the wet and windy weather to tackle the tough ten-mile race which passes many of the historic landmarks around Portsmouth, including the HMS Victory.

Great South Run regular Emma Hine ditched her usual superhero costume this year and finished the tough course in a speedy 1 hour 26 minutes.

Left to right: Sharon Burgess, Emma Hine and Heather Patterson.

Front: Keith with Shelly Bullard.
Back L-R: Pub's committee - Chris, Jason, Paul, Chris, Ronnie and Chris

Annual event raises smashing amount for ASBAH

In time honoured tradition, The Woolpack Pub's annual Conker Championship raised a smashing £1012 for ASBAH.

The event, now in its sixth year, was again held in the garden of the pub, in Stanground, Peterborough.

The Woolpack staff also arranged other fundraising activities including a raffle and a BBQ. One very dedicated member of staff even spent the day dressed as a lady, raising £80 towards the fundraising total. A local artist also kindly donated four original drawings which were auctioned off through sealed bids.

Several members of ASBAH's fundraising team went along and took part. Shelly Bullard, an ASBAH fundraising officer said: "It was great to see so many people having fun, celebrating an old tradition and raising money at the same time. I would like to say a big thank you on behalf of ASBAH to all who participated."

Robin Revs Up £1,000

ASBAH benefited to the tune of £1,000 when Robin Middleton fulfilled his life long dream of becoming a racing driver.

Since the age of 12, Robin, a self-confessed 'motor racing anorak', has dreamed of racing a car, so when he got the opportunity to compete in a gruelling weekend of racing at the Stock Hatch Challenge race in Pembrey, South Wales, he jumped at the chance.

Driving a 15 year old 1.6 litre engine Ford Fiesta, Robin, from Newbury in Berkshire, battled against 35 other cars to complete ten laps of the one and half mile track.

In his first race he got off to a flying start, but was black-flagged because of leaking oil, and he fell to 22nd place.

A new day brought a new race and on Sunday he hit the track like a pro. In the penultimate lap he manoeuvred to overtake but unfortunately hit another car causing him to spin off the track and stall. By the time he got the car started he had dropped to last place.

Robin, whose niece has hydrocephalus, said: "I was going to do the race anyway but thought I may as well try to raise some money for charity at the same time. My niece has always received a lot of support from ASBAH and I wanted to give something back."

Robin's race raised a fantastic £655 and matched funding from his employer, BP, has been applied for, which could lift the total to over £1,000.

Teeing off to a big total

A big thank you goes to Malcolm White and colleagues at White Bros. and Speed Ltd who have donated the proceeds of their annual Golf Day to ASBAH in Wales for the past six years.

The company, in Newport, Gwent began supporting ASBAH in 2001, raising £300 in the first year.

The figures have steadily risen each time and in 2007 they donated an incredible £6,401. In total the company has raised a fantastic £18,777 towards ASBAH's work in South Wales.

Elin Ifan, Regional Manger for ASBAH in Wales said: "We are very grateful to all who participated in these Golf Days. Their efforts ensured a very successful outcome."

Pictured above: Margaret Stanton is presented with a cheque by Malcolm White, Managing Director of White Bros and Speed Ltd.

Nicola (left) and Elin Ifan

Birthday girl raises £500

Big hearted Nicola Pritchard raised £500 for ASBAH when she asked friends and family to make a donation to her favourite charity in lieu of presents.

Nicola Pritchard, who celebrated her 40th birthday with a party at Bangor Cricket Club, said: "We had a great night, with wonderful food and a disco. Instead of presents I asked people to donate money to my favourite charity, ASBAH, and raised £500.

Elin, Regional Manager for ASBAH in Wales, told *Link*: "Nicola and her family have supported us for many years, and we are so grateful for their support. We wish Nicola many happy returns for her 40th birthday".

A mountainous challenge

Employees from Cannons Health Club in Nuneaton raised more than £400 for ASBAH after climbing the three highest mountains in Britain.

The Three Peaks Challenge includes walks up Ben Nevis in Scotland, Scafell Pike in the Lake District and Snowdon in Wales, throughout the morning, noon and night, with little rest except for drives between the mountains. The three summits have a combined height of more than 3,400 metres.

The team proved they had been putting the health club's facilities to good use when they managed to complete the challenge, which should take 24 hours, in just 22.

Ben Helsby, Steve Warner, Craig Richards and Wesley Williamson tackled what many people describe as 'one of the ultimate challenges in the United Kingdom' in the summer.

Luckily a support team were on hand to drive the team between the mountains and cook their food for them.

Ben explained why he took on the challenge: "My wife has a mild form of spina bifida – when she was diagnosed she found a lot of useful information on the ASBAH website; obviously fundraising contributes to the maintenance of that and other useful resources.

"At times it was hard and conditions weren't ideal. For example we climbed Scafell in the pitch black with nothing but head torches to guide our way.

"However, we reached the top at dawn and the spectacular views, as well as knowing we were raising money for ASBAH made it all worth while."

> My wife has a mild form of spina bifida – when she was diagnosed she found a lot of useful information on the ASBAH website; obviously fundraising contributes to the maintenance of that and other useful resources

Moira Foggo (centre) and members of the North Cumbria Tractor Club; Chris Stan, Davy, Terry, Sandy, Jim and Doug

Tractor Power

Five intrepid members of the North Cumbria Tractor Club ploughed almost £1,200 into the ASBAH coffers after completing an amazing 138-mile drive.

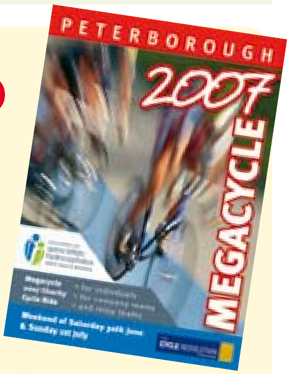
The team revved up their engines in Penrith, setting out on their incredible journey through the glorious Cumbrian countryside.

Passing though the beautiful Lake District, their trip included a ferry crossing, which gave the drivers the chance to stretch their legs.

On their return the following day they were greeted by fellow Club members and celebrated with a hearty meal at the Stoneybeck Inn.

Money was raised through sponsorship and donations and thanks to everyone's effort the total amount raised beat all expectations.

Megacycle Round Up

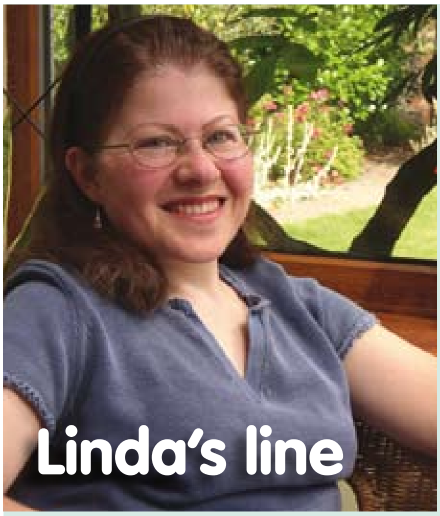


The 14th annual Megacycle in Peterborough raised a total of £4,234 towards the work of ASBAH in the community.

Ian Morley (left) meets Tim Davies

Megacycle – Cyclic Rotations

Tim Davies, Jason Soilleux and Phil Nightingale took part in the megacycle for the first time this year. The aptly named 'Cyclic Rotation' team not only collected significant personal sponsorship but also approached employers Perkins Engines for support under their fund matching scheme; resulting in another significant cheque. Team leader Tim Davies even cycled all the way to ASBAH's national office on a very cold day to ensure sponsorship money reached us safely. They raised a total of £943 which is fantastic!



Linda's line

During one of my many visits to the dentist over the summer, I came across a leaflet explaining the facts about dental implants, which whiled away a few minutes of tedium in the waiting room.

I can now add to my store of medical trivia that these implants sit on top of tiny metal spikes made of titanium welded into the jawbone. Possibly useful for your next pub quiz?

Coincidentally my own collection of implants, allegedly still holding together a few dodgy vertebrae, are also made of titanium.

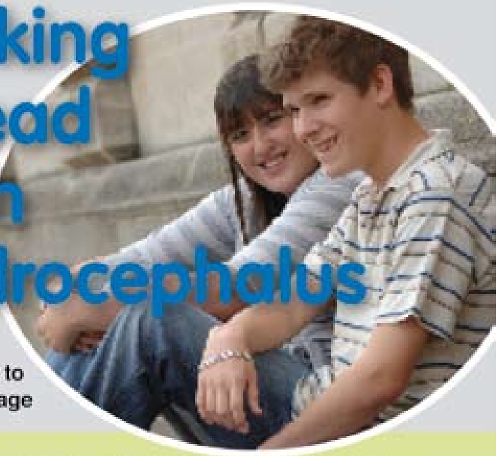
Without wishing to sound like I am blowing my own trumpet, this is a seriously more impressive array of implanted metal than a few tiny spikes in your teeth. And then I got to wondering how surgeons got all these ideas for implants in the first place - maybe they watched the Six Million Dollar Man in their youth. Those of a certain age will remember Steve Austin, the TV space pilot, who was injured (can't remember how) and then rebuilt with various bionic parts, which cost around six million dollars (hence the title). He certainly got value for money as far as implants were concerned and he had some fantastic features. For example when he ran, it looked as though he was going in very slow motion but amazingly he could catch a speeding train! We must have had similar implants, as I am excellent at doing the going in slow motion bit but the only trains I've caught recently have been stationary so I haven't managed to do a full speed trial yet.

However, I can regrettably confirm that I don't have the bionic eye feature. That would be really helpful when I am craning my neck round in the car trying to join the Leatherhead one-way system every morning, and leads me to suspect I didn't get quite the same upgrade. I don't suppose my kit cost six million dollars either, or else the NHS would not have stumped up the money for new parts. Mind you, I've been taken apart and put back together more times than an MFI wardrobe so it's amazing that there weren't any bits left over really. Or perhaps there were and they didn't tell me - after all it wouldn't look too good if surgeons handed you a bag of screws and rivets after the operation saying sorry it didn't all fit together, but the instructions were translated from Chinese. I'm not sure what you'd do with the bits anyway – part exchange them when you have the next upgrade perhaps?

ASBAH Eastern Region
Information Day

association for spina bifida hydrocephalus
ability beyond disability

Looking Ahead With Hydrocephalus



Aimed at 12 to 25 years of age

Wednesday May 14th 2008 at the
East Midlands Conference Centre
University Park Nottingham

TOPICS INCLUDE:
- hydrocephalus explained
- shunts
- independence
- responsibility
- taking control
- transition
- positive outlook

For further information contact
Eastern Region Tel: 01733 421309
email: shirleyl@asbah.org
Helpline:0845 450 7755

THE ROALD DAHL FOUNDATION

GREAT MANCHESTER, NORTH AND SOUTH RUNS
'Places Available'

RUN for ASBAH

ASBAH is a registered charity that provides advice and support for over 15,000 babies, children and adults with spina bifida and hydrocephalus.

We need your help so we can continue to promote awareness, help families and carry out vital research.

For sponsor forms, please contact:
Ian Morley, ASBAH, 42 Park Road,
Peterborough PE1 2UQ
Tel: 01733 421328
Email: ianm@asbah.org
www.asbah.org

association for spina bifida hydrocephalus
ability beyond disability

Registered charity no. 249338

Pregnancy

SUPPLEMENT

Contents

Welcome to our special supplement which covers many of the issues surrounding pregnancy and spina bifida and/or hydrocephalus.

We hope the information within this section will allay any fears or anxieties you may have about conception and pregnancy, to help you enjoy this special experience.

Pregnancy should be one of the happiest times of your life, taking things a little easier as you nurture the new life inside and looking forward to meeting the new addition to the family.

For some, things do not always go to plan and routine tests can reveal conditions such as spina bifida and hydrocephalus.

Women who have spina bifida and/or hydrocephalus will have many concerns about pregnancy. ASBAH's senior medical adviser Rosemary Batchelor gives plenty of practical advice in her article below.

There are articles on folic acid and two interviews with mothers whose child has spina bifida and/or hydrocephalus.

Area adviser and psychologist Elizabeth Miers writes about psychological problems plus there's a review of the new Pregnancy and Disability booklet by Jackie Rotheram.

Of course if there are any questions you may have which haven't been answered here, you can ring the ASBAH Helpline 0845 450 7755 Monday to Friday, 10am – 4pm.

Spina bifida and hydrocephalus and pregnancy

The chances of women with spina bifida and hydrocephalus having straightforward pregnancies and deliveries have never been better.

This is partly due to increased knowledge and expertise amongst obstetricians and midwives, but also due to healthier, better informed and better prepared potential mothers.

Ideally, all women should see their GP for preconceptual advice: if you have spina bifida or hydrocephalus, this is **essential.**

Be prepared Remember FOLIC ACID!

If you or your partner have spina bifida or a family history of spina bifida, you have an increased risk of having a baby with spina bifida. By taking folic acid for at least a month before you start trying for a baby (and continuing until the end of the 12th week of pregnancy), you can help reduce this risk by about 70%.

For you, the folic acid tablets available at chemists or supermarkets are not enough. You need **5mgs** a day and this is only available on prescription from your doctor.

Then, before you get pregnant you should arrange to see these experts:

- **urologist:** your kidney function will be checked to ensure that your kidneys are fit for the extra work they will have to do during pregnancy; your urine will be checked for infection

- **continence adviser:** self-catheterisation may be difficult late on in pregnancy and you need to plan how you will manage.

  You will be prone to constipation and may need to change your bowel medication or management.

  If you have a stoma, this can be affected as your abdomen gets larger – it may change shape, your ostomy products may not stick well and may leak.
- **physiotherapist:** your balance will alter as you get bigger and you may need to use a wheelchair more often. The physio will advise on exercises to help prevent swelling of your legs and feet, advise on skin care and prevention of pressure sores and help if the growing baby causes you some breathlessness.
- **neurosurgeon:** having a shunt is no contraindication to pregnancy. It will not harm the baby's growth; a pregnancy will not harm the shunt. (for more information contact Nancy Bradley on ***hydrowoman@aol.com*** She has conducted a long term study on the relationship between pregnancy and shunts)

  If you haven't seen your neurosurgeon for years, now is the time to catch up with him.
- **dietician:** she will help you to keep your weight at a sensible level
- **GP:** you may be the first patient with spina bifida or hydrocephalus that he has cared for in pregnancy.

Give him and the Practice Midwife time to brush up their knowledge.

And tell your ASBAH Adviser who may be able to put you in contact with another woman with a similar disability to yours and who has had a baby. She will have lots of tips and advice for you!

When you are pregnant

Get to know your midwife really well and educate her about your disability and how it affects you (she should read 'Pregnancy and Disability' published 2007 by the Royal College of Nursing ***www.rcn.org.uk*** Tel: 0845 772 6100).

Decide where it will be best for you to have antenatal care – at home, at hospital, at GP surgery?

Ask about suitable antenatal classes.

Arrange a visit to the local Maternity Unit – look at accessibility. Are they prepared for disabled mums? Are examination couches and beds height adjustable? Will there be a cot that you can manage? What equipment will you need to take into hospital with you?

Discuss antenatal testing and scanning and decide what you are comfortable with.

Does she know of an obstetrician who has delivered babies of women with spina bifida?

Write a birth plan

Involve your partner and midwife in this. Include:

- natural birth or Caesarean section? (C-section is rarely necessary for non obstetric reasons)
- pain relief (the anaesthetist will discuss the possibilities of having an epidural)
- positions for labour
- will you be able to get into (and out of!) a birthing pool?
- will your partner be able to stay overnight if you rely on him to assist with your care?
- if you want to breastfeed, will there be help and encouragement?

After the birth

All new parents find the first few weeks difficult and you will be no different!

Accept all help you are offered by your family and friends but don't let them take over.

Disability Pregnancy and Parenthood International ***(www.dppi.org.uk)*** will give advice about obtaining specialist equipment you may need.
Freephone 0800 018 4730
Email info@dppi.org.uk
Ask for their free (to disabled parents) quarterly magazine.

Disabled Parents Network ***(www.disabledparentsnetwork.org.uk)*** is an organisation of and for disabled parents who can offer peer support.
Helpline 0870 410 450
Email e-help@disabledparentsnetwork.org.uk

See your continence adviser to get your bladder and bowel regimes re-established.

Try to rest when the baby sleeps.

Rely on your Health Visitor if you have worries or questions about your baby. Don't feel you're being a nuisance - she's there to help you.

Most women with spina bifida and/or hydrocephalus have normal pregnancies, uncomplicated deliveries and lovely babies.

With a little forethought and care, you could be one of them!

New information guide for midwives

A new booklet, Pregnancy and Disability, has been published by the Royal College of Nursing to improve the level of care available to disabled women who are pregnant.

Midwives and nurses have welcomed the 32-page publication which will help them to provide high quality, client-led care for disabled women during pregnancy, birth and beyond.

The author, Jackie Rotheram, herself a disabled mother, writes with the authority of long experience gained in pioneering and running the first specialist midwifery service for disabled women at a large women's hospital.

With her collaborators she gives a thorough description of how others can deliver the kind of service that meets the needs of disabled women by seeing the woman first and her impairment second.

The complex issues of what it means to be disabled, with relevant statistics, are discussed in full.

The legal background to disability discrimination is well covered, highlighting the new Disability Equality Duty - all public sector

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organisations including the NHS are now positively required to promote equality for disabled people.

Case studies of the four broad categories of disability – physical, sensory, learning and long-term mental illness – illustrate vividly the issues for health care workers.

These will assist midwives and nurses to consider and plan in advance with disabled clients how their particular needs can be accommodated, working with other agencies and professionals where appropriate.

Rosaleen Mansfield, Chair of Trustees, Disability, Pregnancy and Parenthood International (DPPI) said: "I warmly commend this new guide. A large proportion of the enquiries DPPI receives come from disabled women considering parenthood, or who are already pregnant.

"They want to be as actively prepared as anyone else. They also need extra information, possibly to help them source support and equipment in good time.

"This new guide on pregnancy and disability is an invaluable new resource."

The Author

Jackie Rotheram is Disability Advisor and Specialist Midwife at the Liverpool Women's Hospital NHS Foundation Trust Disability Service.

As a disabled mother and midwife, Jackie was given the opportunity to bridge the gap in service provision she had identified so that equality of access to services was assured for childbearing women with disabilities.

Jackie has a strategic role advising all trust directorates and working with trust and external activities, groups and networks.

She also works with human resources and occupational health on supporting disabled staff and is responsible for disability awareness training.

Jackie has spoken extensively in the UK and abroad and has received several prestigious awards, both individually and with her trust. She is currently engaged in research, teaching and further writing.

Case study Pregnancy and Disability

The Pregnancy and Disability booklet features a case study of Mary, who has spina bifida and is a long term wheelchair user.

She contacted the maternity services through ASBAH and her local support group.

Genetic counselling was included and urine testing arranged because of fears of infection related to catheterisation, which Mary performed for herself.

Other issues discussed included breathing as her uterus enlarged, her ability to care for herself, tissue viability, pregnancy changes, antenatal care provision, type of delivery, and pain relief, including epidural use.

Six months later and now pregnant, Mary visited the antenatal clinic where a needs assessment was performed alongside the booking history.

Antenatal screening tests were all accepted. Referrals were made at Mary's request to professionals including a dietician, physiotherapist, health visitor and urodynamics specialist, because of repeated infections.

Mary expected no difficulty regarding her wheelchair when her girth and weight increased, as it was of a good size.

Early pregnancy proceeded normally but Mary experienced some difficulties later on when bending forward became difficult.

In addition, her increased weight and reduced mobility increased pressure on her lower back, so Mary was admitted at 28 weeks gestation for rest and help with tissue viability.

She had no pressure sores but her buttocks were becoming increasingly red and tender. The tissue viability nurse visited and a special mattress was provided.

Physiotherapists provided advice on exercises and taking regular periods of lying flat, out of the wheelchair.

In preparation for the birth, appointments were made with the obstetrician to discuss the mode of delivery and a tour of the delivery suite and postnatal ward was arranged.

At 34 weeks gestation Mary's large uterus was compromising her breathing so it was decided to perform a caesarean section.

Mary remained awake for the delivery and her partner stayed with her throughout the procedure and afterwards.

Mary was seen by the physiotherapist and a manual handling assessment was performed, identifying no risk issues. Her partner took responsibility for bathing the baby as bending was difficult for Mary.

She concentrated her efforts on breastfeeding and a five-day hospital stay helped her to establish this and gain more confidence.

The occupational therapist performed a home assessment and found that Mary and her partner had planned well.

The community midwife visited daily at first, gradually decreasing her visits until transfer on day 21 to the health visitor who Mary already knew.

Europe – a new battle begins

ASBAH's campaign to get flour fortified with the vitamin folic acid in the UK is not yet won, but it believes it is close to success after 15 years of lobbying and publicity.

But the battle to see flour fortified throughout Europe is just beginning and UK experts are backing colleagues who are determined to see mandatory fortification across the Continent.

The International Federation for Spina Bifida & Hydrocephalus (IFSBH) convened a high-level meeting in Brussels in early November to plan a campaign.

ASBAH's Chief Executive Andrew Russell said: "ASBAH and the UK took a leading part in the symposium because of its long experience in this matter, which we hope will make the journey easier for our European friends."

As well as Spina Bifida Associations, the meeting consisted of scientists and doctors, senior representatives of the international milling industry, and the European Commission.

Generously hosted by PR company Fleishman-Hillard, the meeting concluded that each country will have to fight its own battle, because the European Commission does not have the power to impose such food regulations.

However, a co-ordinated approach will be vital to making the case scientific, and convincing the doubters that fortification is the only responsible and effective public health policy, and is a golden opportunity to improve health in Europe in the 21st century.

> **ASBAH and the UK took a leading part in the symposium because of its long experience in this matter, which we hope will make the journey easier for our European friends.**

ASBAH speaks out over fortification delays

Ministers have delayed a decision on whether to fortify UK flour with the vitamin folic acid, because a research study in America seemed to suggest that bowel cancer rates have risen since flour fortification there.

Sir Liam Donaldson, England's Chief Medical Officer, has requested further expert consideration before the government gives the final go-ahead for mandatory fortification.

This is disappointing news for ASBAH as the possible link between high levels of folic acid and bowel cancer was studied in detail by the Scientific Advisory Committee on Nutrition (SACN) last year.

There is considerable evidence that folic acid helps to prevent bowel cancer, but there may also be cases of pre-existing benign tumours where very large doses of folic acid might stimulate the tumour.

Flour fortification would not provide large doses and ASBAH believes the Food Standards Agency (FSA) review will confirm its advice in favour of compulsory fortification.

Since hearing of the delay ASBAH has worked urgently with top international experts to evaluate the evidence and its review shows that far from causing cancer, folic acid has an overall preventive effect.

A letter from ASBAH, co-signed by its expert colleagues, has been sent to the world-respected medical journal, "The Lancet".

ASBAH's Chief Executive Andrew Russell said: "We hope that this will convince a government expert group, which will meet in January, to review the evidence and advise the FSA on folic acid policy to go ahead with fortification.

"The intervention of the Chief Medical Officer is an unwelcome delay because there is no new medical evidence in recent reports.

"We're in touch with the FSA and it agrees that recent press activity and the new research report don't give any cause to change the advice. SACN looked closely at all the evidence, including cancer incidence, and unanimously recommended fortification."

Some parents of newly born babies with spina bifida and/or hydrocephalus still have complaints about the quality of care and attitudes of some members of the medical profession. But on the whole the outlook towards babies with disabilities is more positive and the level of support and care much better than 20 years ago.

Aged 6 weeks

Aged 2 years old

Aged 5 years old

Case study Val's story

Val Mason, mother of Vicky, one of the models in ASBAH's new Below the Belt book, said her experiences when her daughter was born 17 years ago, were "horrific".

During her pregnancy she had no idea that the baby she was carrying had spina bifida. Nothing was picked up during three routine scans and the only potential problem seemed to be that Vicky was a breech baby.

"It was assumed that because I had already had two healthy pregnancies, this baby would be healthy too," Val said.

"When we asked some questions later on we discovered that the scanner used on me was an old model, which is why Vicky's condition wasn't picked up.

"I was in labour for about 24 hours but the baby seemed to be stuck because the Myelomeningocele was protruding so much, which no-one realised at the time."

When the baby became distressed doctors decided on an emergency section and Val's epidural was topped up, allowing her to stay awake during the caesarean.

It was assumed that because I had already had two healthy pregnancies, this baby would be healthy too

"I knew something was wrong straight away," Val said. "There was a lot of commotion and Vicky was whisked away immediately.

"Of course I was desperate to know what was wrong and made them tell me straight away. I had obviously heard the term 'spina bifida' but I knew very little about it at the time.

"It was a very difficult time for all the family. Vicky wasn't allowed home until she was six weeks old and some people thought that we'd never cope because we had two other children, Kimberley who was six and Simon 4.

"Vicky's prognosis was very poor and the doctors decided not to operate until they had examined her again at six months old.

"But Vicky had been born weighing 8lb 11oz and to us she seemed a very strong and healthy baby. Once she came home she

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just seemed to thrive."

Vicky finally had her back closed up just after her first birthday and had additional surgery on her feet and bladder.

Val added: "Of course life was difficult, but then it would always have been hard with three children under the age of six.

"We were visited by an ASBAH adviser fairly early on but apart from ASBAH, there wasn't much help out there for us. Thankfully we did have great support from the family and just got on with things."

But Val said that when Vicky was first born she never imagined how things could turn out.

"Vicky is an incredible girl, "she said. "She has brought so much joy into all of our lives.

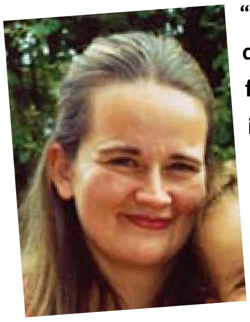
"Today she's independent, drives a car, and has a boyfriend – she just lives life to the full."

Turn to page 30 to see what Vicky is doing today and how she enjoys her independence.

Aged 14 years old

Case study

ASBAH made a big difference to our lives



Lisa Nicholls Sykes

"Enjoy your child and accept them for who they are" is the advice Lisa Nicholls Sykes would give to the parents of a disabled child.

Lisa and husband Nigel have first hand experience of the tough times parents of a disabled child can face because their son Barney, now 7, was diagnosed with hydrocephalus at eight weeks old.

The couple, from Ashby de la Zouch, near Leicester, say that contacting ASBAH was the single action that really made the biggest difference to their lives, giving them access to information and the much-needed emotional support.

Lisa said: "As well as having hydrocephalus, Barney is severely autistic. He has no speech and his means of communication is very basic.

"If he doesn't know or like someone he won't make eye contact, in fact he tends to block them out.

"But he's a wonderful, affectionate child, who is much loved by his family and he's very popular at school.

"Barney may have problems communicating but he's very clever in other ways. He certainly knows how to manipulate people."

Lisa said that Barney was only diagnosed with autism in April 2006 even though she had recognised autistic traits much earlier on.

"It was difficult to know whether it was just an effect of the hydrocephalus in the early years, "she explained. "But I did notice that he did many of the things autistic children do such as flapping his hands, liking routine and being incredibly particular about the food he eats."

Barney now attends a school in nearby Coalville for children with special needs, happy to travel there on the school bus.

"To begin with it was very hard letting go, especially as Barney has no speech," Lisa said. "He had gone to my daughter's playschool, where he had been very happy, but by the time he was four I knew that unless a miracle occurred, there was no way he'd cope in mainstream school.

If he doesn't know or like someone he won't make eye contact, in fact he tends to block them out

"The school he attends is wonderful, with very enthusiastic, caring staff and the teachers say that he is developing.

"For example at one stage he wouldn't ask for a drink, he would just sit there getting upset.

"Now though he'll go to the cupboard where the cups are kept so they know what he wants. It's very slow progress but every step Barney makes is a huge achievement."

Barney Nicholls Sykes

Lisa said that she and husband Nigel are aware that Barney's needs do affect the lives of their three daughters, Madeline, 10, Mariella, 8 and Beatrice, 3.

"They do have to put up with a lot, "Lisa said, "and we try to compensate as much as we can.

"For example they have a lot of dance lessons which are very expensive, but we want to treat them because there are many things which we can't do as a family because of Barney.

"At their dance shows I can't go into the auditorium to watch, I must stand outside with Barney because he gets very upset.

"But the girls know that although I can't watch them dance on stage I will be there to do their hair and wish them luck, and of course I'll be waiting there for them at the end.

"They love Barney very dearly and I think that having a brother who is disabled will help them develop into caring people who appreciate the needs of others."

Elizabeth Miers, ASBAH area adviser for the North West, talks about the emotional problems associated with pregnancy and disability.

Coping with the news that your baby has a disability

Pregnancy is an emotional time for all parents, and to learn that your baby will have a disability can seem a devastating blow.

When you are told the diagnosis, your world changes in a few moments. Hopes and expectations are altered and you face a bewildering new set of questions and decisions.

In a lot of ways the diagnosis is like a bereavement – you will grieve for the pregnancy, the baby you had expected, and the loss of your "perfect" child.

Parents talk of a sense of shock and bewilderment, and then grief and anger; "why me?"; "what have we done wrong?". And all this emotion is made harder because of decisions that have to be made.

Once parents have decided to go ahead with the pregnancy, there is so much new information to be taken in and acted on.

So many people know nothing about spina bifida, and even less about hydrocephalus. At this stage, it can be really helpful to talk to an ASBAH adviser, who will try to give as much information as possible and "signpost "other sources of help and support.

It can also be good to talk with someone who is not emotionally involved like a close friend or family member – friends and family are themselves shocked, upset and worried. Grandparents especially find themselves doubly distressed, worrying about both their child AND grandchild.

It often feels that everything about this pregnancy is out of YOUR control, and that contributes to the sense of anger and being overwhelmed by the situation.

It is really important that the parents have the information and support to be fully involved in decisions such as what kind of delivery will be best for both mum and baby, and where and when that should take place.

A sense of confidence and trust can start to be built up with the team of specialists who will be treating the baby. All this is reassuring and starts to rebuild the confidence that has been knocked by the news that the baby will have a disability.

The pregnancy can become a parallel experience – one of grief and yet trying to remain positive. One mum described it to me as building a high wall round the grief.

After the baby is born, friends and family may find it hard to know how to act. Do they send baby congratulations cards or get well soon!

Several parents have described to me an ongoing sense of sadness which will suddenly overwhelm them for no apparent reason.

Heightened emotions, caused by changing hormones during and after the pregnancy may make it hard for mothers to keep "in step" over the months.

Talking to someone is often a big help and many people find a release after sharing even their darkest thoughts and fears.

Pregnant and disabled?

Most disabled mothers will have planned pregnancy very carefully, taking pre-conceptual advice from several specialists.

It can therefore be doubly upsetting when people make negative comments about your ability to cope with a pregnancy and care for the baby after the birth.

Very often disabled parents may have heard negative comments from their own parents. Hurtful remarks, often said in the heat of the moment, such as "how would I cope with two of you?" can stay with you for the rest of your life and damage your self-confidence.

Then there are the self-doubts and health fears to contend with. Many couples hoping for a baby are very fearful of passing on their own disability.

But this concern can be viewed in a more positive light – "I've coped and so can my child, especially with all my experience and support."

After the initial excitement of a positive pregnancy test, the parents-to-be experience huge apprehension in the days leading up to the first scan - then disbelief that all is well after all.

At this stage you need lots of emotional support and information. Find positive role models – disabled parents networks and ASBAH may be able to put you in touch with disabled parents who have experienced the same highs and lows. They will give you reassurance that you CAN cope.

And remember, Disability Equality Duty means all public sector organisations are now required to promote equality for disabled people. Social Services don't often take a baby away – they have to be supportive!

Try to get a good Care Package geared to your parenting role. Use Disabled Parents Network. Cheshire Disabilities Federation (CDF) have produced a self assessment toolkit for parents to use when setting up a package.

Disabled Parents Network
www.disabledparentsnetwork.org.uk
Tel : 08702 410 450

Disability, Pregnancy & Parenthood international (DPPi)
www.dppi.org.uk
Freephone: 0800 018 4730

The Cheshire Disabilities Federation
www.cdf-northwest.org.uk
01606 872760

"We're not there yet"

Sir Bert Massie CBE, former Chair of the Disability Rights Commission, was the guest speaker at the ASBAH AGM.

He delivered his talk on the serious issue of the struggle for equality, spiced with humour to keep his audience entertained and listening.

Sir Bert told the gathering that disability equality has moved a long way from the 1960's approach of looking after disabled people and sending them to the day centre to make "very pretty baskets".

He explained that by the 1970s there was a realisation that a lot of the problems disabled people encounter are a result of the built environment.

Instead of seeing the wheelchair as the problem that's preventing the person from getting into the office, maybe the stairs should be considered as the barrier and one that could be overcome, he suggested.

> The success of the Disability Rights Commission can be measured by real changes to the lives of disabled people.

As a result MPs began to call for new laws and environmental changes after research showed that there were lots of inaccessible places, including taxis and buildings.

Further studies in the early 80s highlighted that patronising attitudes of non-disabled people were also impacting on the lives of disabled people.

But it was to be another decade and a half before the Disability Discrimination Act (DDA) was passed in 1995 and a further five years until we got the Disability Rights Commission (DRC) to help enforce it.

What has the DRC done?

It provided advice on disability law through its helpline and fought to get changes made to the law itself.

All schools and universities are now covered by the DDA and the definition of disability has been strengthened.

The success of the DRC can be measured by real changes to the lives of disabled people with improved access for wheelchair users – in all aspects of life.

That includes everything from taxis, shops and housing - all new housing now has to be accessible), through to education and employment.

Many thousands of disabled people now have more qualifications and are in employment.

But what has changed most is not only the public's perception of disabled people but disabled people's perception of themselves.

This increased confidence was illustrated by Sir Bert, using a quote from a disabled young person, "I'm me and if you don't like it that's your problem."

But despite pointing out many of the DRC's achievements, he didn't paint a totally rosy picture. He told the AGM that for some companies, it would still pay to discriminate because the cost of bringing a discrimination claim could add up to much more than the fines imposed.

More battles ahead

Although the DRC ceased to exist shortly after Bert Massie spoke to us, he assured the audience that their work would carry on through the disability section of the new Equality and Human Rights Commission, including updating important codes of practice.

There would still be a helpline to raise important questions and gain advice on disability discrimination and he urged ASBAH's members to make use of this and give feedback.

Sir Bert ended his talk with a look at how disabled people's rights in law are not yet backed up by social, educational and housing services to make sure they are enforceable.

Some of the battles ahead which the Commission will continue to fight will be to achieve better social and health care and the basic right to life for disabled people.

To find out more about the new Equality and Human Rights Commission (CEHR), visit their website at ***www.equalityhumanrights.com***

The following helplines offer information and guidance on discrimination and human rights issues.

The CEHR dedicated Disability Helpline for England
Tel: 08457 622 633

The Equality and Human Rights Commission Helpline for Wales
Tel: 0845 604 8810

You can also find out more about what the DRC achieved by reading their recent publications: Celebrating the Journey - Impact Report 2000-2007, and DRC Legal Achievements 2000-2007 (both of these can be downloaded from the recent publications section of the CEHR website).

Brandon Conley

New school gives Brandon a taste for sporting success

Young Brandon Conley's hopes of a trip to Lord's to take part in the national Table Cricket finals were cruelly dashed when he landed up in hospital with a broken leg.

Brandon, who has spina bifida and hydrocephalus, was kneeling on his bed to look out of the window when he fractured a bone, which landed him in hospital for a week.

But the 12 year old from Houghton-le-Spring, Tyne and Wear, isn't easily deterred from sporting victory.

A few weeks later, complete with cast and a weighty hospital wheelchair, he came fourth in 100m wheelchair slalom at the National Junior Athletics championships in Blackpool.

Mother Ann explained: "Brandon is very sporty, and although his primary school was excellent, it wasn't until he started at secondary school last September that he could really get involved."

The philosophy at Oxclose School in nearby Washington is to let everyone have a try, no matter what their ability… or disability.

"The staff are wonderful," Ann added. "There are quite a few children there who use wheelchairs and they are always included. If there's something the child can't manage they look for a way around it.

"Brandon has always been outgoing but he's really blossomed since starting at Oxclose. I can't praise the school more highly."

The six-strong table cricket team got through the regional heats winning a coveted place at the national championships at Lord's on 21 June.

The team finished a creditable 7th and brought Brandon back a mini cricket bat which they had all signed.

Disappointed at missing out on the finals, Brandon was determined to take his place in the line up at the Nationwide National Junior Athletics Championships in Blackpool on 4 July.

There are quite a few children there who use wheelchairs and they are always included.

Ann explained: "Brandon entered the regional heats in May, although he had never really done much wheelchair racing before and to everyone's delight he got through.

"Even though his leg was still in a cast he was adamant that he'd take part in the finals in Blackpool.

"We had to borrow this heavy old wheelchair from the hospital which slowed him down, but he won his heat and came fourth in the event."

The annual event saw more than 400 young athletes compete in the biggest national junior disability athletics event in the country, held at the Stanley Park Stadium.

In his spare time – when he has any – Brandon loves playing wheelchair tennis at the Puma Centre in Silksworth, a sport he took up over a year ago.

"It's amazing what Brandon has achieved this year," Ann added. "It's given him a taste for success. There will be no stopping him now."

What is Table Cricket?

Table Cricket gives youngsters with physical or learning disabilities the chance to play competitive cricket… whatever the weather.

The competitive version of the game was first launched in 1991 by the England and Wales Cricket Board (ECB) and The Lord's Taverners.

Two teams of six play on a table tennis table or similar sized surface area with side panels featuring nine sliding fielders.

A plastic ball is bowled by a ball launcher at one end of the pitch, while at the other the batter uses a mini cricket bat.

The game has become so popular that national championships are now held every year with the final played at Lord's.

This year a total of 44 teams from 33 schools competed in the ten regional heats…with over 400 children taking part.

If you fancy playing Table Cricket or would like to get your school involved contact Andrea Ward, at the Lord's Taverners. Tel: 020 7821 2808 or email: *Andrea.Ward@lordstaverners.org*

Benny Bear can help

Benny Bear has gained hundreds of fans around the world since he was introduced by Codman in 2001.

The cuddly teddy, who has a hydrocephalus shunt, features in five Benny Bear books, which explain to children some of the issues surrounding living with a shunt.

The books, produced by ASBAH and sponsored by Codman, are available in many English speaking countries and have been translated into German, French and Japanese.

Children with hydrocephalus have embraced the loveable bear who has the same worries and concerns as them.

Edward Lamb, Codman's UK Country Manager, told *Link*: "Families are often worried about the robustness of Hydrocephalus shunts, so Benny Bear is an important character in highlighting to both children and parents that many activities can really be enjoyed."

The books are available from ASBAH – either order through the website or call the Helpline on 0845 450 7755. The books cost £8.00 for the complete set of five. Benny's New Shunt is available on its own, price £2.00.

A set of three Benny Bear Shunt Malfunction posters is also available price £2.50.

Benny Bear books

Benny Gets Better
Benny Bear Goes to School
Benny Goes on Holiday
Benny's New Shunt
Benny's Team Wins

"A diagnosis of hydrocephalus can be worrying for both children and their parents. I hope that those children lucky enough to meet Benny the Bear in hospital will read the books and discover that hydrocephalus needn't be scary."

Mr Conor Mallucci, Consultant Paediatric Neurosurgeon, Alderhey Children's Hospital, Liverpool.

Pedal power gives big boost to ASBAH

A big thank you goes to Katryna Quiggin from Codman who raised a wonderful £700 for ASBAH after completing a gruelling six-hour cycle ride.

Katryna, London Sales Specialist, took part in the 47-mile Isle of Man End to End Challenge off-road event

The tough course runs from the Point of Ayre at the northern tip of the Isle of Man to The Sound at the southern tip, taking in some challenging hills and mountains on the way.

Katryna, who joined 400 competitors in the September event, collected £350 for her efforts and was delighted when Codman agreed to double the figure.

Codman gives a welcome boost to a new charity working to establish a National Centre for Hydrocephalus Control in Romania.

Romanian orph
Hydrocephalus

F.R.O.D.O. – the Foundation for the Relief of Disabled Orphans – was set up in June 2006 to transform the quality of life of children from developing countries such as Romania who have disabilities or life threatening illness.

Many of the disabled children it supports live in orphanages, often with poor care and little love.

Working with partners, the charity identifies those whose lives would be transformed if they receive treatment for their disability. Treatment for their condition often improves their chance of adoption.

The Hydrocephalus project – part of the F.R.O.D.O. Medical programme – aims to establish a National Centre for Hydrocephalus Control based in Targu Mures.

The charity is working with Dr. Alexandru Lupsa and several other neurosurgeons in Romania to set up the project.

It is hoped that seven satellite hospitals around the country will provide a national programme in the diagnosis and treatment of children with hydrocephalus.

Vanessa Cummings, Director of F.R.O.D.O., said: "Romania has many skilled surgeons but there is no established programme for treating hydrocephalus.

"Children from poor families are

Dr. Alexandru Lupsa

ans helped by programme

often abandoned in institutions where they have no love and little care. Lack of medical attention causes brain damage and ultimately a very sad death.”

A draft european report published in May 2007 said that while there have been improvements, children in Romanian orphanages still suffer from physical and sexual abuse, and lack of food and medication.

> **I emailed Graeme asking if Codman could help us in any way and I received a reply immediately, asking us what we needed. The donation has been greatly appreciated**

F.R.O.D.O. Medical works by harnessing the resources available – acting as facilitator between medical and other volunteers; negotiating with hospitals to donate their facilities; seeking funding and other support required – to ensure that life-changing treatments may be delivered to as many children as possible.

Vanessa approached Codman’s EMEA Product Director, Hydrocephalus, Graeme Loughlin, to see if the company could help in any way.

She was delighted when Graeme agreed to donate a quantity of shunts needed to treat children with hydrocephalus.

Vanessa said: “We were all thrilled with Codman’s support. I emailed Graeme asking if Codman could help us in any way and I received a reply immediately, asking us what we needed. The donation has been greatly appreciated.”

The Hydrocephalus programme includes devising and delivering appropriate training to doctors and identifying what equipment is needed to help them achieve consistently high standards.

It also plans to establish a system so doctors and all hospitals know where they can go to get more information about hydrocephalus, and where to send patients for treatment.

Another key element of the programme is to establish monitoring networks in maternity hospitals so that babies born with hydrocephalus can receive treatment as soon as possible.

The charity recently took on an administrator which Vanessa said is an “enormous help” in moving the programme along.

She said: “Setting up the National Centre is a very exciting project. Once a child has had the necessary treatment they will continue to receive proper after care, and their progress will be carefully tracked.”

The charity hopes that within three years the Romanian Health Ministry will take over the running of this project so the charity can bow out.

Vanessa said: “Everyone at F.R.O.D.O. is very proud of what we have achieved in such a short time. There is a huge willingness and determination to get things done.

“We know there is a huge task ahead of us in our aim to help the thousands of disabled orphans in Romania, but we’re taking it one step at a time.

“Providing babies and young children with improved health makes a huge difference to their long-term self-sufficiency and confidence.

“This in turn may increase their chances of being kept by families and not abandoned in hospitals, thus giving them hope for a loving family.”

“I was initially contacted by Vanessa to see if we could help a little boy, Levente, who had hydrocephalus.

“My immediate concerns were for the little boy who required medical attention. The instinctive reaction is always “what can I do to help?” and to cross the bridges and overcome the barriers later.

“At the time I had just been given added responsibility to support the Codman business development in Central and Eastern Europe and Russia and the CIS, so I was already sensitive to the limited access to healthcare in many of these areas.

“I also know many neurosurgeons who travel abroad on a charitable basis to support under-privileged and unsupported communities and others who are predisposed to help, so was quickly able to recommend Richard Edwards as a UK Neurosurgeon able to get involved.

“The donation itself of the devices was just a small short term aid to plug a technology gap.

“I hope really that we can do much more in Romania through our local infrastructure and education efforts over time, working in partnership as much as possible with F.R.O.D.O.

To me the inequalities in access to healthcare, even within Europe, are far from acceptable and I am very happy to work for a company that also recognises that fact.

“To be able to help through partnerships with charitable organisations such as both F.R.O.D.O. and ASBAH is the icing on the cake for me.”

Graeme Loughlin, Codman’s EMEA Product Director, Hydrocephalus.

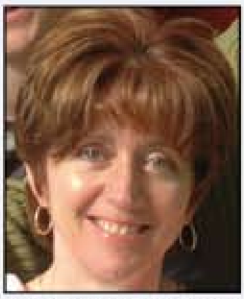
Are you satisfied with your bowel care?

Would you like to hear about the latest research and a revolutionary bowel management product?

association for spina bifida hydrocephalus ability beyond disability

sia spinal injuries association

Bowel management can be a significant challenge for thousands of people who have a spinal cord injury or spina bifida. Maureen Coggrave is a Research Nurse from the National Spinal Injuries Centre in Stoke Mandeville and is passionate about improving the quality of life, not only for her own patients, but for anyone who could benefit from reviewing their current methods of bowel management. Maureen has researched this subject extensively for her PhD and is known throughout the UK as a pioneer in her field of expertise.


Maureen Coggrave

The SIA and ASBAH, in conjuction with Coloplast Limited have arranged a study presentation meeting where Maureen will present and discuss her exciting research studies for anyone who needs to use bowel management methods or indeed anyone who assists in carrying out these procedures. In addition we are excited that we will also have a presentation by Michael Cogswell who is aiming for the sailing Paralympic Gold for Great Britiain. Michael will discuss the various bowel management options he has used and how they have impacted on his career as a professional sportsman.


Michael Cogswell

It will be an informal and relaxed meeting and is an excellent opportunity for individuals, partners or carers to improve their knowledge in this important area - hear about the latest research and **a revolutionary new innovative bowel management system, available on prescription.**

To book your FREE place on this or future meetings please call Sarah Clark on: 01733 392349 or email gbscl@coloplast.com

Wednesday 20th February 2008
12 midday - 4pm

at the Holiday Inn Hotel, Aston Clinton Road, Aylesbury HP22 5AA

12.00 Buffet lunch

1pm Introduction by Paul Smith, Executive Director, SIA

Presentation of bowel management research – Dr Maureen Coggrave, Research Nurse, National Spinal Injuries Centre, Stoke Mandeville

Presentation of a Revolutionary New Innovative Bowel Management System

Bowel management 'the reality' - Michael Cogswell

Questions and discussion

4pm Close of meeting

To ensure we cater for you please could you contact us to book your **FREE** place at the meeting.

Further meeting dates are planned and dates will be confirmed soon.

We are currently arranging other meetings around the country in the spring/summer - please let us know if you are interested and we will contact you with the details.

Coloplast

Can I use your loo?

Researchers from University College London who conducted street surveys in several cities reported that even if people knew where the nearest public toilet was, only just over half of them would use it.

Nearly three quarters of those surveyed also said that there weren't enough toilets open in the evenings.

For disabled people it could be even more difficult to find a suitable loo and over 90% of respondents to an ITAAL (Is There An Accessible Loo?) survey said that lack of suitable facilities could even deter them from going out.

ITAAL also found that over a third of those surveyed didn't use or didn't know about the RADAR key scheme which enables key holders to use locked accessible toilets in the scheme.

Some people with hidden disabilities said that they had been challenged when they tried to use toilets for disabled people.

Obviously, there's still a long way to go in providing public toilets which are adequate to meet everyone's needs but ASBAH's new Need to Go card could at least go some way to helping those with spina bifida with this tricky situation.

See the article below for details of how to get your free card.

For your convenience

ASBAH has launched a free continence card to help service users access toilet facilities more easily.

The credit card-size laminated card, entitled Need to Go, has ASBAH's Helpline information on one side, and the simple message, "Please Help. The person holding this card has spina bifida and needs to use the toilet urgently" on the reverse.

The person holding this card has spina bifida and needs to use the toilet urgently. Thank you for your help

Hopefully the cards will make it easier for service users to approach staff in stores and shops which don't have toilet facilities available to the public.

Helpline and Information Service manager Linda Lewis said: "The Continence Foundation have offered a similar card for some time and one was recently launched by the MS Society.

"We always directed callers requiring a card to these organisations, until one caller asked why ASBAH didn't produce one themselves?, which was a very good question."

Production of the 'Need to Go' card was made possible through Big Lottery funding for the Helpline and Information Service. The card is available free of charge but anyone requesting one will need to register their contact details with ASBAH so they can be logged on the database, for validation purposes.

Linda added: "People with spina bifida can have continence issues and need to use the toilet at regular intervals. Having one of our cards should help them to access a toilet more easily.

"Some people are embarrassed about having to explain their urgency so hopefully the cards will make their lives easier and give them the confidence to go out and about more often."

Anyone wishing to have a 'Need to Go' card should call the Helpline on 0845 450 7755 (local rate call) or email: helpline@asbah.org. Alternatively you can write to Helpline, ASBAH House, 42 Park Road, Peterborough, PE1 2UQ.

Thousands speak out against Government proposals

The Government is expected to make an announcement regarding its payment system for urology and stoma products following a two-year consultation.

Manufacturers and suppliers of these products have spoken out against the proposals which could halt payments for home delivery of prescription continence products to thousands of urology patients.

In May a petition signed by more than 4,000 people was sent to the Prime Minister asking him to reconsider the recommendations.

The Consultation paper, published by the Department of Health, proposes that the payment system for products and services listed in part IX of the drug tariff should be reviewed to secure value for money for the NHS as well as maintaining the current quality of care to patients.

Manufacturers of continence and stoma products and service users fear that if funding is reduced, essential services such as the home delivery of products will be affected.

In the UK more than 350,000 patients use continence appliances, with approximately 40 per cent relying on home deliveries.

The NHS currently reimburses Dispensing Appliance Contractors for the services they provide to NHS patients who require continence and stoma care. Services include home delivery of prescriptions, specialist nurse visits and telephone helplines.

According to Government figures released in 2006, the NHS spends in excess of £200m per annum on items and services for incontinence appliances, stoma appliances, in primary care in England.

One of the options proposed by

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the Department of Health is a restrictive banding structure which will force the manufacturers to severely scale back their services to urology and stoma patients and reduce the number of products and services they offer.

A spokesperson from one of the leading manufacturers and suppliers told *Link*: "The implications of these proposals would jeopardise patient care, their quality of life and their ability to maintain their independence.

"The Government has acknowledged the need for home delivery services but if payments are reduced, it will not be viable for manufacturers to provide that service to all of their customers.

"If we are forced to reduce the number of products and services we offer this will have a detrimental effect on their quality of life.

"It is very frustrating situation for our company. We have built up good relationships with thousands of patients, providing them with products and services for their individual needs."

The industry, is working very closely with the Urology Trade Association (UTA) and British Health Trade Association (BHTA) to secure the best possible outcome to the Consultation.

The deadline for responses to the consultation document was 28 December and an announcement is expected in the New Year.

ASBAH contributed to a response to the consultation from a coalition of voluntary organisations and product suppliers and manufacturers.

Many *Link* readers rely on home deliveries of continence products. This is what they think….

A repeat prescription takes up to three days to obtain. I would have to wait at least another three days for the products to arrive at the chemist.

For me it would be very time consuming and inconvenient because I work full-time.

Incontinence as a life-changing problem is hard enough. Discontinuing this service will create major problems for users.

To see the complete comments from our service users go to www.asbah.org

Your Voice presents

Looking Good Feeling Great

Social, leisure and self image

Open to all adults (aged 18 and over)

Date and venue:

Friday 11th July to Monday 14th July 2008

North West England

Register your interest NOW

£ to be announced

The delegate rate will be subsidised by Your Voice

About the next event:

This event is to celebrate the end of the Comic Relief Funding. We are intending to have a photographic exhibition promoting Your Voice and to also show what the Your Voice group has achieved during the Comic Relief Funding.

Details of the precise content to be confirmed

For further information and to register your interest contact:

Barbara Robinson
ASBAH House
42 Park Road
Peterborough PE1 2UQ
Email: barbarar@asbah.org
Telephone: 01733 421322

association for spina bifida hydrocephalus
ability beyond disability™

Registered charity no.249338

Top marks for YV event

Members who attended the recent Your Voice Moving on Up event picked up plenty of valuable information on all aspects of independent living.

The weekend away, at the Wokefield Park Hotel near Reading, attracted 17 delegates keen to learn more about topics such as effective money management, Benefits and accessible housing, among others.

Barbara Robinson, Policy Officer (Your Voice) said: "I think Moving on Up was one of the best events organised by Your Voice. The speakers were excellent and gave lots of valuable information. The delegates certainly seemed to get a lot out of it.

"It was a shame more people didn't attend but those who were there attended most of the sessions and the feedback has been extremely positive."

The Speakers

Accessible Housing – Paul Gamble, Deputy Chief Executive of Habinteg Housing Association which has 30 years experience in housing and disability. *www.habinteg.org.uk*

Effective Money Management – Liz Dunscombe from Credit Action. *www.creditaction.org.uk*

Direct payments and individual budgeting – Wendy Gross, information manager at the National Centre for Independent Living. *www.ncil.org.uk*

Independent advocacy – Caroline McAleese, information manager at Action for Advocacy. *www.actionforadvocacy.org.uk*

Benefits and You – Christine Moore, Advice Services Manager at Reading Citizens Advice Bureau. *www.citizensadvice.org.uk*

Coping strategies for living independently – Gill Yaz, specialist adviser for ASBAH South East region for medical and continence issues and the local adviser for north east London.

What they thought…

"A tremendously informative and great social weekend. Thank you".

"I found the independent advocacy really interesting and helpful".

"PAs, direct payments and individual budgets - very good advice"

"So very helpful"

Questionnaire reaps results

There was a great response to the Your Voice questionnaire which was sent out in March last year to help the YV Committee plan future campaigns and events.

More than 110 responses were sent in with 54% of the responses coming from people aged 31-50 living in urban areas.

Of those who returned their questionnaire, 30 said that they had never heard of Your Voice. The launch of the new Your Voice newsletter and extra space in *Link* should address this problem and make people more aware of the adult user group and its activities.

The questionnaire asked 'What would improve your life long term' and 'What is your most important social need'.

The top five responses were:

Transport (13.3%)
Help socialising (12%)
Personal care and/or support when out (10.5%)
Better medical care (8.8%)
Need for adaptations or equipment (7.6%)

It also asked what sort of events people would be interested in attending. There were 38 suggestions for leisure and social events, 26 for lifestyle and confidence and 16 for medical.

The Your Voice committee is grateful to everyone who took the time to respond and plans to use the information to develop future campaign issues and events.

Committee training

Your Voice committee members brushed up their skills at a training day earlier this year.

The intensive session, held in Birmingham, was run by Pauline Nugent, and was aimed at finding democratic and inclusive ways of using the combined talents to progress work of the 'Your Voice' committee.

Many subjects were discussed ranging from committee roles and responsibilities, ASBAH committee development plans, scenarios and feedback.

The 11 committee members who attended voted the day very successful and worthwhile.

Diary dates

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

Eastern Region Local Association Forum Meeting

Date: Saturday 5 April 2008
Time: 11.00 am start
At: ASBAH House, 42 Park Road,
Peterborough PE1 2UQ
Lunch and parking
Speaker: Colin Roberts, Fundraising Director
More information contact the
Eastern Region Office on: 01733 421309

Eastern Region Looking Ahead with Hydrocephalus

Date: Wednesday 14 May 2008
At: East Midlands Conference Centre
University Park, Nottingham
Aimed at 12 to 25 years of age
More information contact the
Eastern Region Office on: 01733 421309

Your Voice presents: Looking Good Feeling Great

Theme : Social, Leisure and Self Image
Date: Friday 11th July 2008 to
Monday 14th July
Location: North West England
Cost: TBA

Contact Barbara Robinson on ***barbarar@asbah.org*** or call 01733 421322 to register your interest in this and future Your Voice events.

Bowel Management Meeting

Learn about the latest research and a revolutionary bowel management product.

Date: Wednesday 20 February 2008
Time: 12.00 midday to 4pm
At: Holiday Inn Hotel,
Aston Clinton Road,
Aylesbury HP22 5AA

To book your FREE place call Sarah Clark at Coloplast on 01733 392349 or ***email gbscl@coloplast.com***

Suffolk / Norfolk Spina Bifida / Hydrocephalus Support Group

A group for adults with spina bifida and/or hydrocephalus and their carers meets every two months at Roydon Village Hall, High Road, Roydon, Nr Diss, Norfolk. Parents of teenagers with spina bifida and /or hydrocephalus are also very welcome. For further details please contact Margaret & Alan Twyford on 01728 860916 or by email to ***twyfords@aandmtwyford.plus.com***

The following dates have been fixed so far:

10 January 2008	10.30am -12.30pm
13 March 2008	10.30am-12.30pm
8 May 2008	6.30-9.30 pm

Northern Region Dates for York Drop-in 2008

Low Moor Community Centre, Bray Road,
Fulford, York YO 10 4JG
2nd Wednesday each Month - 10.15-12noon
13 February 2008 • 12 March 2008
9 April 2008 • 14 May 2008

For further information please contact the Northern Region Office on 0113 255 6767 or email **sylvieb@asbah.org**

Please e-mail the editor (Link@asbah.org) dates of your events for the next issue of Link *by Friday 15 February 2008, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.*

Holiday let

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

ISLE OF WIGHT ASBAH - HOLIDAY BUNGALOW

Wheelchair-accessible bungalow, sleeps six. Open-plan lounge/kitchen, wetroom. Site facilities. Local heated accessible pool. Beautiful area. Transport advisable. **Details and rates: Sylvia Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF Tel: 01983 863658,** *www.iwasbah.co.uk*

New Adviser for West Wales

Jim Dunne has joined ASBAH as West Wales Area Adviser, covering the counties of Neath, Port Talbot, Swansea, Carmarthenshire, Pembrokeshire, Ceredigion and South Powys.

Since he moved to Swansea from the Midlands in the early 1980s, Jim has spent the last 25 years working in the mental health and supported housing/ homelessness fields in West Wales, gaining a Nursing qualification, a wife and three daughters, and the ability to speak a bit of Welsh in the process.

Jim said: "I am excited to be given the opportunity to use my existing skills and knowledge and transferring these into this role.

"I'm also looking forward to learning new skills from my colleagues, service users and their families, to make positive changes and to empower people who use our service."

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.*

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 15th Feb 2008

Please send to: Editor, ASBAH
42 Park Road, Peterborough PE1 2UQ.
Tel: 01733 421362. Email: *Link@asbah.org*

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Fax: 01733 555985
Email: ***ero@asbah.org***

ASBAH NORTH
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This time we catch up with busy student Vicky Mason, one of the models from ASBAH's new *Below the Belt* book.

Vicky Mason

Vicky Mason is a girl looking at a bright future. The bubbly 17-year-old from Boston in Lincolnshire is determined to carve out a successful career in theatre make-up… and she won't let her wheelchair get in the way of her plans.

Vicky, who was delighted to be asked to model for the Below the Belt book, is currently on the second year of her Beauty Therapy course at Boston College and is applying to study theatre make-up at Stamford College next year.

> Ever since I was a little girl I've loved being creative with make-up and working as a make-up artist in the theatre has been my ambition for a long time

"It's something I've always wanted to do," she explained. "Ever since I was a little girl I've loved being creative with make-up and working as a make-up artist in the theatre has been my ambition for a long time."

Vicky, who has spina bifida, relies on a wheelchair to get around, but refuses to let her mobility problems hamper her.

She told *Link*: "I try not to let my wheelchair get in the way of my life. Of course every now and again it does get me down, but I have to try not to let it.

"The beauty therapy course I'm currently on is full-time and it can be very demanding, but I thoroughly enjoy the work. The other girls on the course are lovely and give me a bit of help if I need it."

At the age of 16 Vicky passed her driving test and was thrilled when her parents bought her a car which has enabled her to be even more independent, which her family has always encouraged.

Mother Val says she always tried to treat Vicky the same as her elder siblings, sister Kimberley, now 23, and brother Simon, 20, encouraging them all to get on with life.

And Vicky certainly took her advice, living life to the full by playing tennis, partying with friends and her boyfriend Ben, not to mention fitting plenty of shopping into her free time.

Vicky said that modelling for Below the Belt with her best friend Laura was great fun.

"I was really pleased to be asked," she said. "It was great to be involved with such a useful book and it was lovely to have some great pictures taken with Laura."

To order your copy of the *Below the Belt* book call the helpline on 0845 450 7755 or order on-line www.asbah.org

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