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The magazine for people with
hydrocephalus and spina bifida

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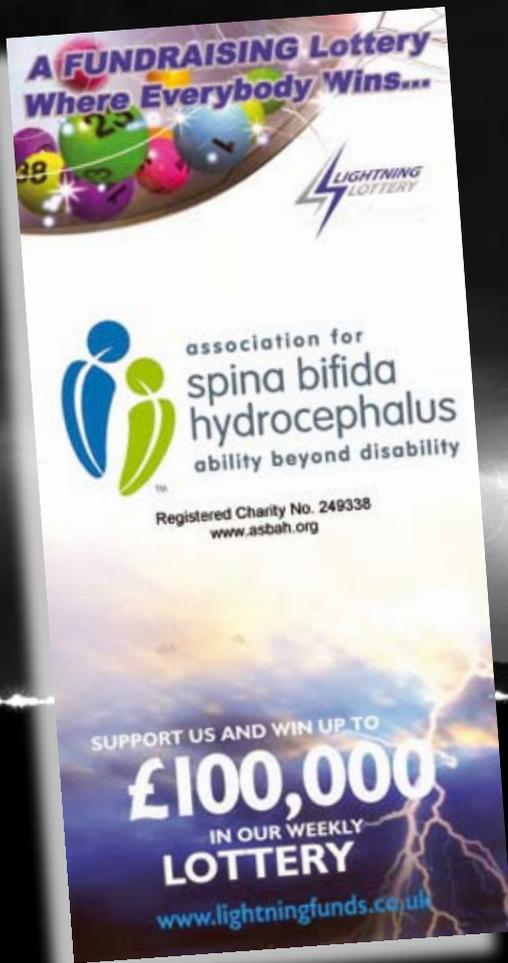
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spina bifida
hydrocephalus
ability beyond disability



Lightning Lottery

ASBAH has just launched an exciting new lottery where players have the chance to win £100,000 every week!

Everyone can join in by requesting a leaflet from Cerys Long of our fundraising team on 01733 421329 or email cerysl@asbah.org or visit the Get Involved section of our website www.asbah.org

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the lifestyle magazine for people with hydrocephalus and spina bifida



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Gill Winfield writes



Welcome to the autumn issue of *Link* in which we're looking back on activities enjoyed during summer (whatever the weather!) and forward to the festive season, with our new range of Christmas cards.

This summer may have been a washout but that hasn't stopped *Link* readers getting out and about.

A group of young people thoroughly enjoyed their time at the annual Summer Experience where they faced a host of exciting outward-bound challenges.

Our skiing feature, by Your Voice committee member Lisa Cain, might whet your appetite for a winter holiday where the weather is actually supposed to be freezing!

As always ASBAH fundraisers have been hard at work and you'll find lots of coverage about the wild and wacky ways which have helped them to bring in the money.

We've received lots of positive feedback about the special supplements we have featured in recent issues. This time we turn our attention to adults, with lots of information and advice from service users as well as professionals.

Also in this issue is an article by solicitor Anthony Fairweather, who writes about the importance of writing a Will as well as a preview of the new professional section on our website, information about how to play our new lottery game and much more.

Gill Winfield

Marketing and Communications Manager
gillw@asbah.org

Patron:

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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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Professional area launched
on ASBAH website
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Joanne Grenfell
Education Adviser
(see p30)



Experts reveal new findings at annual meeting

Experts from around the world presented their findings at the 52nd annual meeting of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB).

Forty three new research papers were presented at the annual event, held this time at Brown University, Providence, in the United States on 11 – 14 June.

The ASBAH contingent included Chief Executive Andrew Russell, Senior Medical Adviser Rosemary Batchelor and Medical Advisers Gill Yaz and Marie McGonnell.

Dr Roger Bayston, Associate Professor in Biomaterials Related Infection, from the University of Nottingham, presented the findings of his and Rosemary's research into ventriculo-peritoneal (VP) shunts in the community. This included information provided by many *Link* readers. This was a follow up to their first paper on ventriculo-atrial (VA) shunts which was presented at the Cambridge SRHSB meeting.

Rosemary said: "It was exciting to have our papers accepted by this international society – and to hear the comments (and compliments) of the delegates."

The society prides itself on being multidisciplinary with neurosurgeons, urologists, scientists, neurologists, psychologists, therapists and paediatricians attending from all over the Western world as well as some from Asia, India, Africa and some Eastern block countries.

Their interests are as diverse as their nationalities but they all attend with one goal – to increase their expertise and knowledge in spina bifida and

hydrocephalus, both clinical and academic."

Andrew Russell, told *Link*: "It was good to be back together with experts from all round the world who are dedicated

to better understanding of spina bifida and hydrocephalus, as well as being such good company!

"As usual with the SRHSB, there was a very broad spread of topics, from social development to molecular biology.

"This year there was a particular emphasis on the complex biochemistry of hydrocephalus, a growing field which promises much for the future. At the meeting, Professor Andy Copp from London gave the Casey Holter lecture on this subject. ASBAH is co-operating with Professor Copp to help find women participants for his study of the vitamin inositol, which may help prevent spina bifida pregnancies."

Andrew added: "It was a stimulating meeting in the lovely surroundings of Rhode Island. I'm pleased to say that Dr Roger Bayston, our Medical Advisory Committee Chairman, was made President Elect of the Society, and will take over as President at the meeting in Belfast next year."



Bristol Local Association closes

Bristol and District Local Association recently closed after 42 years.

This is the last issue of *Link* magazine in 2008 and any former Bristol members wishing to continue receiving the magazine will need to subscribe directly to ASBAH.

Either complete the form included on the inside front cover of this issue or call the helpline on 0845 450 7755.

Service users in the Bristol area can also contact the helpline for other information or to be put in touch with Ann Gillard, area adviser for Bristol and Somerset.

Arise Sir Nicholas! Knighthood for birth test expert

A distinguished scientist who helped to prove that the vitamin folic acid can prevent spina bifida has been knighted in the Queen's Birthday Honours list

Professor Nicholas Wald FRS, director of the Wolfson Institute of Preventive Medicine at the University of London, directed an international study which found that by taking folic acid before conception, a woman could reduce the risk of spina bifida or anencephaly by up to 72%.

ASBAH works closely with Professor Wald on our Folic Acid Campaign, meeting politicians and government representatives to



Professor Nicholas Wald

emphasise the importance of the vitamin.

As a result of his work, doctors and health authorities all over the world advise women to take folic acid supplements before and during pregnancy.

In some countries, fortification of flour with folic acid has led to a 50% reduction in the incidence of spina bifida. However, Professor Wald is disappointed that the UK Government has yet to agree to mandatory fortification of flour.

In 1988 Professor Wald also discovered a means of screening pregnant women for Down's Syndrome. Working with colleagues, he showed that the measurement of three substances in a pregnant woman's blood could be used to screen women for Down's

syndrome pregnancies. His work resulted in an "integrated" test, which can detect 85% of Down's pregnancies, and throws up a very low rate of false-positive results.

Professor Wald has also played a key role in developing the polypill, a combination of drugs and folic acid, which research suggests could cut the rate of deaths from heart attack or stroke by over 80%. Given to everybody over the age of 55, it has been calculated that the pill could potentially save 200,000 lives every year in the UK alone.

Professor Wald said he was "delightfully surprised" by his honour. "I am very pleased, particularly since it reflects on preventive medicine, an important field that can be quite neglected, with so much attention on treatment and curative services," he said.



Outward Bound for summer fun

Youngsters faced a host of new activities at ASBAH's Summer Experience run by ASBAH's Northern Region.

Archery, abseiling, tree climbing, canoeing, and the Team Challenge were part of the fun-filled four-day residential camp from 11 to 14 August, again held at The Keppleway Project in the Lake District.

The group of 16 young people, aged between 11 and 16, travelled from Birmingham, Staffordshire, the North West, Yorkshire and Northumberland to enjoy a busy daily programme of events that tested their abilities and boosted their confidence.

The fun didn't stop when the sun went down, evening activities included 'getting to know you' sessions and a BBQ and disco on the final night.

The ASBAH team – Joan Pheasant, Regional Manager; Mary Malcolm, Director of Services and Area Adviser, Julie Turnbull - were helped by a team of nine occupational therapy students, from universities across the country, who worked alongside the youngsters.

Joan Pheasant said: "Everyone had a brilliant time. The archery was particularly popular this year and even though the weather wasn't brilliant it didn't dampen spirits".

And this is what they thought...

**"The most fun ever!"
Lucy, occupational therapy
student from York**

**"I had a brilliant time at
Keppleway, you can't fault it.
It was so wheelchair-friendly.
The staff and the helpers were
so friendly and I have made
some really good friends."**

**Natalie, aged 15,
from St Helens**

**"Just wanted to say a huge
thank you to everybody
involved in the trip to
Keppleway this week.
Robert had a wonderful
time and really got a lot out
of it. We are so grateful to
the staff and volunteers for
making it possible."**

**Chris & Jenny Mooney,
(parents of Robert age 13)**

Fortification debate gets airing in Eastern Europe

Folic Acid and Neural Tube Defects (NTDs) were high on the agenda at a recent health conference in Eastern Europe.

ASBAH's Chief Executive, Andrew Russell, and Carole Sobkowiak, former President of the SRHSB and member of ASBAH's Medical Advisory Committee, were among the experts attending the 1st Central and Eastern European Summit on Preconception Health and Prevention of Birth Defects.

The three-day conference, which was held in Budapest, Hungary, at the end of August, had a full agenda covering folic acid and NTD prevention, infections, preconceptual health, and even the lasting effects of the Chernobyl disaster in parts of Ukraine.

Andrew said: "Many of the health issues faced in the Eastern European nations, as they progress towards the rewards of full market economics, mirror the problems of Western Europe: obesity, alcohol dependency, smoking, and a widening division between rich and poor. All of these present a challenge to improving the health of women and their babies."

Continuing evidence of the benefits of folic acid flour fortification was presented by the USA and South America and Andrew described the UK folic acid campaign.

Andrew added: "It is hoped that momentum will build up, towards one or more European countries mandating fortification in the next two or three years."

Carole Sobkowiak said she felt the Summit was very successful and was pleased that participation from Eastern European countries including Poland, Romania, Bulgaria and Russia was so strong.

"This was the first time that we have really had any major involvement with health experts from Eastern Europe and the Summit has helped to foster new relationships and encourage a greater sharing of information," she added.

Following on from the meeting in Brussels in November 2007, the second Flour Fortification Initiative meeting will be held in Bucharest in October, with Andrew Russell and Carole Sobkowiak attending.

enABLE 08 – new show for UK

Make a date in your diary this autumn to visit enABLE 08 - the name of a new UK national consumer show dedicated to people with disabilities who seek an active and independent life.

To be held in the Jaguar Exhibition Hall at the Ricoh Arena, Coventry on 28-29 November 2008, the very first enABLE show will be free to attend and will meet the information needs of visitors while offering an engaging seminar programme covering wide-ranging topics. With around 120 companies at the show, there's something for everyone. Exhibitors displaying aids, holidays, financial and professional services, training, recruitment and education will be present. ASBAH will have a stand in the charities area – so please make sure you come and see us and meet helpline staff and advisers as well finding out about our latest news, information and publications.

The Ricoh Arena, which offers the most disabled-accessible exhibition halls in the UK, boasts excellent travel links by car and train plus plenty of parking spaces. That, together with the estimated core audience of 1.2 million living within a two-hour drive time of Coventry, makes it the most convenient venue for this first-time exhibition. Visit www.enableshow.co.uk for further details.



Back from Beijing

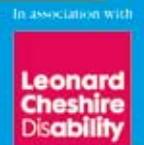
Nine-year-old Gareth Picken has recently flown back from this summer's Paralympic Games Hand-over Ceremony, in Beijing, after winning Blue Peter's 'Postcard to Beijing Competition'.

Gareth, who has spina bifida and hydrocephalus, was judged as one of two overall winners and won the opportunity to take part in the hand-over ceremony on 17 September.

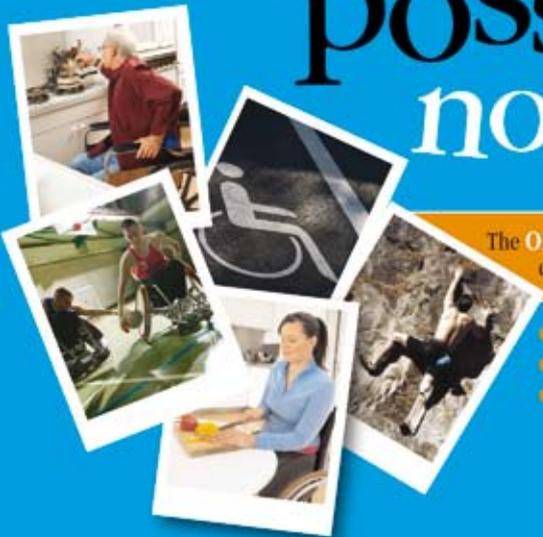
He is pictured here (bottom left) with Blue Peter presenters, Andy Akinwolere and Zoe Salmon (back row) and paralympic athletes Dan Lucker and Clare Strange.



enABLE08
 creating independence
 for people with disabilities
 28th - 29th November 2008, Ricoh Arena, Coventry



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Group gains support

A small support group on the Norfolk/Suffolk border is going from strength to strength and is now looking to include teenagers and families among its number.

The Suffolk and Norfolk Spina Bifida and Hydrocephalus Support Group was launched on 1 May last year by Alan and Margaret Twyford, who both have spina bifida.

The couple left Surrey in 2005 to retire in the village of Debenham, in Suffolk, but soon found they wanted to join an ASBAH group in their new area, having previously been involved with Surrey ASBAH.

Alan, who also has arrested hydrocephalus, told *Link*: "The East Anglia support group was sadly defunct so we contacted our adviser, Val Meyer Hall, about the possibility of starting up our own.

"Val wrote to a number of people within a 25 mile radius of Debenham to see how many would be interested, and received some positive replies."

Now the group, which meets every other month at Roydon Village Hall, near Diss in Norfolk, enjoys a core membership of 20 regulars.



Left to right: Val Meyer-Hall ASBAH Area Adviser talking to Karen and Paddy O'Brien

Val attends most meetings to offer information and answer queries, and an ASBAH medical adviser also gave a talk to the group.

But Alan, who once served as an ASBAH Trustee, said that now the group is established they would like others to join, including young families and teenagers.

"If enough young families are interested we will also help them to set up their own meetings also," he added.

Members were recently thrilled to hear that the East of England Co-op had awarded their group a £200 grant which will pay for the hire of the hall and refreshments and will allow them to consider grants to members for attending study days etc.

For more details about the group, including meeting times and contact numbers, turn to page 29 or contact Alan and Margaret Twyford on 01728 860916 or by email: twyfor@sandmtwyford.plus.com

New rights for disabled and less mobile passengers

Under new European law, if you are disabled or have difficulty moving around, you will have improved rights to assistance when you fly to, from and within Europe from 26 July 2008.

This new regulation on air travel means that airports have to provide services that enable disabled passengers to board, disembark and transit between flights.

The law affects the whole of the air travel process, not just the flight itself. It also covers booking flights, arriving at the airport, checking in, getting on and off the plane and leaving the airport.

This is the second stage of measures designed to protect disabled passengers when travelling by air and creates a consistent standard across Europe.

On 27 July 2007 it became illegal for airlines, travel agents or tour operators to refuse a booking on the grounds of disability or to refuse to board a disabled person who has a valid ticket and reservation, except for safety reasons.

For passengers, this will give continuity to the assistance given at airports across the European Union, whereas previously standards may have differed, they are now set and passengers are entitled to full assistance regardless of the airport they are travelling to or from.

Any person who feels that there has been a breach of the law has the right to complain to the Equality and Human Rights Commission. If guilty, an airport, airline, travel agent or tour operator could face an unlimited fine.

TRIBUTE: Mary Oughtred

ASBAH says a sad farewell to Mary Oughtred MBE who was the first Director within the organisation.

Mary not only showed a great commitment to ASBAH and the many other organisations she was involved with over the years but her passion and enthusiasm engendered it in others too.

The service celebrated the life of a remarkable woman whose faith and interest in others never dwindled. We owe her a deep debt of gratitude.

Gary's ticket to Ryde

On the day Boris Johnson was celebrating his win in the London Mayoral election, Gary Axford was celebrating his own political victory.

Gary, 24, gained a seat on the newly formed Ryde Town Council on the Isle of Wight in his first foray into local politics.

The budding politician, who has spina bifida and hydrocephalus, has been involved with the Isle of Wight local association since birth and has served on the committee for more than three years.

Gary said: "I was thrilled to be elected. It's very exciting to be on the Town Council, particularly since it is a new council for the area.

"I think it is important to have someone younger on the Council and I will also be able to put forward issues affecting disabled people in Ryde."



Gary Axford

But Gary is no stranger to publicity. When he was 14 his home was selected for a BBC Ground Force make-over and the team built him a remote control car track around the garden.

The programme later won a national award and the team was so impressed with Gary's attitude to life that they donated the £500 prize to the local association.

Derek Sprake, Secretary of the Isle of Wight Local Association told *Link*, "Gary is an inspiration to all his colleagues and he can now serve his local community and raise issues affecting disabled people in his home town."

Daredevil siblings abseil for ASBAH

The fearless Whiting siblings took a mighty step for an ASBAH support group by abseiling from the top of Ipswich Hospital.

Naomi Whiting, and her brothers Nicholas (who has hydrocephalus) and Timothy, tackled the 150ft abseil challenge in July to raise more than £200 in sponsorship money for the Norfolk and Suffolk Spina Bifida and Hydrocephalus Support Group.

While their nervous mum and hundreds of spectators watched from the bottom, the Whitings strapped up and one after the other edged their way down the tower.

"We all travelled up to the top together but I pulled the short straw and went first," said Naomi.

"I'd done abseiling once before but it was nowhere near as high as this. I don't think any of us anticipated how high it was, you



could literally see for miles. But once I got going there was no stopping me, I loved every second of it," she added.

The family decided to do the charity event to boost finances for the recently established Norfolk and Suffolk support group.

"We often go together as a family to the group and have received a lot of valuable support from adviser Val Meyer Hall, as well as making many new friends. Hopefully the money that we've raised can help to really get the group up and running," said Naomi.

Pocketfuls of cash for ASBAH

A clothes sale hosted by Lindsey Howell at her home in Pembrokeshire has raised approximately £300 for ASBAH.

The fundraising event, held in early June, was attended by 12 of Lindsey's friends from the local area.

Guests enjoyed wine and nibbles and the chance

to grab a real bargain on some designer samples that Lindsey had acquired from a fashion designer friend.

Lindsey said, "I was having a clear out and thought it was the perfect excuse to have a get together with friends and raise some money for ASBAH at the same time.

"My 14-year-old daughter Emily has hydrocephalus and ASBAH has been great and offered us a lot of support. We especially wanted to help ASBAH because it is a smaller charity."



Left to right:
Mey Khulusi,
Beth Meadway,
Ellie Penrose,
Pixie Pickering,
Hannah Meadway



Hannah takes on fun run challenge

For the third year running, youngsters, parents and staff from Hymers College in Hull ran up funds for charity at the Humber Bridge Half Marathon and Fun Run.

This year's event saw more than 140 pupils entering the two-and-a-half-mile fun run which formed part of the Humber Bridge Half-Marathon. Many ran in fancy dress to raise money for the Marie Curie Cancer Appeal.

But Hannah Meadway, her twin sister, Beth 11, and some of their friends decided to run on behalf of ASBAH.

Paul Meadway, Hannah's dad, explained: "Hannah was diagnosed with hydrocephalus in November and had an endoscopic third ventriculostomy followed by the insertion of an adjustable VP shunt.

"She has recovered very well and we found the people at ASBAH comforting and very helpful so we wanted to give something back to say thank you for their hard work and dedication."



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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:
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Peterborough PE1 2UQ

Tel: 01733 421328
Email: ianm@asbah.org
www.asbah.org



Registered charity no. 249338

Left to right: ASBAH Chairman Richard Astle, Danny Mills and friends Chris Makin and Neil Ramsey.



Bank Hits Massive Target

A Swedish bank, based in London, has raised around £90,000 for ASBAH at their annual clay pigeon shoot fundraising day. Every year SEB (Skandinaviska Enskilda Banken), a Northern European financial group, chooses a different charity to benefit from all the money raised. This year ASBAH was the charity of choice.

SEB employee Alan Loader's daughter, Rachael, has hydrocephalus and the family have had valuable support from ASBAH, so Alan nominated us for this year's event.

Fifty-two teams spent the day at Bisley Shooting Ground in Surrey, considered one of the leading shooting locations in Europe. There was also an ASBAH team which was made up of ASBAH Patron, Danny Mills, two of his friends and ASBAH Chairman Richard Astle.

Each team paid £1,100 for the day's shooting, breakfast, lunch and supper and further funds were raised by selling raffle tickets at £10 a time and through an auction of fantastic prizes, donated by the teams.

ASBAH's fundraising staff cajoled, charmed and shook their raffle buckets at every opportunity and the generous shooters spent a whopping £15,000 on raffle tickets. Prizes donated for the raffle included great treats from meals at famous chefs' restaurants to days out at major sporting events.

After the day's shooting finished, the evening auction had the audience in fits of laughter as the auctioneer, who is also a professional comedian, mixed comedy with fast moving bidding and managed to boost the total raised even more.

ASBAH is absolutely thrilled with the result. Colin Roberts, Fundraising Director, said: "We can't thank SEB enough for raising this huge amount towards our work with families with spina bifida and hydrocephalus."

We can't thank SEB enough for this once in a lifetime opportunity to raise this huge amount

Birthday fundraiser

Rebecca Young from Newmarket raised £200 when she asked friends and family to give charitable donations to ASBAH instead of buying her birthday presents.

Rebecca, whose four-year-old son Charlie, has hydrocephalus, celebrated her 40th birthday with a BBQ and karaoke party at a local club on 28th June.

More than 80 friends and family joined in the fun and were very generous in their donations.

Rebecca's husband, Ian, said: "The advice and help we have received from ASBAH since our son, Charlie, was diagnosed with hydrocephalus has been brilliant and Rebecca really wanted to give something back."

ASBAH's Lightning Lottery

ASBAH has just launched an exciting new lottery where players have the chance to win £100,000 every week.

It's called the **Lightning Lottery** and everyone can start playing it right now.

Colin Roberts, ASBAH's Director of Fundraising, said: "Ever since the old Play Monday Lottery finished I've been looking forward to replacing it with something better.

"The Weather Lottery has been around for some time and many charities have signed up for it.

"They have now introduced a new game where players have the opportunity to win cash prizes of £2, £20, £250 & **£100,000** every week.

"The stake is £2 a week to play and a **massive 60% of the stake money comes directly back to ASBAH.** This is more than double the National Lottery percentage going to good causes and far better than the old Play Monday game.

This is a great way to have a flutter and help ASBAH at the same time.

Tell your friends and get them to sign up now."

The game is based on choosing six numbers which are matched against the second digit of temperature in six locations around Europe (as reported in the Daily Telegraph) – so if you choose **3 6 1 7 2 4** and the temperatures are **83 96 81 77 62 64** - you win a guaranteed £100,000 (no splitting of the winnings).

Winners are sent their cheques automatically and direct from Lightning Lottery Head Office so you don't even have to check the Daily Telegraph for the temperatures to see if you've won!

Everyone can join in by requesting a leaflet from Cerys Long of our fundraising team on 01733 421329 or email cerysl@asbah.org or visit the Get Involved section of our website www.asbah.org

London Fire Brigade Tackles Mountainous Challenge



A group of fire fighters bravely tackled one of the toughest challenges in Britain this summer – and for a change it was not heat, but freezing temperatures that they were battling against.

The Three Peaks Challenge is a gruelling event which involves climbing the three highest mountain peaks in the UK: Ben Nevis in Scotland (1344m), Snowdon in Wales (1085m), and Scafell Pike in the Lake District (978m) and all in just 24 hours.

Alan Hudson is a fire fighter based at Leytonstone fire station in London. He and his colleagues from the White Watch heard about the event after the Brigade put flyers out, and immediately decided that they would take part to raise money for ASBAH.

Alan's son Bradley, eight, has hydrocephalus. Bradley was diagnosed at five weeks, and since then the family, who live in Great Yarmouth, have found ASBAH services really helpful. This is what gave Alan and the White Watch the motivation to bravely sign up for the gruelling challenge.

Their team, which was made up of five walkers and three drivers, had never taken

part in an event like this before and although their profession requires them to keep fit and healthy; they still had to undertake a lot of training to prepare for the challenge. This training consisted mainly of long distance walking, as this is what the Three Peaks Challenge mostly involves, and strong legs are essential.

Alan and the White Watch team had obviously prepared well as they managed to complete the challenge in 22.5 hours, which is better than they expected. Fortunately there were no accidents or injuries although everyone did feel very sore at the end and there were a lot of blistered feet!

The team experienced different extremes at each mountain. Ben Nevis proved most challenging; at the summit the team had to struggle against 60mph winds while trudging through snow with a wind chill factor of -20 degrees. Scafell Pike was dry, but very cloudy at the highest points, and Snowdon was very clear and calm.

Sponsorship for the event has so far reached a £2,300, but this figure is expected to rise even higher. Well Done!



ASBAH make a splash in the River Nene

The 'ASBAH Ability' team took to the water at the Peterborough Dragon Boat festival to raise ASBAH's profile in the local area.

The festival, which is based on ancient Chinese tradition, saw teams of 16 people paddle a 40ft boat along a 250-metre course, with a drummer at the front beating in time and someone at the helm steering in the right direction.

The crew was made up of ASBAH staff and some of their nearest and dearest including Jane Ayres and her son Luke, Shelly Bullard and her husband Michael, Helen Donald, Matthew Donald, Darren Fower, Sue Knickle, Cerys Long, Ian Morley, Tony Nero, Shaun Pitchers, Colin Roberts, Andrew Russell, Emma Swick and Christine Wheatley.

Hundreds of spectators watched from the river bank as 'ASBAH Ability' battled it out against 52 other teams, including crews of Vikings, pirates and even the Flintstones.

"During the course of the day our team had three races. In the first race there were paddles everywhere, lots of splashing and everyone got soaked. We came fourth in that race, not bad, though there were only four teams in it," said Tony Nero.

"Overall we came 46th out of 52 – bearing in mind this was a first attempt at least we weren't the worst – we didn't come last and we didn't get thrown in the river."

"It was a brilliant event with fun being had by all. I'm already looking forward to next year."

Donation helps ASBAH Wales to continue its hard work



The Bangor and District arm of the Royal Antediluvian Order of Buffaloes has kindly donated £1300 to ASBAH to help our work within the District.

The Royal Antediluvian Order of Buffaloes is a social and benevolent fraternal organisation open to men. It helps members and their families who are in need and the families of deceased members as well as supporting other charitable groups.

The money was raised by Brother Alan Bates ROH, who was the Provincial Grand Primo 2007. Mr Bates has spina bifida, and

nominated ASBAH as his Charity of the Year.

The cheque was presented to Elin Ifan, ASBAH Regional Manager for Wales, by Mr Bates at a Presentation and Investiture meeting which was held at AKA's Club RAF Valley, Holyhead, on 27th April.

Elin said: "ASBAH is very grateful to Brother Alan Bates and the Royal Antediluvian Order of Buffaloes who, through their generosity, have made it easier for ASBAH to help people in Bangor and the surrounding area affected by spina bifida and hydrocephalus."

STAR supporters

Meet the Nicholls Sykes family

The Nicholls Sykes family have invested a lot of time and effort into organising fundraising events during the last three years. To date they have helped to raise more than £1,500 for ASBAH.

Several years ago, Lisa Nicholls Sykes, from Ashby de-la-Zouch in Leicestershire, was chatting with her neighbour whilst they both decked the outside of their homes with lights and decorations ready for Christmas.

They talked about how nice it would be to have some hot food to eat whilst braving the cold December weather. This conversation sparked the beginning of an event that is now in its fourth year.

The Christmas Barbecue is now enjoyed by lots of people across the town. Friends and neighbours of the family play a big part in the organisation of the event, and also help to motivate Lisa and husband Nigel.

Neighbours, Gill and Ian, use their computer skills to make leaflets to advertise the event. It is thanks to this that interest has grown steadily each year, with people coming from all over to join in the festive fun.

Twenty houses surrounding the Nicholls Sykes' family home are decorated with lights which are all turned on at the same time; the effect is very impressive.

The local butcher kindly donates meat for the barbecue, and lots of other tasty winter treats such as mince pies and sausage

rolls are donated by other members of the community. Mulled wine is served to keep everyone nice and warm and to wash down the food. Festive music is played and there are lots of activities for children.

The event is enjoyed by young and old alike. It brings people together and there is a great atmosphere and community spirit. Not only does the event benefit the local people but it really helps ASBAH too. The money is raised through donations which are left in a box with the average amount collected each year being around £800.

Lisa and Nigel have their hands full with



four children. Their son Barney, seven, has hydrocephalus, as well as autism which means he has no speech and severe learning difficulties.

Barney's hydrocephalus was diagnosed at three months. The hospital gave Lisa an ASBAH leaflet, and, after having a bit of time to let the diagnosis sink in, she made contact with ASBAH.

Since then, ASBAH has been instrumental in helping the family in a number of ways: medical advisers have helped when Barney experienced problems with his shunts, and the Benny Bear books have helped Barney's sisters Madeleine, Mariella and Beatrice to understand Barney's condition a little better.

Lisa said: "I am so pleased that we have been able to raise money for ASBAH. The children have benefited enormously from the services available, in particular the Family Weekend which had a lasting impression. Madeleine was six when we attended that event, but she still talks about it now, aged 11."



Family gear up for off-road challenge

A family from South Wales experienced a summer holiday with a difference this year as they took up the impressive challenge of off-roading through ten countries in seven days in aid of ASBAH.

From 13 - 19 September Ian Hulme and Keri Hulme-Webb, along with their ten-year-old son Rhys and four-year-old daughter Olivia, who has spina bifida and hydrocephalus, tackled the Landy Rally™.

The Landy Rally™ is a non speed event which passes through Belgium, Luxembourg, Germany, Switzerland, Liechtenstein, Austria, Italy, the French Alps, Andorra and across a fair amount of remote tracks in the Spanish and French Pyrénées.

The family jumped at the chance to take part in the 4x4 run which would not only challenge Ian's driving skills, but also give them the chance to raise money for ASBAH.

Before they set off Keri told *Link*: "We're aiming to raise more than £1,000. ASBAH have done a lot for us over the last four years and it's nice to be able to give something back. The car is ready and we are all raring to go".

Find out how they get on in the next edition.



Barney Nicholls Sykes

Add a little adventure to your fundraising

ASBAH has secured places on several overseas treks taking place in 2009 for intrepid adventurers looking to spice up their fundraising efforts.

Spaces are available on:

COSTA RICA TREK - 24th Jan / 3rd Feb 2009

KILIMANJARO TREK - 13th Feb / 22nd Feb 2009

SAHARA TREK - 28th Feb / 8th Mar 2009

CUBA CYCLE - 11th Mar / 23rd Mar 2009

Anyone interested in taking part to raise money for ASBAH should contact Ian Morley, ASBAH's Event Fundraising Officer on 01733 421328. Alternatively you can email ianm@asbah.org



I am not always very good at trying out new things, but over the summer I have taken the plunge and tried my hand at cavy showing. To the rest of the world, that means guinea pigs!

It is a remarkably straightforward process actually and a very accessible hobby; all you have to do is take your piggy down to the local show, pop him in a ready made pen with a number on the outside, add a few veggie treats in case piggy gets peckish, and then wait around for ages to see if the judges award a prize.

Dead simple. It's also dead cheap - £1.50 was all it took to enter Roger into the guinea pig equivalent of the Mr Universe competition.

Of course, if you want to look like the guinea pig equivalent of Pierce Brosnan there are a few preliminary matters that have to be attended to, for example ensuring that you smell more eau de toilette rather than eau de toilet (for avoidance of doubt, that's the piggy, not the owner!)

However, when I came down one morning and wished Roger a happy bath-day, he simply looked at me with his usual furry expression and it was not until later on that he realised what this actually entailed.

Having read up on the process, I decided that I would carry out the operation in the bathroom so that Roger could stand in a bowl on the shower tray and I could kneel over him, thereby maintaining some element of control.

Unfortunately, that disappeared after the first dunk when he realised that he was going to end up smelling of lavender and tea tree for the rest of the week!

He managed two laps of the shower tray before I recaptured the soapy runaway, and after another quick dunk he was towel dried and then blow-dried, much to his indignance.

According to the experts, once you have gone to the trouble of cleaning up your piggy, you must then make sure that on the day of the show, he or she does not eat any highly coloured or messy food, such as tomato, as

it can stain the fur around the mouth, and anywhere else come to that.

Roger is never a tidy eater at the best of times and has the table manners of a starving hyena, so on arrival at the show he was checked over to make sure his face, ears and feet were still clean and then he was put into his allotted metal-framed pen.

These are stacked in long rows, three storeys high, and the overall effect was rather like a rodent version of Alcatraz. My particular inmate did a quick tour of his cell and then found the food pile, which occupied him until he discovered that he had a next-door neighbour to interrogate.

The waiting around was rather tedious so if you are thinking of doing this, bring a book or something to do. Your pet will get bored and go to sleep until such time as the judges start placing the coloured cards on the pens to indicate the prize winners in each class, and best in show.

Sadly, we didn't take any coloured cards back with us at the end of the day, just a tired out furry critter who still wasn't sure why he had spent the day in piggy prison, but was very pleased to be going home.

(Please note - no guinea pigs were harmed during the making of this article)

ORDER NOW • ORDER NOW

Christmas Cards

If you would like to order some ASBAH Christmas Cards, please complete the attached form.

Each pack of 10 cards and envelopes comes with a greeting inside each card that reads:
With all Good Wishes for Christmas and the New Year.



association for
spina bifida
hydrocephalus
ability beyond disability



Three wise sheep



Starlit night



Sprout



The Holy Infant



Robin and berries



Plaiice mats

ASBAH Order Form Christmas Cards

Please send me:	Qty	Price	Total (£)
Three wise sheep		£3.00 inc p&p	
Starlit night		£3.00 inc p&p	
Sprout		£3.00 inc p&p	
The Holy Infant		£3.00 inc p&p	
Robin and berries		£3.00 inc p&p	
Plaiice mats		£3.00 inc p&p	

Total order (inc. postage and packing) £

Payment

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

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

Or

VISA Mastercard/Access

Card no.

Start date Expiry date

Signature _____

Mr/Mrs/Miss _____

Address _____

Postcode _____

Telephone _____

Email _____

**Please send the completed order form together with your payment to:
ASBAH, 42 Park Road, Peterborough PE1 2UQ**

Registered charity no. 249338

Adult issues

In the latest of our supplement series we turn our attention to adults. This eight-page special is packed with information and advice from service users as well as professionals.

Medical matters include an in-depth piece about pressure sores, cellulitis and lymphoedema. There are two personal stories relating to these issues highlighting the importance of good health care.

Naomi Marston, ASBAH's employment and education adviser,

talks in detail about how to find employment which suits your needs by identifying your strengths and weaknesses.

There's also a feature about Mobility Assessment Centres which help to keep disabled drivers on the road, plus Link reader Luke Martin's experiences.

We hope you'll find plenty to interest and encourage you to live your life to the full.

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Finding the perfect job

Finding employment that interests you and suits your needs can prove a tough prospect if you have a disability.

So before you even think about work, it's worth spending time identifying your skills, strengths and abilities... and coming up with realistic employment goals.

Naomi Marston, ASBAH's employment and education adviser, said that people thinking about applying for their first job, or returning after a long break, should consider voluntary work.

"It's a great way to ease yourself back into the work environment," she said. "It gives you a good chance to get back into a routine – perhaps part-time to begin with – and see how you cope without feeling under too much pressure. Voluntary jobs often lead to permanent positions too."

For job hunters the local Job Centre Plus or Connexions service is the most obvious place to start.

Disabled people will be allocated a Disability Employment Adviser (DEA) who can

provide specialist support on employment issues.

DEAs can work with you to plan the best way for you to return to work and help you find a job that is suitable. Jobcentre Plus offices have good links with many local employers who make every effort to meet the needs of disabled people looking for work.

You and your DEA can draw up an action plan to help you into work.

This may include:

- Giving you an employment assessment to help identify your abilities and strengths. You will get an action plan to help you achieve your goals.
- Provide a job matching and referral service to let you know about jobs that match your experience and skills.
- Refer you to a specialist programme for disabled people such as the Job Introduction Scheme and Work Path Programmes.

Training

A Jobcentre Plus Disability Employment Adviser (DEA) should also be able to help you find the training that will be right for you. DEAs are in contact with local colleges and training schemes, so they can tell you what is available and help you apply.

My Story: Vicky Rose

Life at her family home was very happy and comfortable, but Vicky Rose was keen to live independently and learn to do things for herself. Now she is looking for more support (visit www.asbah.org/ASBAH+Community/livingwithhydrocephalus to find out why).

Help and advice available from ASBAH

Naomi Marston, ASBAH's education and employment adviser, heads The Employment Project, which is funded by the City Bridge Trust.

It aims to help people with spina bifida and hydrocephalus in the London area find suitable work.

Naomi said that people who have hydrocephalus often find it difficult to assess their own capabilities.

"One symptom of the condition is that people with hydrocephalus have a limited sense of self – they can't really see how their disability affects them," she explained. "Their perception of their condition is often from what others tell them."

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Another problem is that Disability Employment Advisers and employers often know very little about hydrocephalus and sometimes match people up with a job wholly unsuitable for them.

Naomi said: "This is an area where ASBAH can really help. Before meeting a DEA it's worth downloading some information sheets about hydrocephalus or getting hold of a copy of our new pack on transition and employment which will be available later in the year.

"It's also important to be open and honest about what you are capable of doing."

"Much of my work is providing direct support and information about hydrocephalus. Employers and Further Education colleges have really tapped into the service I provide.

"Many professionals in establishments have little knowledge of spina bifida and know even less about hydrocephalus.

"This means that they have 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 worked closely with a number of organisations and individuals to implement and support strategies such as these."

Useful websites

Voluntary work

www.volunteering.org.uk

Connexions Direct - offering information and advice to 13 – 19 year olds.

www.connexions-direct.com

Modern Apprenticeships

www.apprenticeships.org.uk

New publications

ASBAH is publishing a series of four leaflets which cover all aspects of transition and employment for people with spina bifida and/or hydrocephalus.

The leaflets include: transition (a guide for parents; transition (a guide for young people); getting a job; and a guide for employers.

The leaflets will be available online and from ASBAH's helpline this autumn.

My story

Emma Kirk

Age: 30

Occupation: Health care assistant, Leeds General Infirmary

Lives: Adel, near Leeds with husband Ron.



When it comes to job hunting, Emma Kirk is a firm believer that honesty is the best policy.

Emma, who has hydrocephalus, and cerebral palsy which affects her mobility on the left side of her body, has been in full-time employment since the age of 21.

She works as a health care assistant on an oncology ward at Leeds General Infirmary, a hectic role which she relishes.

Unfortunately, arthritis in her knee has meant that Emma, now 30, has been unable to work for several months, but she hopes to be back on the wards very soon.

She has had hydrocephalus since birth and shunt failures and infections have disrupted her studies at the mainstream school she attended.

Emma explained, "I missed a lot of school during Year 11 and as a result didn't do as well as I'd hoped in my GCSEs.

"I went to college to retake them and then studied for the BTEC First Diploma in Health Studies. After passing, I went on the two-year BTEC National Diploma in Health Studies course, but I had another infection and so missed out on more lessons and didn't pass.

"I did think about giving up but my family talked me into returning to give it another go."

Emma's family had always encouraged her to try her hardest at everything, so she returned to college and after a lot of hard work came away with her Diploma.

She applied for the position of health care assistant at Leeds General and decided to be open and honest about her disabilities.

Emma explained: "If you are desperate for a job it's very easy to sit down and say that you can do it all, even if you know that

you can't.

"I made the decision to be completely honest and say what I was capable of and admit that I might need some help to begin with in some areas. It paid off because I was given the position and I've been there ever since.

"My Ward Sister, Cathy, and the other staff are very understanding. There are a few things I sometimes need a little help with, but I have other qualities and abilities which make up for any shortcomings.

"We work with patients who have bowel cancer and have colostomies. Because I have a disability they feel they can relate to me and perhaps talk to me more easily.

"Working full-time can be very tiring but I love my job and get a great deal out of it. Like anyone I have days when I feel down, but helping people soon lifts my mood. Being on sick leave is very frustrating. I can't wait to get back to work."

Emma added: "When you are job hunting my advice to anyone with a disability is to be honest about your weaknesses and promote your strengths. I have always found that most people are very approachable and admire your honesty.

"But above all never give up your dream. If there is something you really want to do, give it your best shot and show people how capable you are.



- Emma Kirk talks about job hunting
- Pressure sores and what can be done

Pressure sores

Many people with spina bifida will, at some time or another, develop a pressure sore (also called pressure ulcer). This is usually no one's fault and there are many things that can be done to prevent them.

Causes

Poor circulation below the waist means that the cells don't get adequate supplies of oxygen and nutrients to keep them healthy.

The lymphatic system works with the body's circulation to remove fluid and waste products. But this does not work as efficiently in people with spina bifida as it should, so there can be a build-up of fluid in the legs called oedema.

All these factors mean that pressure sores can develop very rapidly and then be very slow to heal.

Neurological (nerve) problems associated with spina bifida and the resulting loss of feeling means that little or no discomfort is felt so there is no trigger telling you to move and reduce the pressure on a particular part of the body.

Incontinence will cause the skin to become even more prone to damage as both urine and faeces contain substances that break down the skin and cause it to become infected.

Prevention

Change your position - every 20 minutes lift your bottom off the chair and change the position of your legs to allow the blood to flow normally for a few seconds.

Regular inspection of the skin – ideally the whole body should be inspected night and morning for signs of any redness or changes in the skin.

Diet - a good balanced diet with plenty of fruit, veg and fluids is essential for both the prevention and healing of pressure sores.

Wear suitable clothing - avoid clothes that are too tight or have hard seams, zips or buttons that might cause pressure. Tight shoes or socks can cause rubbing which can lead to a pressure ulcer – and make sure that tights and socks are clean with no holes. Natural fibres such as wool or cotton will help prevent sweating and keep the skin dry.

Barrier creams - such as Sudocrem and Zinc and Castor Oil Cream can offer protection for the skin where there is wetness or soiling, and should always be applied to washed and dried skin.

Treatment

If a sore develops, it should be assessed as soon as possible by a specialist nurse or doctor who will 'grade' it and start the most appropriate treatment.

The best treatment of all is relief of pressure from the affected area. Special cushions and mattresses are available and the community team (occupational therapist or nurse) is responsible for assessing and arranging provision of these.

This information was taken from ASBAH's Pressure Sores information sheet. For the full document go to www.asbah.org and click the Spina Bifida

information Sheets link. Alternatively, call the helpline on 0845 450 7755.

Lymphoedema

Lymphoedema is caused by a blockage to the lymphatic systems, which causes fluid in the limbs and subsequent swelling. It is the term used to describe swelling that can occur anywhere in the body, but most commonly affects the limbs. If lymphoedema is left untreated, there is a risk that it may worsen over time.

The condition is not curable, but there are ways to control and manage symptoms that can also help to improve quality of life.

Cellulitis

Cellulitis is an infection of the tissues in the skin which can develop from a cut or a sore.

A variety of bacteria groups live on the skin's surface but do not normally cause any problems. But once inside the skin, the bacteria produce powerful enzymes that break down the natural barriers that normally prevent bacteria spreading in the tissue. This allows infection and inflammation to spread. Any area of the body can be affected but the leg is the most common region.

The symptoms are tenderness and redness of the skin, heat, sickness and flu-like symptoms.

You need to see your GP as soon as possible; do not leave it hoping it will get better on its own – you are likely to need antibiotics.

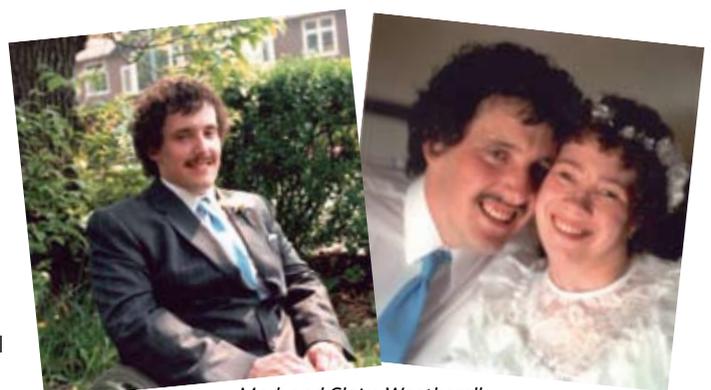
Pressure sores – don't ignore the warning signs

Mark Weatherall, who had spina bifida, died on 6 March as a result of complications of pressure sores and lymphoedema. He was aged 43.

His widow Claire is determined that others should know more about the condition so they don't suffer the same fate.

She said; "Mark knew that his pressure sores were getting worse but didn't tell anyone until it was much too late. He was very independent and private, but unfortunately he didn't realise that sometimes you have to swallow your pride and ask for help."

The couple, who were together for 26 years, met at the National Star College in Cheltenham, a specialist college for disabled young



Mark and Claire Weatherall

continued from previous page

people and adults.

Claire, who has Cerebral Palsy, told *Link*, "Mark was such a great guy; he was always there for everyone.

"We met at college and were together ever since. We looked after each other without much outside help at all.

"Mark had lymphoedema for about four years and the treatment he received wasn't great. We found that the district nurses who came to put on the compression bandages rarely knew much about spina bifida which didn't give him much confidence."

Claire, who lives in Tunstall, Stoke-on-Trent, said that Mark began to go downhill in September 2007, following the death of his mother.

"She was a wonderful lady and Mark was very close to her. He became very depressed and lost interest in himself.

"He'd always had so much get up and go, getting around on crutches as much as possible.

"I had an inkling that his pressure sores were becoming worse but whenever I asked, or suggested that he see his GP, he just shut down and got cross.

"When you're dealing with a grown man it is difficult to insist, and because I didn't know how serious his condition was, I didn't push it. Now I wish I had.

"At college we'd been taught to be independent... but Mark took this too far. He was a very proud and private man so he found it difficult to ask for help. Looking back I realise that he was very clever at hiding things from me."

"I think that towards the end he realised how serious his condition was and because he was depressed, felt that he'd had enough.

Mark finally confided in Claire on 5 March and the following day he was rushed into hospital. Surgeons warned Claire that Mark had a 1 in 3 chance of survival, and sadly he wasn't one of the lucky ones.

Claire said: "When Mark told me about his pressure sores he said, 'I didn't want to bother you.'

"If he had, he might still be with us today."

ASBAH service user Michelle Wild has a lengthy history of lymphoedema and when the condition worsened, she found her health and quality of life were severely affected.

Michelle, who lives in the North West with partner Adrian and three-year-old son Aaron, was offered specialised bandaging treatment which has worked extremely well.

She receives treatment at the clinic at her local hospital and is full of praise for the treatment and service she receives there.

Now Michelle, who has spina bifida, is keen for others to learn more about the treatment. Here she tells her story.



My words, my story by Michelle Wild

I think I first got lymphoedema when I went away to college and got a cellulitis infection. This wasn't treated as I didn't know very much about the condition, and unfortunately it went unrecognised by my GP.

My legs became so big that it really affected my health and way of life. I began to get out of breath and was struggling to get in and out of the car.

I found it hard to go to work and I was put on the sick ten years ago. That meant I wasn't getting to see people as much as I wanted to.

I now have a three-year-old son and I haven't been able to get down on the floor to play with him. I have spina bifida and find it very difficult because there are many activities I cannot do with him.

But I am very lucky in that my GP referred me to the clinic. The nurses there treat you as an individual; they care about you as a person, not just a number.

The treatment was quite hard because I do have spina bifida and have no feeling in my legs. I also have a longstanding pressure sore on my foot and my legs are very misshapen.

The first day I went into pressure bandages was awful. My legs were twice the size due to lots of padding and bandages.

I cried so much because I thought I wouldn't be able to drive my adapted car, but the nurses, Lol and Janice, came up with a way that allowed me to move my knee and foot, so I could still be independent.

I was supposed to have three weeks in

bandages, which meant visiting the clinic almost every day.

But my legs reduced very quickly and my skin became softer. Cream was put on to the skin on my legs every time the bandages were changed, making sure that the cream didn't get into the hair follicles which could cause infection.

The next step was to put a lining on my legs, then layers of wadding and finally two layers of stretch bandages. It took between 30 minutes and an hour.

My leg was measured for a stocking after two weeks. Due to fitting difficulties and the thickness of the garment, it took longer to make, but Janice and Lol kept bandaging me until it arrived, fitting me in the clinic as an extra patient.

Pictures were taken of my legs before and after. Comparing the difference is amazing.

There are side effects such as headaches, feeling sick and dizzy, but don't let that put you off.

Clatterbridge Wirral Trust Hospital's lymphoedema service is so valuable and I hope it continues to stay open. The only way this will happen is for people to use it.

It also offers a support group so you can meet other people, see that you aren't alone and learn more about their experiences.

I can't thank Lol and Janice enough for giving me back my independence. It means the world to me and my family and I can finally play with my son on the floor, like any mum should be able to do.

One of the speakers at the Your Voice weekend was Simon Wrigley.

Simon gave a rousing talk about the importance of self-confidence, how it affects your daily life and, perhaps more importantly, how to develop it.

Here is an extract from his presentation...

Glass half-full or half-empty?

The title I chose for my talk reflected the popular question 'is the glass half full or half empty?' - a simple test of whether a person is thinking in an optimistic or pessimistic way.

Whether we are an optimist or a pessimist in life has a profound effect on our confidence, which in turn affects our assertiveness.

In a way our lives are like the glass. There are parts of our lives that are 'full' and parts that are 'empty'. It's the same for everyone. I have never met a person whose glass is totally full.

As for me, well I have a good job, which pays me a fair amount of money. I have a loving wife who cares for me very much. I have a nice car on the Motability scheme. I have parents who are supportive. I have a house. I go on holiday every year. Those are the parts of my glass that are full.

But I have empty parts too. Work is sometimes too challenging and I can't have children, which is something that can be upsetting for me and my wife.

But I consider my glass to be half full and focus more on what is there than what isn't.

You see, we all wish for things we haven't got - maybe a job, or a partner, a car, or a house.

But equally we all have things too - everyone at the Your Voice weekend has the ability to travel, to stay away somewhere.

Confidence

When someone complains, we might look at them and think 'what a fool they are making of themselves'. But sometimes we look at them and think 'I wish I could

stand up for myself like that.' This is where confidence comes in.

The psychiatrist Raj Persaud says that true self confidence comes from an attitude where you "promise yourself, no matter how difficult the problem life throws at you, that you will try as hard as you can to help yourself."

Your efforts may not result in success, as often being properly rewarded is not in your control."

Confident people make mistakes - confidence doesn't guarantee you're going to get everything right.

But the complaining person is trying to help themselves - they have a problem and they are trying to sort it out.

But if you look on another level are they actually confident? Maybe all they are doing is saying 'Hey I have a problem!'

Are they actually taking control of the situation and trying to sort it out, or are they just giving their problem to someone else and saying 'You sort it!'

It takes a certain amount of confidence to say that you have a problem in the first place. Some people don't feel confident enough to take that step so they just put up with a bad situation.

But what would a really confident person do? Would they cause a fuss by shouting to the waiter about the wine? Or would they quietly get his attention and explain their problem to him, suggesting to him how the

problem can be sorted out?

A truly confident person knows they are in the right and that the problem can be solved - they don't need to scream and shout about it. They are polite and positive and they take control. THAT is true confidence.

Assertiveness

Very simply, assertiveness is taking control of a situation. In the situation with the complaint about the wine, assertiveness is telling the waiter about the problem AND suggesting how it can be solved.

It does take a certain amount of confidence to be assertive, because it is easier to just let other people take control and to 'go with the flow' even if that's not really what you want.

But if a person has too much confidence this can result in them being too assertive.

Maybe they have confidence in a situation where actually they shouldn't, or maybe their confidence leads them to take so much control of a situation that they overrule everybody else. Both of these can result in over-confident and over-assertive people looking arrogant.

A truly confident person is happy to let other people express their opinions and ask questions because they are confident that they can answer the questions and explain why they hold their opinions. They don't need to talk over other people. They don't need to be rude.

Useful websites:

www.mindtools.com/selfconf.html

www.bbc.co.uk/relationships/improving_your_confidence

www.ivillage.co.uk/relationships/famfri/emotwb/articles/0,,156471_176432,00.html

A parent's experience... by Nicholas Fincham

Nicholas Fincham

Age: 52

Occupation: A Priest in West London

Family: Wife Rosemary and two children, Hannah, 14 and Aidan 7.

Medical history: Hydrocephalus following several strokes.



I know the date I became disabled: I am told that on 9 February 2006 I became unconscious while hospitalised with extremely high blood pressure.

I then suffered several strokes and also developed hydrocephalus. Apparently by chance, a specialist registrar in neurosurgery was in the scanning dept with another patient. He looked at my scans and said something like "If we do nothing, he'll die; if I shunt him, he may not survive but he deserves the chance."

Early on that Saturday morning I unexpectedly went into a coma and my wife believed I was going to die.

If I had died, Rosemary and the children would no longer be able to remain in the home we had shared as a family, since the free accommodation comes with my job.

It was Rosemary who held the family together during this unstable time, and months and couple of years that followed.

She explained to the children, in ways they could relate to, about my condition and estimated the best time to share certain events and procedures with them.

Recently we asked our children what they remembered. Hannah said she didn't want to talk about it and told Aidan not to discuss it either.

With time, Hannah said that she was not really bothered about being away at boarding school when I was at my worst, as she did not think I would die.

Rosemary did all the caring for the children and supporting of me during those early days. Aidan seems well adjusted and is not filled with fear as he reminisces about the events when I was so very ill.

Rosemary encouraged Aidan to bring his reading book to read to a lady across the ward who was always willing to chat to Aidan and hear about his day at school and what he had enjoyed. These small things drew his attention

away from my problems and helped him see a wider picture of the ward rather than just dwelling on his Dad being stuck in a bed.

When I was off the ventilator and holding my own I was moved to the high dependency unit and it is from this point that I can begin to remember something of my illness.

I realised I had been very ill when I remembered the Bishop coming for the third time. People from university days that I had not seen for many years also made the effort to visit. It was then that I began to appreciate my recovery.

When I was moved to the local Stroke Unit, no-one knew I had a shunt because I'd been sent alone in a taxi with my notes, which then got lost. They didn't find out until my wife told them, so when I was unwell, the staff didn't know whether it was shunt related or not.

There was no allowance made for my dreadful short term (working) memory. I couldn't even remember whether I had showered as I was "encouraged to be independent".

Apparently I knew I should undress for bed but didn't recognise what pyjamas were so slept in my underwear for several days. In my locker were several days worth of clean clothes and PJs.

After about five weeks I was discharged to the care of my wife at home. She was my voice in the early days - chasing appointments and discussing queries with different organisations.

I received regular visits from a physiotherapist whose support I found invaluable and soon I was walking around the block then further.

My wife's Godmother, a senior adviser for ASBAH, guided us more than anyone else

in this area of health care. She gave us local contacts of people who have been able to support us.

ASBAH also gave the children Benny Bear books which were perfect for explaining the symptoms in a way they could understand.

I had six months off work although not away from the parish. We live opposite the Church and as the main key holders we were often the first port of call.

A year and a half after my initial health scare I suffered from severe depression. This is now controlled by drugs and I am beginning to feel much more motivated and in control of life.

I think when I was ill the main concern for everybody was my physical ability to speak and walk and to return to work.

What was overlooked was time and support to help me to come to terms with what had happened.

But my community occupational therapist was wonderful - recognising that transferring skills was difficult so she conducted my therapy in my church to get me organised to take services.

I rely on others to give me information, as for three weeks in February 2006 I have no recollection of being anywhere, or of how I got there.

I am speaking with a Doctor every six weeks who is helping me a lot to talk about my experience and helping me to identify areas that are still not as they were.

The telephone bill arrived yesterday and I have paid it, knowing that if it is not done immediately it will never be done!

I am so grateful to be alive, every day now is a bonus and another day to thank God for.

Our lives, our disabilities

A group of disabled adults with spina bifida and/or hydrocephalus living in the West Midlands, formed the 'Connect' group which meets twice a year for social interaction, crafts, practical advice sessions and lunch.

Connect have now put together some information for adults with the disabilities, their carers and families, based on their own experiences. The idea came from their discussions around their disabilities and how their lives are affected by practical difficulties and by other peoples' perceptions of disability.

Advisers Geraldine Long and Jenny Green, who run the group, helped the members to get their thoughts and ideas into some sort of order and down on paper.

Entitled '*Our Lives, Our Disabilities*', the material was put together by the members and gives a valuable insight into their thoughts about their abilities and disabilities.

Geraldine said: "A common perception is that people with disabilities can be lumped together, so whether their disability is sensory, or causes mobility problems or maybe neurological problems, as in epilepsy, it doesn't matter – a disabled person is simply that, someone different from the norm but somehow the same as anyone else with difficulties.

"This, of course, is nonsense: everyone needs and deserves to be



treated as an individual. All disabilities have different effects and no two people with the same disability are the same – and why should anyone expect them to be?"

Taking this as a starting point, the *Connect* group members looked at the areas that they identified as affecting them in everyday life.

These include; communication, interaction with peers, self esteem, learning and employment, transport, and last, but not least, their thoughts on parents.

Our lives, our disabilities will be available to download from ASBAH's website at www.asbah.org this autumn and if you don't have access to the web you can ask the helpline (0845 450 7755) to download and print it for you.



Lynn Kirkman

Lynn Kirkman from Warwickshire. Lynn, who has spina bifida and hydrocephalus, works as a part-time administrator with the Connexions service.

"I joined the group last year. There isn't a local association in my area and I felt a little isolated, so Geraldine suggested I came along to one of the *Connect* group meetings in Birmingham.

Going along the first time was quite daunting because, apart from Geraldine and Jenny, I didn't know anyone.

But everyone was very friendly and welcoming and I was pleased to meet new people with spina bifida and hydrocephalus.

At my first session, ASBAH Senior Medical Adviser, Rosemary Batchelor gave a talk on hydrocephalus which I found fascinating. No-one had ever really talked to me properly about my condition.

Every session I have been to has been interesting and lively."



Carl Dean

Carl Dean has spina bifida and is a wheelchair user. He joined *Connect* two years ago.

"I always enjoy myself at the *Connect* meetings. The members and advisers are very friendly and we have a good chat and a laugh.

It is very interesting to meet up with others who have spina bifida and hydrocephalus to see how they are affected by their condition. I feel that I get a lot of support from everyone.

I was very nervous at the first meeting but we all settled in very quickly. I was surprised to see a couple of people I knew from the Brays Road special school I went to in Sheldon. I hadn't seen them for years, so it was great to meet up.

All the meetings are interesting but I have particularly enjoyed contributing to the information for adults we are producing."



Clair Coverdale

Clair Coverdale from Bloxwich, near Walsall. Clair has hydrocephalus and has been a member of *Connect* for two years.

"My adviser Geraldine thought I should come and have a look at *Connect* because she thought I'd enjoy meeting the other members.

I have had hydrocephalus since birth, but I didn't really know much about it. Just being able to talk to other people who have the condition has taught me a great deal about myself and why I am the way I am.

Connect has given me my life back and has given my self-confidence and self-esteem a huge boost. It has provided the missing part of the jigsaw in a way, helping me to understand why I do or don't do things.

For example I'm very untidy. I know a piece of rubbish should go in the bin, but somehow my brain doesn't connect to my hand to actually put it in the bin. Just learning that this isn't unusual for someone with hydrocephalus is very reassuring."

Getting Luke on the road

For most young people, learning to drive is high up on their 'To Do' list.

But while Luke Martin had faith in his own abilities, unfortunately his doctors did not and told him that it was very unlikely that he'd ever be able to drive.

Luke, now 19, had a brain tumour removed six years ago. Whilst the operation was a success, he then developed hydrocephalus.

Mum Julie explained: "The hydrocephalus has resulted in a slowing of Luke's reactions and has affected his eyesight.

"Doctors told us that Luke would not be able to drive safely, so applying for a provisional licence was out of the question. My husband and I were also concerned for Luke's safety."

When they mentioned the problem to their ASBAH adviser, Val Meyer Hall, Val suggested that Luke be assessed at their local Mobility Assessment Centre.

Julie said: "I was quite reluctant to let Luke go along. Only the previous week Luke's GP had said that he'd never drive so I thought it would all be a waste of time and I didn't want him to be disappointed. But Luke was so keen that we agreed."

Luke took part in a range of tests including visual assessment (ability to read a standard number plate from a distance of 20.5 metres and peripheral field screening) and cognitive assessment (looking at the way the brain processes information).

Julie added: "To our surprise and delight Luke passed with flying colours and he's now waiting for his Provisional Licence to come

I enjoyed the day at the assessment centre, particularly when they let me have a go at driving a car



Luke Martin

through."

The assessment at the Thetford Centre, the closest to their home in Haverhill, Suffolk, has given Luke a real confidence boost.

Luke told *Link*: "I was really keen to learn to drive and I thought that it was something I was able to do. It was very frustrating to be told by doctors that I wasn't capable.

"I enjoyed the day at the assessment centre, particularly when they let me have a go at driving a car. It was good fun and I'm looking forward to starting lessons.

"I'd certainly recommend that anyone in a similar position has an assessment. I'm just pleased that Val Meyer Hall suggested it to us."

Hit the road

If you're a disabled driver needing information and support, or have always wondered if you have the ability to drive then look no further than your nearest Mobility Assessment Centre.

There are 17 independent centres based around Britain to help keep disabled people mobile and independent, all offering comprehensive help and support on a wide variety of issues. All are recognised by other mobility organisations including Motability and the Driver and Vehicle Licensing Agency (DVLA).

They cater for individuals who have a medical condition or are recovering from an accident or injury which may affect their ability to drive.

The services the centres offer include:

- Comprehensive assessment of fitness to drive.
- Specialist advice and information on car adaptations and driving with disabilities.
- Assessment for and advice on outdoor powered scooters and wheelchairs.
- Advice on loading and transporting a wheelchair or a scooter in a motor vehicle.

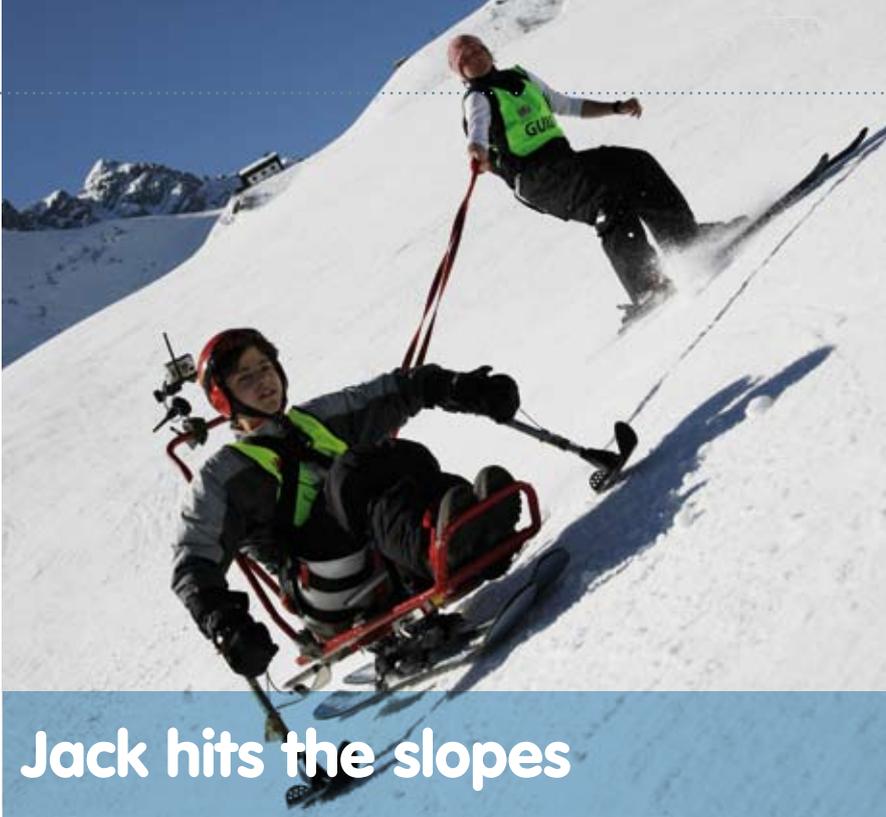
You can find out more about the centres and download information sheets at the website www.mobility-centres.org.uk or call the Freephone number 0800 559 3636 between 9.00am and 5.00pm

Mondays to Fridays.

ASBAH's leaflet on driving is also packed with helpful information and is available from the helpline and downloadable from the website www.asbah.org



- **Mobility Assessment Centres and how Luke got on the road**
- **Have fun - go skiing, Jack and Lisa talk about their experiences**



Jack hits the slopes

Keen wheelchair athlete Jack Spencer from Southport, discovered the joys of skiing on a special holiday in Italy.

Jack, 14, who competed in the World Junior Games in New York this July, was offered a coveted place on a Katie's Ski Tracks trip earlier this year.

The invitation came only a couple of

weeks before the departure date and Jack, who has spina bifida and hydrocephalus, was keen to experience the once-in-a-lifetime holiday.

His mother Karen told *Link*: "Jack has always been very sporty and is quite a dare devil, so he was delighted when the offer came through.

"My husband Geoff and I were a little more apprehensive – we just hoped he'd come back in one piece!

"But he had a brilliant time and thoroughly loved skiing, something we never imagined he'd ever be able to do.

"The trip was very well organised and there was plenty to keep the youngsters entertained in the evenings too.

"Jack made a lot of new friends on the holiday and the goodbyes were very emotional, particularly because some of the children had terminal illnesses."

Karen added: "We're very proud of everything Jack has achieved."

Katie's Ski Tracks

Katie's Ski Tracks provides skiing holidays of a lifetime for disadvantaged children and young people with a disability or terminal illness – children who are often excluded from family activity holidays.

For more information about Katie's Ski Tracks visit www.katieskitracks.org.uk or call 0151 928 7595.

Skiing my way by Lisa Cain

I first tried skiing in the late 1980s with a charity named the Uphill Ski Club.

I wasn't sure what to expect and I was really nervous as I did not know anyone. I was taught to ski in a group of beginners - this was great as it meant that we could all learn from each other.

I started off as a 'four tracker' – meaning that I had skis on my feet and I used outriggers elbow crutches with short skis on the end to help my balance. The evenings were spent discussing the day's events and swapping stories and sometimes we would go to local bars or bowling.

On a club holiday all skiers are allocated a buddy to help them in any way they need. By the end of the week I had been bitten by the skiing bug and summer holidays were to become a thing of the past.

Over the next few years my skiing technique continued to improve as I went on many skiing holidays to Italy, Austria, Switzerland and France.

However, I was finding it harder to stand

up for long periods of time so when an opportunity arose for me to ski in America, I took the huge decision to start sit-skiing.

I realised that being a sit-skier opened up many more opportunities as I could sit for longer and therefore explore more of the mountain and more trails than I would ever be able to ski as a four-tracker. I prefer skiing in America as I feel that the conditions for skiing are better than in Europe; the trails are wider and you are more likely to get powder rather than ice!

I have skied in many parts of America, from Bear Mountain in California in the West; to Sunday River in Maine in the East; and Breckenridge and Winter Park in the middle.

While skiing in America you can also learn a completely new vocabulary. For example, a perfect blue sky is called a 'Blue Bird Day' and while stopping on the slopes for a breather you should always make sure you are always facing the sun for the 'MTA' - Maximum Tanning Angle.

Then you have the added bonus of being the only person in your office with a suntan in February.

After skiing in Whistler in Canada, my friends and I decided to organise our own holiday

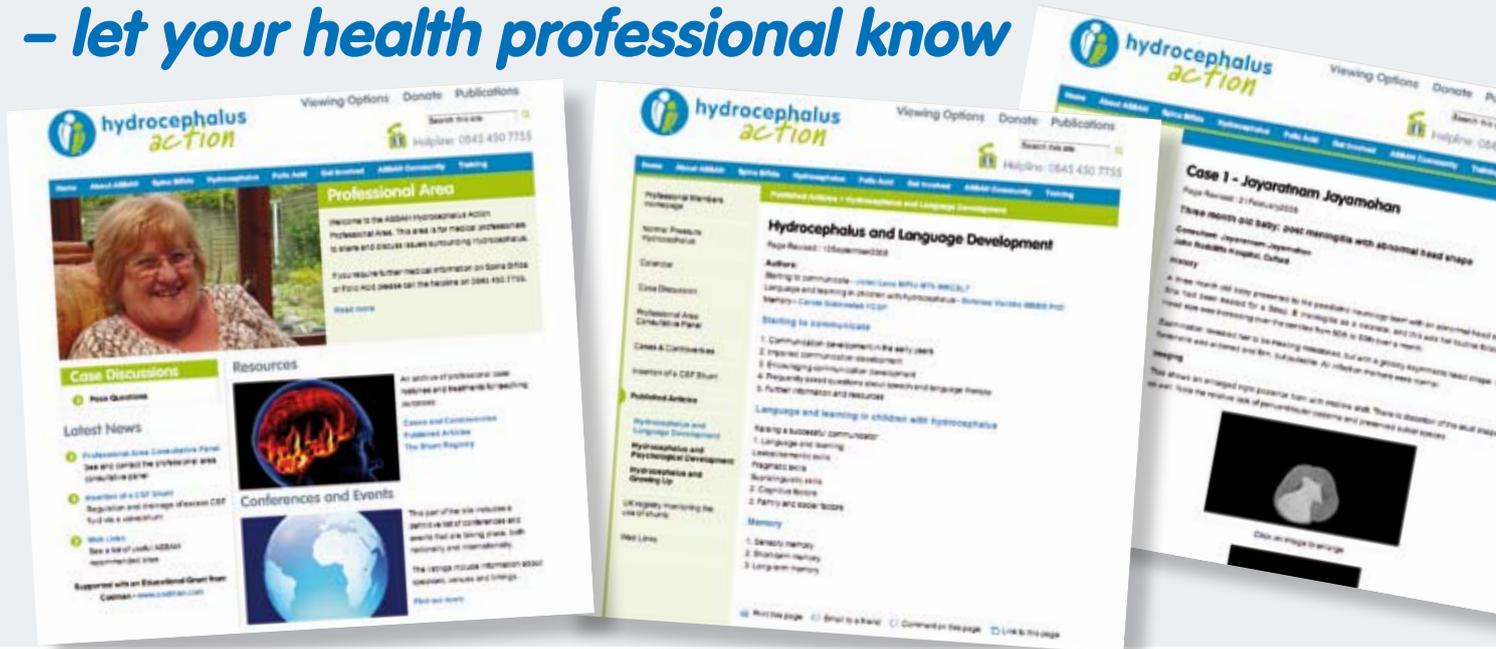


so that we could choose the resort and dates that suited us. The trip went really well and it is something we would all definitely repeat.

As well as going on holiday with the ski club, I have been a trustee on the committee and helped to organise our stand at numerous ski shows. I have also skied at my local dry slopes and at the Tamworth and Milton Keynes Snowdomes.

As a result of learning to ski, I have made some great friends, been to some wonderful places and had some fantastic experiences. I would definitely recommend that anyone tries it if the opportunity arises.

New Professional Area – let your health professional know



ASBAH is keen for *Link* readers who are affected by hydrocephalus to let their doctors, nurses and healthcare providers know about an important new development on the ASBAH website

The Professional Area is an innovative new addition to the Hydrocephalus section of the revamped ASBAH website

Open only to health professionals who register with ASBAH, it aims to become a recognised reference area for those dealing

with patients with hydrocephalus.

The section will include information on everything relating to hydrocephalus from shunt surgery through to continence issues.

Users can upload and download medical teaching materials, including videos and information sheets for professionals and case studies. Already posted is an animation showing the insertion of a CSF shunt.

They can also access published articles and download material suitable to pass on

to their patients and carers.

A conferences and calendar section will ensure users don't miss out on forthcoming events.

All material submitted will initially be viewed by the Professional Area's consultative panel and ASBAH's Medical Advisory Committee before being posted on the website.

Mike Gillespie, UK Marketing Manager, at Codman told *Link*: "Codman is delighted

Hydrocephalus Action on the website

ASBAH's revamped website, which went live in May, has received a great response from visitors who have found the pages and links much easier to navigate.

The new design made it possible to highlight and separate the two main areas – Spina Bifida and Hydrocephalus – as well as include a community area comprising personal stories.

The Hydrocephalus Action section has information about all aspects of the condition including how to manage your hydrocephalus.

Your can also order a Shunt Alert Card and publications including Benny Bear books and the Your Child and Hydrocephalus book.



You'll find all the information you need about hydrocephalus by logging on to: www.asbah.org/hydrocephalusaction

Codman - Working in partnership with ASBAH

to support and encourage the wider awareness of hydrocephalus and its effects.

"We believe that the Professional Area of the Hydrocephalus Action Website will engage the differing medical specialisms and help everyone gain a wider understanding of hydrocephalus and its effects.

"Submitted cases and professional papers are being approved by ASBAH's Medical Advisory Committee and will be loaded in the next few months, but the collaboration should result in better and more precise treatment and information being passed to the patient and their families."

How you can help...

In order to become a really useful resource, as many health professionals as possible need to be aware of the Professional Area.

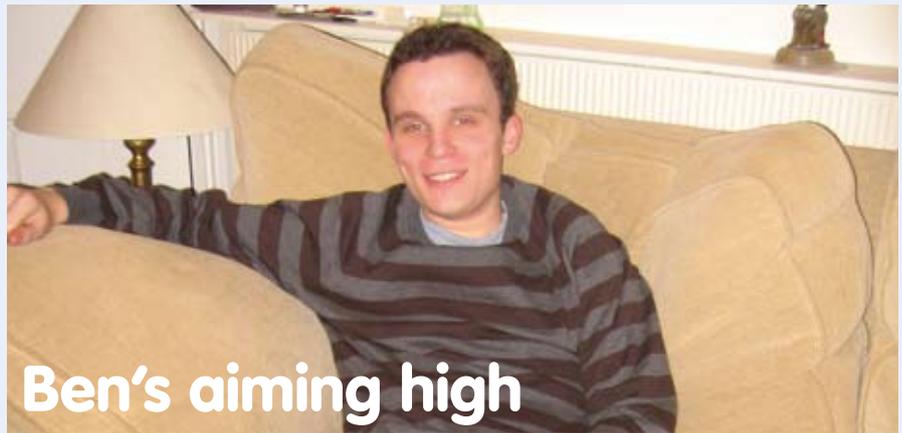
ASBAH and Codman are busy publicising the new section... but we need your help to pass the message on.

So let your GP, surgeon and nursing staff know – it could lead to more understanding and better treatment for everyone with hydrocephalus.

What is Hydrocephalus Action?

ASBAH is working in partnership with Codman to promote 'Hydrocephalus Action', a campaign aimed at raising the awareness of hydrocephalus through many channels and events.

This campaign aims to increase the level of understanding amongst the general public, healthcare professionals and public policy decision makers throughout the UK. Look out for news and further information on this web site.

**Ben's aiming high**

Ben Edwards is a name that many regular *Link* readers will recognise as over the years we have followed his career progression from GCSE student through to trainee barrister.

Ben, who has hydrocephalus, is now working for the Crown Prosecution Service (CPS) as a case worker in the organised crime division.

In the run up to his GCSE's and A Levels his shunt failed and his neurosurgeon tried various types before finding a programmable one to suit.

But Ben, who is now 23 and living in London, was determined that his health scares would not deter him from his dream to become a barrister.

He told *Link*: "I completed my training in 2007 and was called to the Bar in the July. But although I am a qualified barrister I can't actually practice until I have completed pupillage training, the final stage of the qualification.

"Unfortunately there are very few pupillage vacancies around the country and it isn't unusual to see 400 applicants vying for one vacancy. The competition is enormous.

"My position with the CPS is very interesting and I'm dealing with a wide cross-section of people from defendants in prison and their families to other barristers.

My role also takes me to Magistrates, Crown and High Court, which is excellent experience too."

Ben said that while he hasn't experienced any major problems relating to his hydrocephalus, he is still troubled by daily headaches which vary in their severity.

"Often they aren't too bad but then I have days when I feel that I just want to leave work and go home," he explained. "But while that was generally OK when I was at university, now I work in a professional environment, that isn't possible.

"I also don't feel that I can mention my condition to colleagues, partly because I want to be judged on my work and I don't want to be treated differently.

"My immediate boss is aware that I have hydrocephalus but she doesn't really understand what it entails. If I said that I needed to go home because I have a headache I don't think that would go down too well."

Ben told *Link* that he had been brought up to make the best of things and not allow hydrocephalus to prevent him achieving his aims.

"I'm sure that the strong support and encouragement I've received from my parents has helped me to get this far," Ben said.

"Some teachers at school advised me not to study Law because they felt I wouldn't cope but I was determined and I'm pleased to have proved them wrong.

"I believe parents should encourage their children to do the courses they want and follow the direction they want.

Young adults deciding on university and career choices should not be swayed by others' perceptions and opinions, and follow their dream."

KEY POINT

- Professional area of ASBAH website launched
- Ben Edwards training to be a barrister



Feeling great after a weekend away

Your Voice members keen to improve their zest for life enjoyed a packed programme at the recent 'Looking Good, Feeling Great' weekend.

The event, which was held at Worsley Park, Manchester, on 11 -13 July, gave 20 YV members the chance to make new friends and learn more about improving their health and wellbeing.

The committee, which organised the weekend, had worked flat out to ensure that everyone had a great time.

After a welcome meeting and dinner on the Friday evening, the guests were treated to a wide variety of workshops to suit all tastes.

Simon Wrigley kicked off the Saturday session with a rousing talk about the importance of self-confidence – how it affects your daily life and, perhaps more importantly, how to develop it.

The workshops also included a talk about diet and nutrition by a Slimming World adviser, a Tai Chi session, plus a talk and demonstration by Anna Vaughan and Diana Harding from The Body Shop. The day ended with dinner and a quiz.

And this is what they thought...

"The time was filled with a good variety of subjects"

"Excellent - very interactive. No lectures, but a fun learning process"

"A very good mix of listening and doing - well balanced."

"A great weekend. Well done to all who organised it."



Your Voice, Your Choice

The Your Voice (YV) newsletter is going from strength to strength, thanks to lots of input from its members.

Bumper Issue 3 is out now but you can still download previous issues from www.yourvoicegroup.org if you haven't seen them yet.

YV members receive issues of the newsletter free. If you would like to join YV contact the helpline on 0845 450 7755 or email helpline@asbah.org

What's inside Issue 3

- Julie Turnbull gives a behind the scenes look at a week in the life of an adviser
- Paul Manning reports on IASBAH's 40th Anniversary Conference in Cork.
- Andrew Russell gives his views on YV
- YV committee member, Mike Bergin, reviews the International Federation conference in Lisbon



Make a Will to protect your family's future

It's easy to put off making a Will. Although you do not have to make one by law, it is the best way to make sure your estate is passed on to family and friends exactly as you wish. Making a Will is particularly important if you have dependants.

Here Anthony Fairweather, from Clarke Wilmott, writes about what to consider when drawing up your Will or setting up Trusts for dependants.

Wills and Trusts – the legal maze

The tendency to put off facing up to future decisions often leads to nothing being done at all. The outcome can be that a parent or carer makes no Will. The estate will then pass under intestacy.

Martha dies without having made a Will. Her estate is worth £275,000. She has two children with her partner, Jack. They are not married. The estate is shared equally between the children and will be held on Trust if they are not yet 18.

A Will does more than simply direct your

assets. It appoints executors and trustees. It can determine how your assets are passed down and whether a Trust is imposed. You can provide instructions on guardianship. It can stipulate at what age assets should pass to a child. Is 18 too early to receive a large sum? What are the implications if you stipulate it should be 25?

One of the issues that requires careful consideration is how to provide and protect for a dependant in the future. There may be a host of different issues that you need to consider. Is it better to try and set something up in one's lifetime or in one's Will? How do Trusts work? How much do they cost and who runs them?

When a Trust is set up the Trust deed will normally allow for the Trustees to invest in all the normal type of investments such as stocks and shares. The Trustees will need to consider if they are trying to grow a nest egg or generate an income.

The first step is to make sure any adviser has a detailed understanding about your circumstances. For instance, what are your

dependants long term housing requirements? It may be relevant as to whether they are funded by the Local Authority or privately. If dependants are on means tested benefits then assets left to them could disentitle them to those State Benefits.

A well drafted Will or Trust can help avoid and provide answers to these problems.

There are many forms of Trust including Discretionary Trusts and Trusts for the disabled. The benefits may not only include protecting and providing for a dependant. There may well be ways of mitigating any inheritance tax you might have to pay at the same time.

Robert wishes to place £150,000 into a trust to provide for his adult daughter, Chloe. Chloe receives means tested benefits. The money in the Trust will allow Chloe to receive those benefits. After seven years the transfer into the Trust will not reduce Robert's nil rate band allowance.

The key therefore is to take good advice at an early stage. If you are aware of the options then an informed decision can be made. The worst of all worlds is doing nothing.



Michael Cogswell

Bowel Management Road Show

When Coloplast suggested running a Bowel Management Roadshow I really was not sure if my attendance would be helpful – after all I'm not medically trained, but in fact it turned out that many people wanted to meet me and discuss my experience of bowel management and coping as a paraplegic.

The Roadshow was run in conjunction with ASBAH and SIA and was an opportunity for people to come and discuss this difficult subject in depth with specialist Continence Advisors. It was also an opportunity to find out about Coloplast's Peristeen Anal Irrigation System. A good number of people wanted to discuss with me my experience of the system and the impact it has had on my life. Most were surprised to hear that I don't now have bowel accidents at all.

It seems that many people face a number of common problems and go to almost extreme lengths to stop the chance of bowel accidents. Prior to using Peristeen, ensuring that I didn't have an accident was a full-time task and as a member of the British Paralympic sailing team competing all over the world this was not easy. What I used to do was try to keep my body on the edge of constipation for a day or two and then try to empty it out on a strict schedule. This is not easy to do and resulted in a number of problems: poor diet; long toilet times; reliance on laxatives and/or suppositories; haemorrhoids; tiredness; increased spasm and a high number of (Urinary Tract Infections) UTIs. And no matter what I did,

it was not possible to stay 100% free of accidents. However since using Peristeen I now understand that this was because I was trying to force my body to work to my schedule rather than let it run naturally.

I have been using Peristeen now for over three years; I was on the original trial for it and I am a complete convert to the

benefits of using it to manage my bowel. I don't use any laxatives or suppositories of any kind; I eat a healthy and high fibre diet. Generally I use Peristeen every other day and only spend about three quarters of an hour on the toilet. The

system allows me to completely wash out my lower bowel with water. This is a natural process and has encouraged my bowel and my anal muscles to work better and more effectively than they did before. By getting myself out of the unnatural stop start bowel regime and into a more continuous cycle I have benefited in many ways and I am able to get on with my life without the worry or anxiety caused by bowel accidents. I also now have much less spasm and I have not had a UTI since starting to use Peristeen.

The Roadshow was also an opportunity for me to discuss Peristeen with a number

of nurses from the different Spinal Centres around the country and I was pleased to hear that a good many are teaching newly injured people to use the system. Some centres have really embraced it and have found that a large number of patients are reporting much improved bowel management. I understand that an audit of

longer term use is now underway and when this is published I'm sure the other centres will follow suit.

Personally, if this system had been available when I was an inpatient I would have liked to have known about it. A more secure bowel management method and the reduction of UTIs may have had major benefits for me – especially as continual UTIs in the first couple of years seriously damaged my

fertility. Maybe my wife and I might not have had to go through such a difficult conception route before we had our daughter.

Peristeen is available on prescription from your GP and if you wish to try it then it is best to contact your Spinal Centre or Continence Advisor and ask to be trained in its use. Once you have a prescription the easiest way to get hold of Peristeen is by having it delivered directly to your place of residence through Charter Healthcare. I did initially have some problems with my local pharmacy who ordered the wrong items so now a simple phone call to Charter on 0800 132787 gets

Prior to using Peristeen, ensuring that I didn't have an accident was a full time task and as a member of the British Paralympic sailing team competing all over the world this was not easy.

Coloplast - Working in partnership with ASBAH

me everything I need.

Training for the system is very straight forward and quite simple. If you are currently able to transfer to a toilet and do digital evacuation or insert a suppository then you should be able to use Peristeen independently. There are now a number of users who require the help of a carer and these people are also reporting benefits. There is a free training DVD which is available from Coloplast through Charter Healthcare.

The main advice I was giving to the Roadshow visitors either using Peristeen now or planning to use it, was to try and stop using laxatives and any other intervention as soon as possible and most importantly to significantly increase the level of fibre in their diet so that their bowel can work more effectively. Of course, all of this should be done in consultation with your healthcare professional.

Ideally, new users should start by picking a period of a couple of weeks when they won't be travelling or spending any significant time away from home. Try to listen to your body and be flexible; if you want to use it a second time then you can do so. The lower bowel will completely empty the Peristeen water and any faeces in the lower bowel, usually over a period of 20-30 minutes. Massage can help and I personally always have a final digital check. The key, however, to a successful output is the quality of the input. I now have a bowl of All-Bran every day and I'm certainly not afraid of a good hot Vindaloo anymore!

Michael Cogswell

Paraplegic since March 1999

www.paralympic-sailor.com

If you would like further information regarding the Peristeen Anal Irrigation System please call Coloplast on 0800 220622 quoting reference PAILINK1008 and one of their Customer Care Team will be happy to help you.

KEY POINT

- Michael Cogswell reviews the Bowel Management Roadshows
- Continence information online

Continence info goes online

People around the world can now access a wide range of continence information from the new-look ASBAH website.

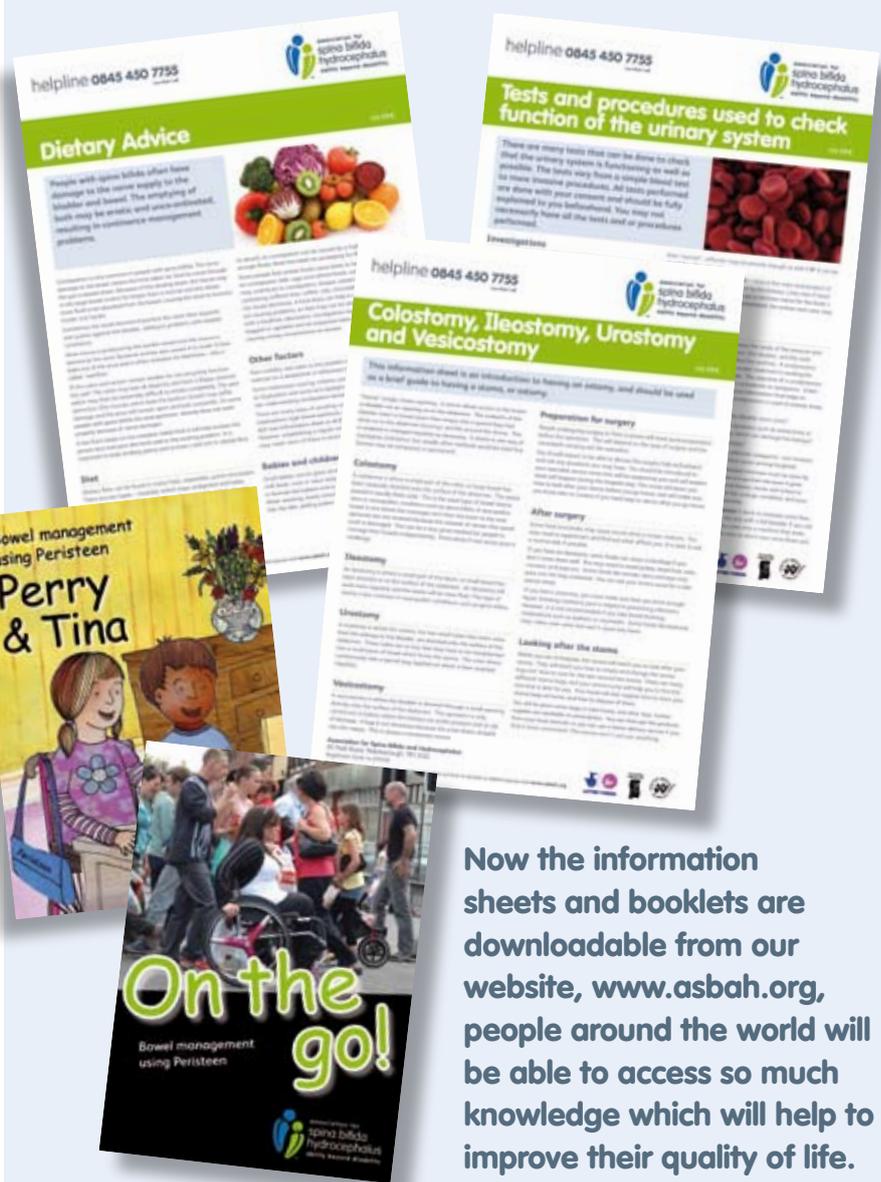
The leaflets and booklets relating to bladder and bowel management strategies, which were sponsored by Coloplast, can now be downloaded from the Spina Bifida section at www.asbah.org

The information includes the two new booklets about anal irrigation – Perry & Tina for children up to the age of 12, and On the Go, which is aimed at teenagers. The 14 information sheets which make up the new Continence Pack can also be downloaded.

Gill Yaz, ASBAH's continence adviser who was involved with the revamp of the continence information sheets said: "We believe that the information will be valuable at every stage of life for our service users and those who care for them.

"Although continence is taken for granted as not very exciting or important to many people, it becomes the single defining factor in the quality of life and independence for those who struggle to manage their bowels and bladder.

"Now the information sheets and booklets are downloadable from our website, people around the world will be able to access so much knowledge which will help to improve their quality of life."



Now the information sheets and booklets are downloadable from our website, www.asbah.org, people around the world will be able to access so much knowledge which will help to improve their quality of life.

In legal terms we have the names you can trust

Medical issues are often complex as well as daunting. As well as dealing with the day to day practicalities, you will also need to consider the implications of long term care.

At Clarke Willmott, we combine legal expertise in medical claims with practical planning using wills and trusts. We are members of the AvMA Clinical Negligence and Law Society Clinical Negligence Panels.

**Call or email us to
find out more**

clarkewillmott.com



Kerry Fifield
Medical issues
T: 0845 209 1268
kerry.fifield@clarkewillmott.com

Anthony Fairweather
Wills, Trusts and Court of Protection
T: 0845 209 1265
anthony.fairweather@clarkewillmott.com

*
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willmott

Diary dates

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

enABLE 08

Date: 28–29 November 2008
Location: Jaguar Exhibition Hall,
Ricoh Arena, Coventry

A new UK national consumer show dedicated to people with disabilities who seek an active and independent life.

Register for FREE entrance at
www.enableshow.co.uk/ASBAH
or call 0870 4866 813

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:

13 Nov 2008 10.30am-12.30 pm
with a talk from ASBAH OT Trained Adviser
8 January 2009 10.30am-12.30 pm
with a talk from Gill Yaz, ASBAH Medical Adviser
12 March 2009 6.30-8.30pm

Northern Region York Drop-in 2008

Low Moor Community Centre, Bray Road,
Fulford, York YO 10 4JG
2nd Wednesday each Month - 10.15-12noon
8 Oct • 12 Nov • 10 Dec

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

Northern Region and North and West Yorkshire ASBAH Drop-In sessions.

Come and see us for coffee and a chat, meet with staff, volunteers and other service users and look at our information library. Children, family and friends are welcome too.

When: First Tuesday of every month
10am -12 noon

Where: ASBAH House North, 64 Bagley Lane,
Farsley, Leeds LS28 5LY
Tel: 0113 255 6767
email: nro@asbah.org

Your Voice presents:

Have Wheels Will Travel

Location: Leicester Marriott
Date: Friday 31 October 2008 to
Sunday 2 November

Contact the helpline for information on this and all other Your Voice events.

ASBAH in Wales Understanding the Patient Journey – making the connections

Date: 15th October 2008
Time: 9.30am – 2.45pm
Where: Technium CAST, Ffordd Penlan, Parc Menai, Bangor, LL57 4HJ
To apply to attend this FREE event including lunch contact ASBAH in Wales on 01248 671345 or email: wro@asbah.org

Please e-mail the editor (Link@asbah.org) with dates of your events for the next issue of *Link* by Friday 28 November 2008, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.

Holiday lets

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

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Details: Liz/Peter Pollard, tel. 01209 891632
Email: peterandliz@roperswalkbarns.co.uk
Web: www.roperswalkbarns.co.uk



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An adapted caravan for disabled holiday makers. Sleeps 6 people (2 wheelchair accessible bedrooms), wheel-in shower with seat, open plan lounge, dining, kitchen area. Caravan has ramp access and is overlooking a children's play area in a site adjacent to the beach at Prestatyn – a small market town on the North Wales coast within easy travelling distance of Rhyl, Llandudno, and Snowdonia National Park. Costs are between £130-£350 per week for members; and from £150-£425 per week for non-members; for further information contact North & West Yorkshire ASBAH, c/o ASBAH North, 64 Bagley Lane, Farsley, Leeds LS28 5LY Tel. 07989 2453994, e-mail nandwyasbah@aol.com

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 28th November 08

Please send to: Editor, ASBAH
42 Park Road, Peterborough PE1 2UQ.
Tel: 01733 421361. Email: link@asbah.org

ASBAH offices

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Parc Menai, Bangor,
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In this issue, we meet Joanne Grenfell, who has worked as an Education Adviser for ASBAH for 10 years.

Joanne Grenfell

ASBAH Education Adviser



Starting school or college can be a daunting experience for anyone. The ASBAH education advisers provide advice and support to parents of children with spina bifida and hydrocephalus and, by working with local ASBAH area advisers, help our young service users settle into education.

Joanne Grenfell covers the North of England. We caught up with her to find out a bit about her and what it is like to be an education adviser for ASBAH.

“Being an education adviser is a really interesting and incredibly rewarding job. No two days are ever the same,” said Joanne.

Joanne works from the Northern Regional office, but her job occasionally involves travel to educational settings such as schools, and visiting families for particularly complex cases.

“The first thing I do when I get in the office is turn on my computer and

open my emails. I will then confirm any appointments or meetings I might have coming up. On this particular day, I ring to confirm our attendance at Leeds Civic Hall where we have a stall booked for the Special Educational Needs Conference next week. I then make a start on completing the end of month new referral forms.”

Education advisers offer advice and support for young people in all stages of education. Exam season is a nerve-racking time for all young people and their parents - it’s no wonder this is one of the busiest times for our education advisers. Often, a child with spina bifida and/or hydrocephalus can

get special dispensation in an examination, giving them more time to complete their paper and alleviating the pressure a little.

It is vital that education advisers keep abreast of developments in new legislation and Joanne takes this part of her job very seriously: “I read up on any new papers or articles to keep up to date with recent and topical legislation and best practice. I then

prepare the information to discuss and share with our advisers at team meetings. Training and empowering regional advisers is a key aspect of my role.”

Another key responsibility of an education adviser is to help parents of young people with spina bifida and/or hydrocephalus find suitable schools and colleges for their child to attend. Joanne explains: “I sometimes have to research possible residential schools both in the North and around the rest of the country for children with severe behavioural difficulties. With the help and support of an equipped and capable school, even children with the most severe learning difficulties can achieve their educational potential, improve their confidence and develop essential life skills. Today I am looking for a school outside of

Being an education adviser is a really interesting and incredibly rewarding job. No two days are ever the same



- Education adviser Joanne Grenfell talks about her working day
- Directory of local associations and contact details

Contacting ASBAH

the area for a child with behavioural difficulties who has hydrocephalus and epilepsy.”

During lunch time, Joanne manages to grab a few moments to relax. She usually reads the Times Educational Supplement and cuts out any useful articles to keep for reference.

After lunch, Joanne heads out of the office to do a school visit in Manchester. School visits are something Joanne only does occasionally and are usually only required for particularly complicated cases. The outcome of such cases and the personal involvement from Joanne can lead to positive changes being made to a child's life. She explains: “The afternoon is spent visiting a school to discuss a child who is a wheelchair user and has hydrocephalus, spina bifida, cerebral palsy and epilepsy, following a request from a concerned parent.

“When I arrived, the Special Needs Co-ordinator was off sick so instead I spoke with the head-teacher, her three teaching assistants, three lunchtime supervisors and a physiotherapist. We had a very useful discussion and shared ideas about planning implications, strategies and raising the awareness of hydrocephalus and spina bifida needs.”

Joanne's last job of the day is to contact the parents of the child from the school to tell them about the meeting and give them the positive feedback.

When asked why she enjoys her job, Joanne said: “Children and young people with spina bifida and hydrocephalus have the right to get the most out of their school life. As an education adviser, it is fantastic to be able to use all the years of experience I have built up and share that with other professionals and parents so the full potential of children and young people with spina bifida and hydrocephalus can be realised.”

NATIONAL OFFICE:

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42 Park Road, Peterborough,
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Email: helpline@asbah.org

ASBAH NORTHERN REGION OFFICE:

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

Northern ASBAH Affiliated Local Associations:

BOLTON & BURY

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

PRESTON & DISTRICT

Mrs Vera Dodd
'Roslea'
Nixon Lane
Leyland
Nr Preston
PR26 8LY

SHEFFIELD

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

STOCKPORT & TAMESIDE

Jean Evans
2a Chillington Walk
Denton
Manchester
M34 6NR
Tel: 0161 337 9528

SUNDERLAND

Mr J Pounder
42 Gowburn
Fattfield, Washington
Tyne & Wear NE38 8SG
Tel: 0191-415 1725

TRAFFORD & SALFORD

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

WARRINGTON & DISTRICT

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

NORTH & WEST YORKSHIRE

c/o ASBAH North
64 Bagley Lane
Farsley
Leeds LS28 5LY
Tel: 07989 245 3994
Email: nandwyasbah@aol.com
www.nandwyasbah.co.uk

WIRRAL

Mrs. Heather Wrigley
16 Venables Drive
Bebington
Wirral CH63 9LT
Tel: 0151 334 8405
Email: wirralasbah@hotmail.co.uk

ASBAH EASTERN REGION OFFICE:

Eastern Region,
ASBAH House, 42 Park
Road, Peterborough,
Cambridgeshire PE1 2UQ
Tel: 01733 555988
Fax: 01733 555985
Email: ero@asbah.org

ASBAH Eastern Affiliated Local Associations:

GRANTHAM

Mrs J Asken
88 Goodliff Road
Grantham, Lincs
NG31 7QB
Tel: 01476-401643

HERTS AND SOUTH BEDS

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

LEICESTERSHIRE

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

LINCOLN & MID LINC'S

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

LINCOLNSHIRE SOUTH

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

NORTHAMPTONSHIRE

Alison Walter
12 Adams Avenue
Northampton
NN1 4LQ
Tel: 01604-475982

ASBAH SOUTHERN REGION OFFICE:

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

ASBAH Southern Affiliated Local Associations:

GREENWICH & DISTRICT

Mrs M Mears
34 Sweyn Place
Blackheath
London SE3 0EZ
Tel: 0208-318 5936

KENT

Office address:
7 The Hive, Northfleet
Kent DA11 9DE
Tel: 01474-536202
Email: admin@kasbah.org.uk
www.kasbah.org.uk

LONDON NORTH WEST

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

SOUTH THAMES

Mrs M Harrison
24 Hawthorn Rd
Dartford
Kent DA1 2SB

SOUTHAMPTON & DISTRICT

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

SURREY

Mrs L Tadd
8 Worcester Road
Sutton
Surrey SM2 6PF
Tel: 020 8642 5082

SUSSEX

Romeen Sanglaji
5a Grand Avenue
Worthing
West Sussex BN11 5AP
Tel: 01903-507000
sasbah.office@fiscali.co.uk

ASBAH South West Affiliated Local Associations

SOMERSET

Mrs Iris Coton
3 Court Gardens
Yeovil
Somerset
BA21 3LZ
Tel: 01935 479233

ASBAH West Midlands Affiliated Local Associations

COVENTRY

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

DUDLEY & WOLVERHAMPTON

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

STAFFORDSHIRE

Mr Roy Pearman
2 Spode Grove
Westbury Park, Clayton
Newcastle-under-Lyme
ST5 4HF
Tel: 01782-625502

ASBAH WALES OFFICE:

4 Llys y Fedwen,
Parc Menai, Bangor,
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Tel: 01248 671 345
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Email: wro@asbah.org

ASBAH Wales, Affiliated Local Associations:

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Mrs Anthea James
61 Westland Close
Loughor
Swansea SA4 2JT
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MID WALES

Mrs Pat Edwards M.B.E
Llawcoed Uchaf
Llanbrynmair
Powys
SY16 7AF
Tel: 01650 521325

NORTH WALES

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

ASBAH NORTHERN IRELAND OFFICE:

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Knockbracken Healthcare
Park, Saintfield Road,
Belfast BT8 8BH
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Email: niro@asbah.org

ASBAH Northern Ireland Affiliated Local Association

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Belfast
BT15 4EG
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OTHER ASSOCIATIONS

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6 Craighalbert Way
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IRISH ASBAH

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

CHANNEL ISLANDS

Mrs Joy Thomson
Belles Roches Cottage
Vallee des Vaux
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JE2 3GB
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Upholds the quality standards of the ASBAH Local Association Compact

Local Association secretaries requiring changes to this list should contact: Link magazine, 42 Park Road, Peterborough PE1 2UQ
Tel 01733 421361 Email Link@asbah.org



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