

link

The magazine for people with hydrocephalus and spina bifida

Tim's summer experience

see more
on page 5

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association for
spina bifida
hydrocephalus
ability beyond disability



Sponsor a balloon

You could be up, up and hopefully far away as a winning sponsor in one of our annual ASBAH balloon races.

For a small cost, which goes to help people with spina bifida and hydrocephalus, you can back a balloon to travel the furthest in one of our 10 races around the country. The winning balloon will win its sponsor a case of champagne.

But you'd better have the wind at your backs – previous winners' balloons

have made it to Germany, Belgium and the Netherlands.

ASBAH holds 10 races a year. The remaining release dates for this year are:

Bonfire Bonanza	5 November
Twelfth Night	4 January 2008

For more information call our telephone fundraising team on 01733 421334

link

the lifestyle magazine for people with hydrocephalus and spina bifida



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Link is published quarterly (Winter, Spring, Summer and Autumn)

Link (1 year subscription)	6.80
All Europe by airmail	10.50
Rest of the world by airmail	16.50
Rest of the world by surface mail	10.50

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Peter Farrall writes

It has been a pleasure to edit the past 20 editions of *Link*, but after five years with ASBAH I am moving on to a new challenge.

Of course I will be sorry to say goodbye to friends and colleagues, and to the many service users and fundraisers I have met during my time in the job.

Hopefully *Link* has been valuable to you, tackling the issues you wanted to read about. My thanks go to the editorial and production team - Nigel and Catherine - who have helped me produce the magazine during the last few years.

So I hope that you'll find plenty of articles to interest you in this, my final issue.

Following the success of the Your Voice Ageing Disgracefully event (page 23), we have included a special ten-page supplement looking at a range of ageing-related issues (pages 13 - 23).

Medical features this time include an interview with Sue Frost of Coloplast, who talks about a new method of bowel management (page 25), and information about latex allergy (page 27), which we know affects many people.

On the news front there are reports about the annual Summer Experience (page 5) and information about the 26 new ASBAH information sheets which have been produced after a lot of hard work by our medical and educational advisers (page 7).

Of course there's the usual mix of fundraising stories and other regular features we know you look forward to reading.

So all that's *Link* 221! All that's left for me to do now is say goodbye, wish you good luck... and do keep reading *Link*.

Peter Farrall
Director of Marketing
and Communications
peterf@asbah.org

Best wishes,
Peter

Patron:

HRH The Duchess of Gloucester GCVO

President: Jeffrey Tate CBE

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

Designed and produced by Bluestation Communications

Link is published by ASBAH,
National Centre, 42 Park Road, Peterborough PE1 2UQ

All *Link* enquiries to:

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Tel: 0845 450 7755 Fax: 01733 555985
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Subscriptions (four issues per year): UK £6.80

All Europe by airmail £10.50

Rest of the world: by airmail £16.50,
by surface mail £10.50

Registered charity number 249338

ISBN 1360-323X

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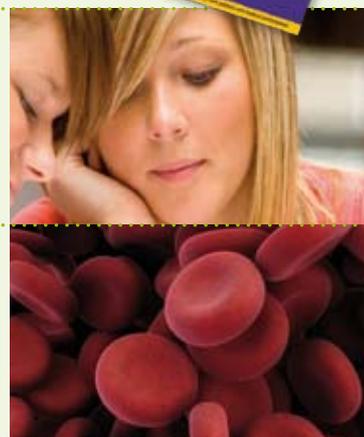
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Louise keeps British Champ title

Congratulations go to Louise Iontton who recently retained her title as British Champion at the National Power Lifting Championships for the disabled.

Louise, who is a ASBAH trustee and Your Voice committee member, won the gold medal in the 44kg category with a best lift of 60kg.

She also picked up the Most Improved Female Lifter improving her bench press lift by 7.5kg over the past 12 months.

Louise, 31, who has spina bifida and hydrocephalus, took up the sport while at college. When she went on to university she gave up because of a lack of facilities.

"I always regretted giving up and last year decided to get back into the sport," she explained.

Louise began training and within months won the national title, which she retained in June.

She added: "It was a great feeling to win the title again, and I was especially pleased with the Most Improved Lifter award.

"I had hoped to win the national title again and I believed that I could do it, but you can't take anything for granted because the nationals are open to anyone."

Now Louise, a full-time Sports Studies student at Leeds Metropolitan University, is looking forward to competing in the Polish Open in October.

Gareth does his country proud at the World Gymnaestrada

One member of Rowan Gymnastic Club has made his club-members very proud by representing Great Britain at the 13th World Gymnaestrada.

Gareth Picken, who is eight years old and has Spina Bifida, was one of 800 gymnasts representing Great Britain at the event which took place from 6th - 15th July in Dornbirn, Austria.

The World Gymnaestrada is the largest general gymnastics exhibition in the world. It is held every four years much like the Olympics, but the focus of this event is not on winning medals, it's about group performances. This year 22,000 gymnasts from 56 countries performed.

The trip was an experience of a lifetime. Gareth was so proud to represent his country and loved wearing his Great Britain tracksuit.

Gareth's team, which consisted of 16 children and 11 adults, and included national gymnasts, based their routine on 'War of the Worlds'. The team practiced for two years in preparation for Austria. The 13-minute long routine was performed three times at the

Gymnaestrada with around 2,500 spectators watching at any one time.

Gareth's wheelchair was incorporated into the routine and he also performed hand stands, straddle lifts and the splits. His forward roll even earned a standing ovation from the crowd!

Nikki Picken, Gareth's mum, accompanied him to the event and said: "Gareth started doing gymnastics after responding to an advert in a local paper five years ago and he really is an inspiration to others to try sport.

"The whole of Dornbirn was so excited about the Gymnaestrada. A lot of hard work went into organising this event. It was particularly great that the national disability team were so well received. Everyone was as supportive of them as they were of the other teams. It was just like you see on television and way beyond any expectations we held before the event.

"The trip was an experience of a lifetime. Gareth was so proud to represent his country and loved wearing his Great Britain tracksuit."

FREE cinema tickets for carers

If you need a carer to accompany you to the cinema then you could qualify for free tickets.

The Cinema Exhibitors' Association (CEA) card is a national scheme that verifies that the holder is entitled to one free ticket for a person accompanying them to the cinema.

However, not all cinemas subscribe to the scheme so it's worth checking before you apply for a card.

To qualify the applicant will need to meet one or more of the following criteria:

1. Be in receipt of the disability living allowance or attendance allowance.
2. Be a registered blind person.

There is an initial £5 fee for processing the application. Cards are valid for 3 years from the date of issue.

Download an application form from www.ceacard.co.uk or contact: The Card Network, The Technology Centre, Rossmore Business Park, Ellesmere Port, Cheshire. CH65 3EN. Tel: 0845 123 1292 and select option 2.



Thumbs up for family fun day

Family, friends and even the sunshine turned out in full force to enjoy Northern Region's Annual Family Day.

Almost 100 people joined in the fun and a packed programme at the Together Trust Conference Centre in Cheadle, Manchester on 1 August.

Parents were invited to attend two workshops on meeting the needs of the brothers and sisters of disabled children and the importance of finding time for themselves. They also had a chance to quiz ASBAH specialist staff.

Carole Sobkowiak, physiotherapist and past president of the Society for Research into Hydrocephalus and Spina Bifida, was also on hand to give brief assessments and advice on individual children.

Young adult service users with spina bifida and hydrocephalus shared their experiences in "We've Been There". Their honesty and humour were greatly appreciated and provided much food for thought.

The popular event included craft and music workshops for the children including professional entertainment from Loubylou; who is not only a clown but also a clown doctor doing weekly rounds at Manchester Children's Hospital.

Joan Pheasant, Northern Region manager, told *Link*: "We aimed to bring together those parents and children who have little opportunity for meeting others in similar circumstances."

She added: "Though some parents will have heard things which distressed them

or become aware of issues which might be awaiting them further down the line, the feedback those who attended was very positive.

"One five year old though wanted to know why parents had to go to boring meetings and we hadn't organised fun things for mums and dads to do!"

Northern Region staff were supported by volunteers including relatives and ASBAH staff from other regions.

None of it would have been possible without the generosity of the Together Trust which waived the hire cost of the superb venue, provided delicious food and gave the ASBAH team every help with a very successful event.



Summer of fun

Youngsters rose to the challenge when they faced a host of new activities at ASBAH's Summer Experience run by ASBAH's Northern Region.

Canoeing, tree climbing, abseiling, archery and Team Challenge were part of the fun-filled four-day residential camp in August, held again at The Keppelway Project in the Lake District.

The group of 11 young people, aged between 10 and 16, enjoyed a busy daily programme of events that tested their abilities and boosted their confidence.

The busy evening sessions included indoor games including pool, table tennis, board games and a disco on the final night.

Joan Pheasant, manager of ASBAH North, said: "Everyone had a great time and luckily the weather wasn't too bad.

"The holiday gives the children the chance to meet others with similar conditions and everyone got on very well. One boy enjoyed it so much last year that he joined us again.

"It was a great experience and everyone achieved so much more than they thought they would thanks to their determination and the wonderful instructors and helpers."

The ASBAH team – Joan and advisers Julie Turnbull and Moira Foggo – were helped by a team of seven occupational therapy students who worked alongside the youngsters.

Joan added: "The helpers were all exhausted by the end of the four days but it's worth it because the children get so much out of the experience.

"It's wonderful seeing their achievements and watching their confidence and social skills improve. On this holiday we're able to offer them the chance to do things they didn't think were possible."

For the second year running, a generous grant from the Four Acre Trust made the Summer Experience possible. Read more about the Trust on page 9.

In the picture

Young photographers from both sides of the Irish border showed off their skills at the Darkroom to Digital exhibition in Buncrana, County Donegal.

The event, organised by the Gateway to Opportunity project, included 33 exhibits ranging from traditional black and white photography to images created by digital techniques.

The 10-week course, which included darkroom and digital training, attracted seven people keen to improve their photography skills.

Project worker Julie McGrory said: "Visitors were very impressed with the quality of prints achieved and thought the exhibition was very positive and highlighted the young people's dedication and level of ability.

"The students genuinely loved the photography - it was particularly rewarding seeing the young people from different areas mix so well together and share their thoughts and experiences.

"More than anything it boosted their

The students genuinely loved the photography - it was particularly rewarding seeing the young people from different areas mix so well together and sharing thoughts and experiences

confidence levels and focused on fun and getting together."

She added: "The project was brilliant fun - we all loved every minute of it. I'm really looking forward to starting the art project in the autumn."

The Gateway to Opportunity project is a cross-border project between the UK and Irish Association for Spina Bifida and Hydrocephalus and Inishowen Rural Development (IRDL).

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



Change of law for WAVs

New legislation has been passed in Europe making wheelchair accessible vehicles (WAVs) a separate category of vehicle.

Many people within the industry are concerned that the new law will lead to increased costs and reduced choice for wheelchair users.

By making WAV a new category of vehicle, the wheelchair is defined as a seat and few wheelchairs have been, or could be tested to the same degree car seats are.

The legislation may save some vehicle converters from spending extra money, while requiring wheelchair manufacturers to either upgrade or crash-test their chairs.

Frances Leckie, Editor of Independent Living magazine said: "Either way, the person who will end up paying the higher price is the disabled person who needs an adapted vehicle and compatible chair to travel."

For more details check out www.independentliving.co.uk/wav/update.html

Help for home owners

Disabled and elderly people who need to repair or adapt their homes in order to stay in them may be eligible for help - although many may not know it.

Home Improvement Agencies (HIAs) are not for profit, locally-based organisations which can help disabled, older and vulnerable home owners and private tenants find the money for everything from an odd job up to major alterations costing thousands of pounds.

Their prime purpose is to help people continue to live in their own homes in comfort, safety, security and independence.

HIAs were set up more than 20 years ago but because they have different names in different areas, many people who could benefit are not aware of them.

There are approximately 250 HIAs located across England, operating in 317 local authority areas.

For more information contact Foundations, the national co-ordinating body for Home Improvement Agencies in England.

Telephone 01457 891909 or check out the website at: www.foundations.uk.com



Updated information to keep you in the picture

ASBAH's specialist medical and educational team have been working to update ASBAH's wide range of information material.

The 27 leaflets have been updated where necessary or replaced with new information sheets and all are downloadable from the ASBAH website or you can request one by contacting the ASBAH Helpline and Information Service on 0845 450 7755 or email them at helpline@asbah.org

ASBAH senior medical adviser Rosemary Batchelor said: "We are delighted to see the new information sheets which have come about through the hard work of the medical and education specialist advisers and the information team.

"We hope that people with spina bifida and hydrocephalus, their families and professionals find them a useful and valuable resource."

Peter Farrall, Director of Marketing and Communications said: "Providing accurate and up-to-date information is a vital part of ASBAH's work. Now the new suite of information sheets reflect ASBAH's new image and are all freely available from the ASBAH website, www.asbah.org, both as text and downloadable pdfs."

Peter added, "This is a work that is never completed and the medical and education specialists are already working on new topics to add to the already extensive list."

The information sheets are:

What is Hydrocephalus?

What is Spina Bifida?

Anencephaly (information for parents, after diagnosis)

Behaviour

Contingence issues for adults with Spina Bifida

Contingence Management

Depression

Developing skills through toys

Driving (for people with Hydrocephalus and Spina Bifida)

Endoscopic Third Ventriculostomy (ETV)

Folic Acid and the prevention of Spina Bifida and other neural tube defects

Going to College/ University with Intracranial Hypertension (BIH)

Leaving Home - for College/ University (cost £2.00)

Information about Pre-School Children with Hydrocephalus and Spina Bifida

Intracranial Hypertension

Intracranial Hypertension and the child at School (formerly known as BIH)

Management of Hydrocephalus

Normal Pressure Hydrocephalus (NPH occurs in older adults only)

Sex and Spina Bifida - Men

Sex and Spina Bifida - Women

Sex: questions you may ask

Shunt Alert application form

Shunt Malfunction - a protocol for Employers

Shunt Malfunction - a protocol for Schools

Spina Bifida Occulta

Supporting Children with Special Educational Needs in Schools

Vaccinations

A new Contingence Information pack (sponsored by Coloplast) will soon be added to the list together with Feeding Problems, and Latex Allergy

Stilton Rainbows' good behaviour earns £50

The parents of a group of Rainbows in Stilton in Cambridgeshire have been treated to a spell of excellent behaviour and lots of good deeds after the girls decided to raise money for ASBAH. They asked their parents to give them a small amount of money every time they did something good.

Katie Wright, a member of the Stilton Rainbows who has hydrocephalus, came up with the idea of raising the money for ASBAH.

The group must have done a lot of good deeds as between them they managed to raise £50!

A big well done and thank you to every Stilton Rainbow that participated.



Bottom row (l-r): Brian Spencer (Lydia's dad), Marie Brennan, Brian Spencer Snr, Victoria Brennan, John Brennan. Top row (l-r): Jamie Penman, Moe Penman, Tina Spencer, Bernadette Spencer Jones, Alan Jones

Black tie ball breaks the bank

When Marie Brennan reached the big '5-0' earlier this year she decided that instead of having a run-of-the-mill gathering at home to celebrate the special day, she'd throw one of the biggest parties to hit Formby this year.

Friends, family and local business people flocked to a glitzy black-tie ball held at Formby Golf Club. Guests tucked in to a delicious three course meal which was followed by an auction and raffle.

The total amount raised was £9,000 and Marie, whose nine year old niece

Lydia, has spina bifida, is delighted: "I wanted this birthday to be special so I asked my friends and family not to buy me any presents this year and instead buy a ticket to the black-tie ball to raise money for ASBAH who have been great in providing Lydia and the rest of the family with advice and support.

"I'm amazed at the generosity of everyone that attended the event and would like to say a huge thankyou to everyone who donated prizes for the raffle and auction."

A marathon effort from heather raises over £500

Heather Boyd has run two marathons to date, helping to raise money for ASBAH, a charity which she has a personal connection with.

Running a marathon is a massive achievement for anyone, but Heather, 45, managed it without any professional help or training. As a fit and active person who enjoys being in the great outdoors, Heather took up running as a hobby, and then made it her goal to complete the London Marathon.

In preparation for the big event she ran everyday from Christmas through to April

I was so pleased to be able to raise £587 to help ASBAH with the wonderful work they do for people

and also joined a local gym which she attended twice a week.

Travelling from her home town of Ballygowan in County Down, Northern

Ireland, Heather's first half marathon was The Great North Run in Newcastle. Following that she did the London Marathon and the Belfast Marathon. Her two

daughters also attended the event, which is watched by millions of viewers on the television, and stood on the sidelines to cheer her along. Heather is having a well deserved break but is thinking of entering



Heather pictured right with Northern Ireland Regional Staff

Courtesy of Newtownards Chronicle

for Belfast again next year.

Heather chose to run for ASBAH because she has witnessed at first hand the effect spina bifida can have on a person. "My brother died from spina bifida forty years ago which is why I was so pleased to be able to raise £587 to help ASBAH with the wonderful work they do for people diagnosed with spina bifida and their families."



In the latest in our series meeting regular ASBAH supporters, *Link* focuses on the Four Acre Trust, which has supported ASBAH's Summer Experience for the past two years.

Four Acre Trust

ASBAH's Summer Experience has opened up a whole new world of possibilities to young people with spina bifida and hydrocephalus.

The popular four-day event held at the Keppleway Project in the Lake District gives youngsters aged between 12 and 19 the chance to try out a host of exciting activities ranging from outdoor sports to indoor games.

The stay also encourages independence and boosts their confidence in their own abilities.

But without the support of the Four Acre Trust none of this would be possible.

For although the young people make a contribution, the sizeable grant from the Trust keeps costs down and enables those on limited income to attend.

The Trust was set up in 1995 with the aim of supporting charities that give individuals – mainly children and young people – help in making the most of their lives. It has a policy of preferring to use its grants to prevent problems occurring rather than trying to cure them.

It also has a policy of expecting participants to make some contribution towards the cost of trips and outings to increase the perceived value.

Founder Trustee John Bothamley said:

These holidays give the young people a chance to experience something they would not normally do.

"We have been happy to support the Summer Experience weekends because we like ASBAH's practical approach to helping young people achieve the most from life. These holidays give the young people a chance to experience something they would not normally do.

"Activities such as these help to build their confidence and enable them to make a positive contribution to society."

John added that ASBAH's practical approach, backed up by sensible and timely reports on their work, also impressed trustees.

Other areas which are supported by the organisation include respite care and holidays for young people who would not otherwise be able to

afford one.

The Trust also supports overseas projects in developing countries including vocational guidance work such as learning schemes. It also runs relief of health disability for projects abroad, which encompasses eye care, as well as water and sanitation projects.

Joan Pheasant, manager of ASBAH North, organises the Summer Experience. She said: "We are very grateful to the generosity of the Four Acre Trust because without its support, the events wouldn't have been able to take place."

STAR supporters

Ken and Blanche Little have been fundraising for ASBAH for nearly 40 years. *Link* caught up with them to find out a bit more about the different, and sometimes unusual ways the couple have raised money for us.

From Donkeys to Tea Cosies

Ken and Blanche Little from Bexley in Kent have been fundraising for ASBAH since 1968. They have taken part in a whole host of fundraising events including donkey derbys, charity dinners and sponsored walks.

The main source of fundraising the couple do is their weekly stall they hold every Wednesday morning at the village coffee morning. They organise a raffle and Blanche sells a range of knitted clothes and gifts which she makes herself at home. "I knit all sorts, from children's cardigans and booties to tea cosies," says Blanche.

Ken and Blanche began raising money for ASBAH 39 years ago after their son Keith was born with hydrocephalus. Blanche explained: "We knew nothing about the condition when Keith was born. It was a difficult time for us but ASBAH were always on the other end of the phone if we needed help and support.

"Without them we would have been lost," adds Ken. "We take part in these events because we want to give something back for all the help everyone at ASBAH have given us over the years. We hope that other families can get assistance in the way that we did!"

Ken and Blanche have no plans to stop yet, with the Wednesday morning stall firmly in the diary for the foreseeable future.



The Queasy Riders: a team of hospital staff who raised £600



Cyclic Rotation: a team from Peterborough engineering firm - Perkins Engines



Jo Skinner & Family - part of the Gotasaurus team

Riding in the rain

The 14th annual Megacycle saw around 40 people battling through the rain to raise an expected £2,000 for ASBAH.

The 24-hour event, which ran from noon on Saturday 30th June through until noon on Sunday 1st July, followed the customary eight mile circuit of cycle paths along the River Nene and through Ferry Meadows Country Park in Peterborough.

Three relay teams and seven individual riders braved the weather to take part in the popular event; showing their determination

Everyone in the team had a great day and we will definitely get together and do it again next year

and commitment to the charity.

Traditionally a summer event, the Megacycle was a little different this year.

The cyclists rode through 14 hours of non stop rain. The weather could not dampen spirits though, Dee Lander of the 'Queasy Riders' team from Peterborough Hospital said: "We were soaked through but it didn't matter. The rain didn't put us off. We all took

several changes of clothes and swapped during the changeovers to have a bit of a dry off, while the rest of the team went round."

This was the first time Dee and the 'Queasy Riders' have taken part in the Megacycle and they raised a fantastic £600. Dee added: "Everyone in the team had a great day and we will definitely get together and do it again next year."

Megacycle has raised around £31,000 over the last 14 years.

Congratulations and a huge thank you goes to everyone involved in this years Megacycle.



A bank manager with a difference

To celebrate 150 years of Group Santander, Abbey employees were invited to apply for up to £2,500 for the charity of their choice and Sue Geraghty, Manager of the Romsey branch of the Abbey building society, jumped at the chance.

"An email came through offering a donation of up to £2,500 for a charity of our choice. It was simple to apply for and a fantastic opportunity to raise some more money for ASBAH," says Sue.

The money from Abbey will be used to fund a financial assistance leaflet to

provide information to parents, relations, helpers, friends and anyone involved in caring for people with Spina Bifida.

Sue began fundraising for ASBAH in 2005 when her neighbour's grand daughter was born with spina bifida. Over the last two years Sue and the Sidecar Motocross Association have helped to raise approximately £1,250 through various events, including a dinner dance with an auction and raffle.

So far, for every sum raised, Abbey has matched the donation meaning a grand total of approximately £5,250, which is fantastic!



Courtesy of the Romsey Advertiser



Louise Setara with Jonah Hodgson

Sharon Hodgson and her friends and family have been treated to a special performance from up-and-coming singer, Louise Setara, after she visited Sharon's home and did a very special performance in her living room!

Over 20 people squeezed into the living and dining rooms to watch the mini-concert and, thanks to the generosity of the guests, they managed to raise over £200 for ASBAH.

Sharon, whose 11 year old son, Jonah has hydrocephalus, said: "ASBAH has done so much for Jonah and our family, especially the educational advisers, that I decided I wanted to do something to show our appreciation.



Up, up and away....

Sponsor a balloon in one of ASBAH's regular races and you could scoop a case of champagne if your balloon travels the furthest.

It would make a great present and is the perfect way to celebrate a birthday or mark an anniversary... with the money going to a very deserving cause.

Ten balloon races, which are organised by ASBAH's Telesales department, have been held each year since 1981 and they continue to prove a huge money spinner.

The profits account for around 80 per cent of the income generated by Telesales – around £800,000 last year alone.

The Peterborough-based department asks companies and individuals to sponsor a balloon, with the one travelling the furthest winning a case of champagne.

In the past balloons have made it

as far as Belgium, the Netherlands. and even Germany.

Tom Logan, Telesales manager, said: "Asking companies and individuals to sponsor balloons is a much easier way of raising money to support ASBAH's many services than by selling adverts."

It would make a great present and is the perfect way to celebrate a birthday or mark an anniversary

Tom said that when the scheme was first launched 26 years ago the department would fill and release the balloons themselves.

But he explained: "It was great fun, but while we were busy doing that it meant there was no-one in the office making calls to raise money."

For the past few years a company, The Party Place, has been hired to handle the actual races while Telesales staff do what they do best... raising cash for ASBAH.

You too can try your luck by calling the fundraising department on 01733 421334 or email amandas@asbah.org. Sponsorship starts at £50 for half a balloon to £300 for 15 balloons.



ASBAH says a fond farewell to Donna...

After 17 years of service to ASBAH, Donna Treanor

is leaving her role as Director of Fundraising to relocate back to the Midlands and be nearer to her family. She will be working as Development Director for a Sutton Coldfield grammar school, focusing on project funding.

Donna started working for ASBAH in 1990 when she joined the charity as a fundraising assistant. Over the years she has climbed the ranks, demonstrating a commitment to her work which has contributed to many of the successes ASBAH has celebrated including the recent launch of the telephone helpline.

Staff and service users alike are sad

to be saying goodbye to Donna. Chief Executive, Andrew Russell, said: "Donna has played a vital part in the success of ASBAH. She continually secured reliable and growing funding-streams which are essential for us to provide direct help across the country to disabled people and fund vital research studies."

Donna said: "It's been wonderful to watch and help ASBAH grow from strength to strength over the past 17 years. I remain very passionate about ASBAH's work, having met many service users over the years I know how vital our adviser service is to them, Your Voice continues to grow in membership and our Helpline now enables greater access to our information. I've made friends with many wonderful people which makes moving on very hard."

...and welcome to Colin



ASBAH has welcomed

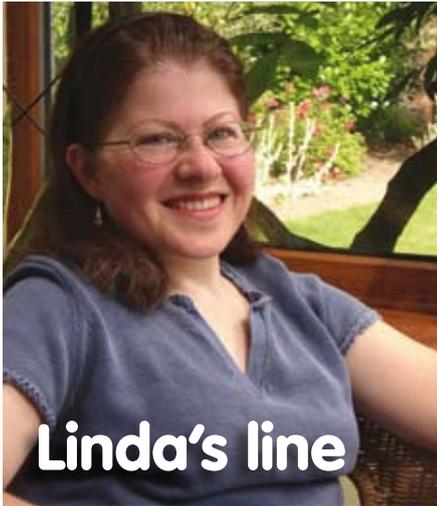
its new Director of

Fundraising, Colin Roberts, who joined the team on 10 September.

Colin, has previously held similar positions at East Anglia Children's Hospices and the Wavertree Charitable Trust.

Colin said: "I am delighted to be joining ASBAH as Director of Fundraising at this important time in the charity's history and development. The cause is superb and my specific role is both exciting and challenging.

"Donna will be a very hard act to follow, but I'm looking forward to carrying on the work she started and adding some new fundraising initiatives along the way."



Linda's line

You may think that I've finally lost the plot if I tell you that I'm currently driving around with the aid of the local telephone directory.

"Sat Nav!" I hear you shouting in between mouthfuls of cornflakes. Yes, well that would be useful for navigation purposes (never my strongpoint), but the phone book is actually being used as a booster cushion underneath the real booster cushion, which is doing less

boosting than it used to. Clearly the cushion is defective, and it has nothing whatsoever to do with the failure of this year's diet plan, or the level of chocolate consumption, which is directly proportional to the amount of stress at any given time.

Recently, things have been very stressful indeed, not least because of a series of increasingly unpleasant visits to the dentist. From a personality point of view, there is nothing unpleasant about my dentist at all, it's more that I am not particularly compatible with his line of work. Nor am I the right height for his torture - sorry, I mean examination - chair. Once the chair is tipped backwards, I feel like my legs have given up lying on the chair and have formed a rigid posture all of their own, and then I start sliding headfirst up the chair. It is also very uncomfortable and reminds me of those stryker beds they used to have in hospital. For those of you who don't know what I am waffling on about, stryker beds were long, thin and

very uncomfortable (and that's before you have the surgery!) Imagine lying on an ironing board and you will get the idea. **WARNING** - do not try this out at home, you will damage your ironing board and probably give yourself a back injury (if you haven't got one already).

We have also had another incident in the front garden. Having finished with the builders, we hired a man with a mini digger to come along and plough up the builders' rubbish and tree roots which were still in the ground. Unfortunately he also ploughed up (and severed) the gas supply pipe that prompted a call to the emergency gas call out service. Clearly their idea of an emergency is not a severed pipe that is leaking gas so quickly you could knock out half the road, as they sauntered along nearly three hours later to fix the leak. Since then we have had daily visits from the gas board, allegedly to test the levels in the road, although personally I think they are just checking to make sure we're not starting any more building work.

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

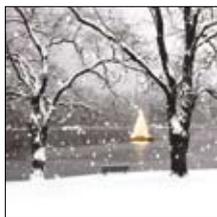
Each pack of 10 cards and envelopes comes with a greeting inside each card that reads: With all Good Wishes for Christmas and the New Year. Please note, ASBAH's old logo is on the cards and the reason for the reduced price.



association for
spina bifida
hydrocephalus
ability beyond disability

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Hat

ASBAH Order Form Christmas Cards

Please send me:	Qty	Price	Total (£)
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Flowers		£2.00 inc p&p	
Wintry Scene		£2.00 inc p&p	
Hat		£2.00 inc p&p	
Benny Bear		£2.00 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 _____

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

Registered charity no. 249338

Ageing

SUPPLEMENT

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It's a well known fact that the average age of the population is rising and most people - including those with spina bifida and/or hydrocephalus will enjoy a longer lifespan than previous generations.

Ageing was the theme at the recent Your Voice weekend, which saw a wealth of experts from different fields talking about how to stay fitter, healthier and happier for longer.

It's clearly an issue about which ASBAH service users are keen to know more and the Ageing Disgracefully event was oversubscribed.

In our special Ageing supplement we talked to several of the speakers who were keen to bring their messages to a wider audience.

What is osteoporosis?

Osteoporosis literally means 'porous bones'. Our bones are made up of a thick outer shell and a strong inner honeycomb mesh of tiny struts of bone.

Osteoporosis means some of these struts become thin or prone to damage. This makes the bone more fragile and prone to break. It often remains undetected until the time of this first broken bone.

Broken wrists, hips and spinal bones are the most common fractures in people with osteoporosis.

What causes osteoporosis?

From our 40s onwards our bones gradually lose their density as a natural part of ageing. One in two women and one in five men over the age of 50 in the UK will break a bone, mainly because of osteoporosis.

Who is at risk?

Our bone health is largely down to the genes we inherit from our parents.

Other factors that can put people at greater risk include: medical conditions which leave

people immobile for a long time; those taking corticosteroid tablets for conditions such as asthma or arthritis and women who have had an early menopause or hysterectomy. People who are wheelchair users and therefore non-weight bearing are at particular risk.

Can I prevent osteoporosis?

About 80 percent of our bone health lies deep within our bodies in our genes but you can take steps to influence the 20 percent of bone health left in your hands. It doesn't sound much but can make a big difference. Everyone should try to protect themselves against osteoporosis.

Get physical

Exercise is the best way to help your bones because your skeleton grows stronger if you do weight-bearing exercise.

Even something as simple as lifting a tin of beans in front of the TV will strengthen your wrist bones, a common site for broken bones through osteoporosis.

Get into a routine. 10 lifts with one hand

and then 10 with the other. Rest and repeat. You can gradually build up the number of repeats. This will help with the strength you need to transfer from your wheelchair.

Healthy eating

It is important we eat plenty of calcium but lots of other vitamins and minerals are also important. Drink milk. Skimmed milk still contains as much calcium as full fat milk, but with fewer calories. Soya milk drinkers will need extra vitamins.

Eat a healthy, balanced diet and try to avoid drinking too much caffeine which can affect the balance of calcium in the body.

Quit smoking

Smoking has a toxic effect on bone by

Eleni Burgess talks about her experiences of osteoporosis

“I knew about osteoporosis but never realised that it would affect my life as a teenager in the way it did.

I hadn't been warned that being unable to stand up would make me vulnerable to it and most literature talks about osteoporosis being a problem for the older person.

In the last week of term in summer 2006 I had almost completed the final assignment for my BTEC National Diploma in Sports Science.

It was two days before the National Junior Athletics Championships in Blackpool and I was confident that I could break all five records for T52 wheelchair races.

I was sitting in my wheelchair in a car park and as I turned my chair on uneven ground I slid slowly out of the chair on to the tarmac.

I have no feeling in my legs so decided I should go to A&E as something in my leg was clicking and I wondered if I had dislocated my hip.

After a three hour wait (I was in no pain so was not a priority even though I explained I was paralysed) the X-ray was done and showed my femur was shattered

inhibiting the construction cells from doing their work... another good reason to give up. Ask your GP or pharmacist for help if you can't go it alone.

Drink moderately

Enjoying the odd glass of wine could actually help your bones but drinking too much alcohol is damaging to the skeleton.

For more information about osteoporosis and what you can do to help yourself visit the National Osteoporosis Society at:

www.nos.org.uk

**National Osteoporosis Society,
Camerton, Bath, BA2 0PJ or telephone
0845 130 3076 (Mon - Thurs 9am to
4.30pm, Fri 9am - 4pm)**

into several pieces.

The orthopaedic surgeon said it looked like I had been in a serious car accident and would need a metal Liss plate and many pins.

I was in hospital for seven weeks. I could not transfer into my chair without a hoist for a further 8 months while the bone healed.

All my fitness and independence was lost and I was told I may never be able to race again as there was no guarantee the bone would heal.

When I got home I used the internet to find the best foods for bone healing and sat out in the sun at every opportunity to get the vital vitamin D.

The osteoporosis consultant arranged for DEXA scans of my hip and spine and later my wrist and these confirmed osteoporosis in my spine and hip.

He thought the lack of osteoporosis in my upper body might have been due to the sport I do.

I now ensure that I drink milk daily, get outdoors as often as possible and plan my diet to include a wide range of nuts, seeds and vegetables.

The bone has healed and I am now able to race again, but I wish I had known I was vulnerable to easily broken bones before the accident happened.

What is arthritis?

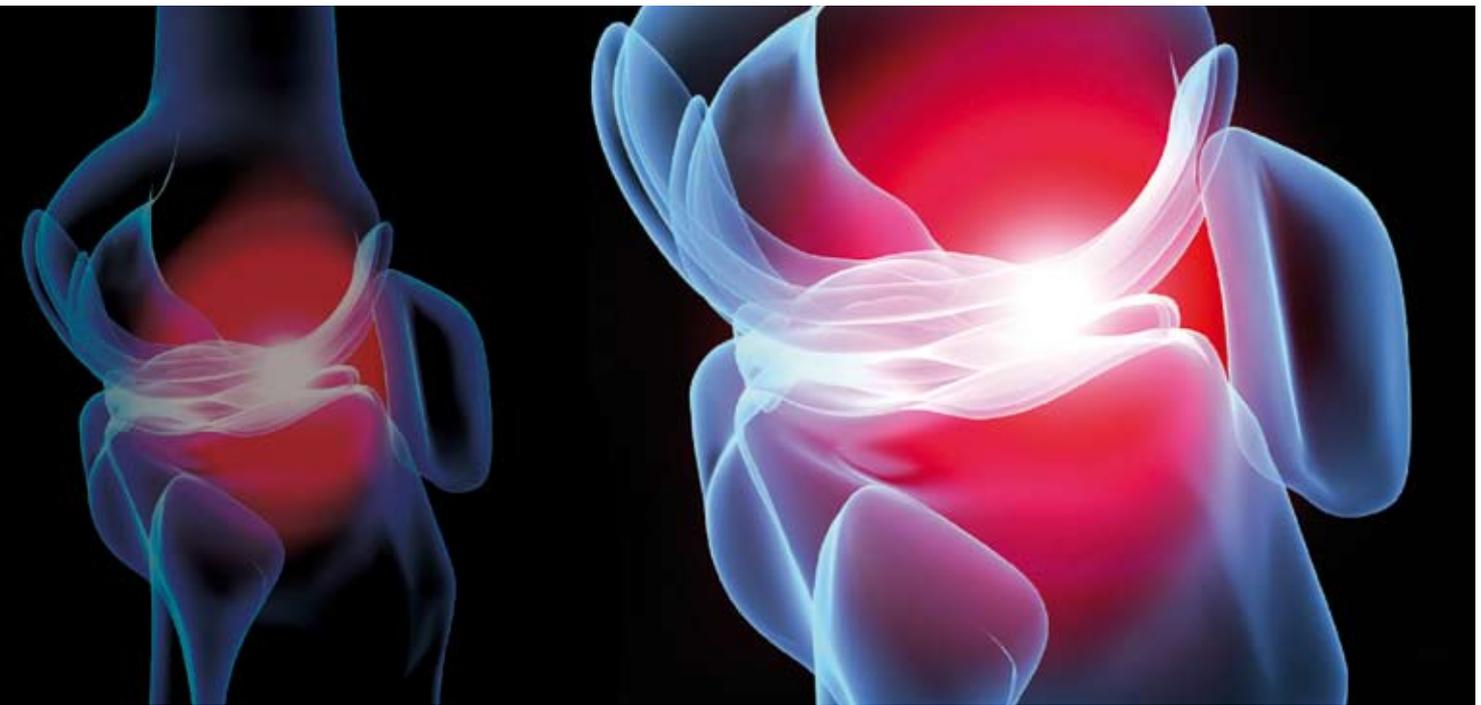
Arthritis means inflammation of the joints. Most people with arthritis will experience pain and difficulty moving around.

Over nine million people in the UK have arthritis and, like them, you can take control of your symptoms and continue to have a good quality of life.

There are over 200 kinds of rheumatic diseases – the word rheumatic means aches and pains in joints, bones and muscles.

Two of the most common forms of arthritis are osteoarthritis (OA) - the type people with spina bifida are most likely to have - and rheumatoid arthritis (RA).

Arthritis can affect people of all ages, including children. There is no cure at present, but modern treatments are good and there is plenty you can do to manage your condition and lead a full and active life.



How you may be affected

For most people, arthritis causes discomfort, pain, stiffness, fatigue – and frustration. It may result in varying degrees of physical impairment such as a loss of strength and grip which in turn may make your movements more difficult.

This may be hard to accept and may mean that you will have to adapt and make some changes to your life.

Arthritis in the hands and shoulders is particularly difficult for wheelchair users.

Treatment

Once you have been diagnosed you will need the right treatment for you, which depends on the kind of arthritis you have and how it is affecting you.

Talk with your healthcare professionals – and don't be afraid to speak out about your symptoms.

You have to explore the options which may include physiotherapy as well as drug treatment to find the most suitable treatment for you.

Most people are treated initially with drugs such as ibuprofen (if you are able to tolerate it) before arthritis specific drug treatments.

Help yourself

Getting medical help and treatment for arthritis is the first step. Do not self diagnose – leave it to the experts, but once diagnosed there is a lot you can do to help control your arthritis.

Look at Your Diet

Eating a healthy diet is a basic way of keeping well. Your body needs a range of nutrients and to get these you need to eat a variety of foods.

If you are overweight you should try and lose some weight to take the strain off your joints. Not easy but there is always help from your GP practice nurse, various slimming clubs or ASBAH medical advisers.

Some people think certain foods make their arthritis worse. If you notice this it makes sense to cut them from your diet and see if this makes a difference.

Cider vinegar and honey seems to have a particular following from arthritis sufferers including Sir Ranulph Fiennes, who first tried the remedy after developing bad arthritis in his hands and his hip 23 years ago. However, the medical profession does not embrace this "cure" and is quick to say that there are no studies to prove that it works.

Other 'natural' remedies are glucosamine, chondroitin, or green lipped mussel tablets. Always check with your doctor before trying them.

Exercise

Stiff joints which aren't exercised become stiffer and may, in the end, stiffen up altogether, although, any exercise you do has to be the right sort.

For many types of arthritis, gentle, regular exercise is very helpful and important. It keeps you mobile, reduces pain and stress and protects your joints by keeping the muscles strong.

However the wrong sort of exercise can put strain on your joints and damage them further. A physiotherapist can help advise you on a safe routine, which will probably include swimming which is good for all of your joints.

Resting is also important, especially when there is a lot of inflammation or your arthritis flares up badly.

For more information about arthritis the following organisations can help:

Arthritis Care
www.arthritiscare.org.uk
 Free helpline 0808 800 4050

Arthritis Research Campaign
www.arc.org.uk

National Rheumatoid Arthritis Society
www.rheumatoid.org.uk
 Freephone Helpline 0800 298 7650

Coloplast - Working in partnership with ASBAH**The ageing bladder**

The phrase, the ageing bladder, sounds rather negative and implies incontinence in the elderly. But while ageing is associated with many changes in the bladder which can increase the risk of dysfunction, it is not by itself a determining factor of urinary incontinence.

As we age we can experience changes in our pelvic floor which causes changes in bladder activity. This, combined with other problems, may cause changes in urinary activity. But those changes do not necessarily cause urinary incontinence and it should not be accepted as a "normal" part of ageing.

The pelvic floor is a sheet of muscle which holds and supports your bladder and bowel. People with spina bifida often have loose pelvic floors, because the nerves to the pelvic floor muscle, from the sacral part of the spine, are affected. Good pelvic floor tone helps maintain continence by holding the bladder neck in a muscular sling which helps it stay closed. When the pelvic floor is ineffective, urine can leak out more easily when the pressure in the abdomen is raised, such as sneezing and coughing, or during exercise. This is called 'stress incontinence'.

Pelvic floor exercises can be helpful for the general population, and need to be taught properly by a specialist physiotherapist. If you have spina bifida, the physiotherapist would need to check out which nerves were working before starting a course of treatment. This is because if the nerves don't work, the exercises won't be possible.

Adults with spina bifida may find their continence changing as they enter middle age; tethered cord and general 'wear and tear' on the vertebrae and nerves may affect bladder function. The pelvic floor is very often damaged during childbirth, which causes continence issues for many women in their middle years. Women with spina bifida who have reasonable continence

might want to consider a Caesarian to prevent this damage. It is important to exercise as much as possible, keep your weight under control, and avoid caffeinated drinks which increase the need to urinate.

Any changes need to be investigated, to ensure the kidneys stay healthy, but there may well be ways of managing your bladder which can improve your quality of life. Botox injections into the bladder have been found to help many people with frequency and urgency of urine, by relaxing the bladder muscle and increasing how much your bladder can hold. Operations such as augmentations also make the bladder bigger (the operation sometimes causes shunt problems though)

If the bladder is no longer emptying

Adults with spina bifida may find their continence changing as they enter middle age; tethered cord and general 'wear and tear' on the vertebrae and nerves may affect bladder function.

completely, or you are getting a lot of urine infections, ask your GP to refer you to a Urologist with an interest in spina bifida, as intermittent catheterisation might help.

If you are on medication for your bladder, the dose may need to be changed from time to time, as the way your kidneys and liver deal with them may alter over the years.

All medications have side effects, and many medications cause constipation, increased urination, or urgency, and

may lead to incontinence. A good plan of care needs to be created by using all information about health, diet, exercise, and medications. The treatment plan may include medication changes, behavioural therapy, or more supportive care, surgical intervention or the use of pads or absorbent pads.

In days gone by, many people accepted that leaking urine was a natural part of getting older, and just 'put up' with it. They were also too embarrassed to bring it up with their GP, so didn't get the support or treatments which could have improved their quality of life. People with spina bifida often, but not always, have continence issues, and may be familiar with treatments and services available to them. However, their needs may change as the years pass, and treatments are improving all the time. It's always a good idea to keep in touch with your continence service, as you may be missing out on something really useful. And if continence begins to be a problem for the first time, do discuss it with your GP, there are services that can help.

If you are finding it physically harder to get to the "loo" in time, an Occupational Therapist may be able to advise on equipment and adaptations to help at home. RADAR also operate a key scheme to let you use accessible toilets when you are out. Incontinence of urine can also be a sign of Normal Pressure Hydrocephalus. If it develops together with difficulty walking and confusion or forgetfulness, discuss this with your GP, as it is often treatable.



Coloplast

Coloplast and ASBAH are working in partnership to campaign for an increased awareness of bladder and bowel health and to support ASBAH's members and families in their efforts to live a full and satisfying life.

Benefits for different ages

Last year more than £8 billion of state benefits went unclaimed because many people simply don't realise what they are entitled to.

Although the process for claiming any benefit or grant can be arduous, it's often worth the effort in the end.

Yvonne Davies, Chief Executive, Birmingham Citizens Advice Bureau, was one of the speakers at the Your Voice Ageing Disgracefully event.

Here are some extracts from her presentation, Different Benefits for Different Ages, which looked at many of the benefits available, and what steps you can take if your claim is rejected.

Yvonne said: "I would urge *Link* readers to find out whether they are entitled to additional benefit."

Yvonne's speech can be read in full on the ASBAH website www.asbah.org

Early Retirement

Sometimes it is simply not realistic for some people with disabilities to work until the statutory retirement age. It is important that people have the full range of choices open to them when they retire early, so that fully informed decisions can be made.

If you feel pressured by your employer to retire earlier than you want - because of your illness or disability, you may be able to bring a case using the Disability Discrimination Act 1995. See Disability Rights Commission website on: drc-gb.org/the_law.aspx

Incapacity Benefit (IB)

This is a state benefit paid to compensate you for an inability to work, due to ill health or disability.

It can be paid up to pension age, but, if you are also claiming an occupational pension, the amount of IB you get will be reduced by 50p for every £1 of your occupational pension over £85.

Disability Living Allowance (DLA)

Paid to people who have need for care or supervision during the day and/or night or who have mobility difficulties. This benefit can be claimed up to the age of 65 years.

Attendance Allowance (AA)

This is paid to people who claim after their 65th birthday with need for care or supervision during the day and/or night. However there is no lower rate of care component or any mobility component at all with this benefit.

It is important that people claim DLA before their 65th birthday if they have any difficulties with mobility or low levels of care needs in particular.

Carers Allowance (CA)

(£48.65/Carers Premium £27.15)

Paid to carers who meet the following criteria:

If the person they are looking after is

getting Disability Living Allowance (DLA) it must be at the middle or high rate.

If the person they are looking after is getting Attendance Allowance (AA) it can be at any rate.

They must 'care' for at least 35 hours a week, but time spent prior and post dealing with cared person can count. Care provided does not have to be active 'caring' – simply 'watching' without any intervention can count.

Aged 16 years +.

Must not earn more than £87 a week.

Not in full time education.

Pension Credit (PC)

A) Guarantee Credit (60 years +)

This is the Government safety net for people over 60 years. It tops up existing income to ensure older people have a basic minimum income guarantee.

This is more generous than previous years and more than 25% of people entitled to this benefit do not claim because they do not think they would qualify.

B) Savings Credit (65 years +)

This provides extra money to those who have made modest provision for their retirement. People who cannot qualify for the Guarantee Credit may still qualify for additional income through savings credit.

The University of the Third Age

Mike Long was one of the speakers at the recent Your Voice 'Ageing Disgracefully' conference where he introduced the audience to the University of the Third Age (U3A).

Mike has been the U3A National Development Officer for the past eight years advising existing U3As across the UK and helping new U3As to set up.

"I rather liked the title of the Your Voice conference, Ageing Disgracefully, because in the U3A you have the chance to become as graceful or disgraceful as you wish.

We can go through life listening to how others say we should act and behave, but there comes a time when we should break through all this convention and repression and just be ourselves, and if people don't like it, that's tough!

The U3A or University of the Third Age is a non-profit making organisation designed and run solely by its members for its members.

The organisation was set up in 1982 and there are now 632 U3As across Britain, with in excess of 186,000 members, celebrating the organisation's 25th birthday this year.

continued overpage

continued from previous page

We are a self-help organisation which draws on the knowledge and expertise of its members. There are no bosses... we have left all that behind. There is no competition either; our emphasis is on helping each other.

Peter Laslett, one of our founders, laid down the tenet that those who teach shall also learn and vice versa.

For a cost of between £5-15 a year you can be a member of your local U3A.

The typical U3A has a monthly or fortnightly meeting where you have the chance to meet other members and hear a speaker.

Members also have a chance to join interest groups, either on subjects that have interested them throughout life or ones they just take a shine to.

The beauty of the U3A is that you can dabble, by trying things out that you've never tried before.

Organised society attaches too much importance to what we are, in terms of the job we do and value us accordingly. They ignore the much more important aspect of us - and that is who we are.

Let's be feisty and show them that we can fill our time with really meaningful things to do.

If you are new to an area you will need a new nucleus of friends that you know that that can trust instinctively. Where else could you find such a group more easily than at the local U3A?

They will make you feel welcome, let you know what interest groups exist that you might wish to try and very soon you will have loads to do, and many friends for company.

Many within the U3A, who have had difficult times or perhaps have lost loved ones, will tell you, I don't know what I'd have done or how I'd have got through such a sad time without the U3A.

Find out more about the U3A and your nearest branch by logging on to www.u3a.org.uk or call the National Office on 0208 466 6139.

Mel Cox



Eat well – age well

Eating a varied and balanced diet is important for everyone. It helps you stay healthy, active and happy.

Thanks to numerous healthy eating campaigns, most people know the benefits of eating a healthy diet, but unfortunately, many of us continue to consume too much fat, salt and sugar, and not enough fruit and vegetables.

While this is leading to the well publicised obesity epidemic, it also means that many people are deficient in certain key nutrients.

Mel Cox, Schools Dietitian for Heart of Birmingham Schools, talked about the necessity of good nutrition at the recent Your Voice weekend event.

She explained: "As we age, our metabolic rate declines and we usually become less active. This means that we don't need the same amount of calories - or energy - than we did when we were younger.

"It is important that we recognise this so that we don't become overweight – something which is especially true for disabled people who may not be as active.

"It is equally important, however, that whilst our calorie intake should usually be less as we get older, our need for a range of vitamins, minerals and nutrients stays the same."

It is crucial that people continue to eat a well balanced and varied diet that provides them with: carbohydrate for energy; protein for repair and maintenance; vitamins and minerals for an efficient immune system; healthy

bones, teeth and blood etc.

Healthy eating is simple really. All you need to do is follow the Balance of Good Health.

- **Eat 5 portions of different fruits and vegetables everyday.**
- **Eat plenty of carbohydrates like bread, potatoes, pasta and rice.**
- **Eat moderate amounts of protein and iron rich foods such as meats, fish, lentils, nuts and eggs. Oily fish like salmon, pilchards, mackerel and sardines are particularly important as they help protect against heart disease.**
- **Eat moderate amounts of calcium-rich dairy foods like low fat milk, cheeses and yoghurts**
- **Eat only small amounts (about 7% of your total food and drink intake) of high fat, sugar and salt foods and drinks (e.g. fizzy drinks, biscuits, sweets, crisps, chocolate, ice cream, alcohol, processed meat products, ready meals etc)**

By following the Balance of Good Health, and keeping as active as possible, helps to reduce the risk of raised blood pressure, heart disease, stroke and some types of cancer. It will also help to keep you trim, mobile and happy into old age.

Mel added: "If you are worried about your weight, and don't forget, being underweight can also be detrimental to health, mention your concerns to your GP who may refer you to see a dietitian."

Fit for anything

Exercise is just as important for disabled people as for anyone. It's essential to maintain good heart and lung health through aerobic exercise, as well as reducing the risk of osteoporosis.

A recent study of disabled gym users revealed that when it comes to exercise, disabled people have staying power - they are almost twice as likely to still be using the gym at any given point in time than non-disabled users.

But keeping fit doesn't necessarily mean sticking to arduous gym regimes; the most important thing is for you to be as active as you can.

It may seem a struggle at first, but find an exercise you enjoy and set yourself achievable goals and you'll feel fantastic.

That's the firm belief of Maggie Pickard, course director with Extend, an organisation which runs classes for the over sixties and less able people of all ages.

Maggie, one of the speakers at the Your Voice conference, said: "It was clear that most of the audience knew of the importance of exercise but 75 per cent of them didn't see it as a priority... which I have to say didn't come as a surprise to me because that's the same for the general population.

"There are so many benefits from regular exercise from improving mobility, circulation and digestion through to psychological benefits.

"Being active improves your sense of well-being and self-esteem. Joining a gym or suitable class also gets you out of the house and among new people.

"Keeping in good shape helps to keep your weight down and also means that people are more likely to be able to live independently for longer."

But Maggie advised: "The main thing is to set yourself achievable goals. Aim too high straight away and you are likely to give up within days."

Maggie also voiced her concerns about the number of facilities available and the number of instructors who are qualified to teach people with conditions such as spina bifida.



Maggie Pickard

"Thankfully the Disability Discrimination Act means that the situation is improving," she said. "There is also a range of new qualifications to give instructors better training, knowledge and awareness of the needs of disabled people."

The Extend organisation was set up almost 50 years ago providing movement to music classes in nursing homes, hospitals and hospices.

Today it is active in many parts of the England and its highly qualified instructors are now running classes for community groups.

For more information about Extend visit www.extend.org.uk

The BBC disability website, Ouch, also has information and motivational tips of getting fit.

www.bbc.co.uk/ouch/closeup/fatnation

For disability sport and fitness go to www.direct.gov.uk/en/DisabledPeople/Everydaylifeandaccess/SportsAndHobbies



Codman - Working in partnership with ASBAH



“The hydrocephalus research presented at the SRHSB is always exciting and this year was no exception. Scientists and surgeons from around the world - from UK to US, from Chile to Europe - looked at the technology of new age shunts to treat hydrocephalus; the efficiency of programmable as opposed to fixed pressure shunts was determined; the composition and absorption of CSF examined. And as always the search for the ultimate in treatment whether by shunting or biotechnology.”

Rosemary Batchelor, ASBAH's senior medical adviser.

ASBAH representatives and other experts from around the world gathered in Germany at the annual meeting of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB).

The delegates were welcomed to the meeting, held at the University of Heidelberg, by Professor Andreas Unterberg and Professor Alfred Aschoff.

The four-day event, held on 27 – 30 June, was the SRHSB's 51st conference since the Society was formed in 1957.

Here ASBAH's medical adviser Lisa Raman writes about her impressions of her first visit to a SRHSB conference.

conference for Research Society

SRHSB (2007) was held in beautiful Heidelberg, Germany. As a first time conference attendee, I was very impressed by both the spectacular sights as well as the conference events!

I found the presentations to be both informative and relevant. I learned about a number of different research perspectives because the group of presenters and attendees was highly multidisciplinary.

Their presentations were interesting, intellectually stimulating, and ranged from psychosocial issues viewed from a qualitative perspective, to highly technical and quantitative research, thereby providing value to professionals at different stages of their careers.

Furthermore, the discussions provided new insights and ideas for future research into spina bifida and hydrocephalus, and addressed many of my unanswered questions.

I was both pleased and proud to represent ASBAH, whose work is highly respected and admired.

The conference was useful because ASBAH's quality of service provision is highly dependent on relationships that we build with respected professionals in

neurosciences, urology, psychology, and other areas significant for our service users.

I was pleased to note the dedication that the participants have to helping people with spina bifida and hydrocephalus. Their commitment to promoting research into this area is very high.

As a medical adviser, it is my responsibility to provide information through a number of media including emails, correspondence with service users and professionals, organising study days and in liaising with

service users and community professionals.

Routine interactions and maintenance of relationships within the research and medical community is necessary therefore, to incorporate the latest information from the medical community into my work. This is important because ASBAH is dedicated to offering insights based upon the most current research findings to our service users and employees.



Lisa Raman

Abstracts of the papers presented at the Conference can be found at www.cerebrospinalfluidresearch.com

“They thought I was drunk”

Chris' NPH experience

Chris Papachrysou was fitted with a programmable shunt in 2006 after being diagnosed with normal pressure hydrocephalus (NPH).

It took more than a year for the diagnosis to be made and Chris felt only relief that he finally knew why he had been feeling so ill.

Chris, 61, from Great Yarmouth, talked to *Link* about his experiences and how NPH has affected his life.

What early symptoms did you experience?

I began to lose my co-ordination and I'd fall down for no apparent reason. When this began to happen more frequently I would stand with my hands out stretched, ready to protect my face when I fell.

I went to my GP who asked me if I'd been drinking. I'm not that much of an idiot, I thought.

Eventually he took some blood samples for testing but they came back clear.

How were you feeling at this stage?

Well my symptoms were becoming worse and I was very tense and uptight. I was also very frightened at this stage because I really felt something serious was wrong.

When was NPH diagnosed?

My GP sent me to see a neurologist and after having several tests and a scan I was referred to Addenbrookes. I was diagnosed with having NPH immediately and I had a programmable shunt fitted.

Apparently the pressure had built up to an extent that I was lucky not to have had brain damage. My consultant

said that although I'd only really noticed the symptoms over the past six or seven months, the NPH had probably started as much as three years earlier.

Have you experienced any subsequent problems?

I have felt much better though I haven't recovered completely. My memory isn't as good as it was and I get agitated more easily.

How has NPH affected your life?

I worked in catering since I left school and ran my own restaurant here in Great Yarmouth since 1963.

Unfortunately I had to give the business up three years ago when I began to suffer from the symptoms. It was impossible to work in a restaurant with those sorts of problems. It wouldn't have given a very good impression to the customers. Selling the restaurant was quite

a wrench and together with my driving licence being revoked led to my loss of confidence.

How has your family been affected by your condition?

It was much worse before the diagnosis when no-one knew what was happening to me. I'd return home from work with my hands grazed from a fall. They thought I'd been fighting and was trying to hide something from them.

My personality changed too. I was uptight and everyone began to get on my nerves.

But my family, especially my wife Olivia, have been very supportive and helped me through. I don't know what I would have done without them.



Chris Papachrysou

What is NPH?

Normal pressure hydrocephalus is an abnormal accumulation of cerebrospinal fluid (CSF) in the ventricles (cavities) of the brain with little or no increase in pressure.

Under normal conditions, about a pint of CSF is produced daily in the adult brain. This circulates through the ventricles and the brain and spinal cord carrying nutrients to the brain and acting as a buffer to prevent injury.

NPH results when the flow of CSF is blocked in some way. It occurs most often in people aged over 60.

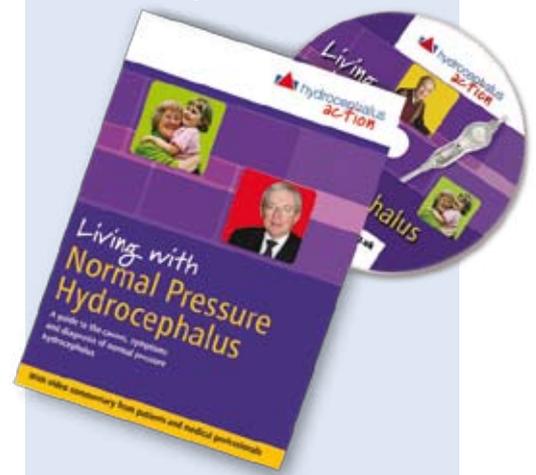
The three main symptoms are mobility problems, forgetfulness/confusion (dementia) and urinary incontinence.

Treatment is by operation when a fine tube and valve (called a shunt) is inserted into one of the spaces of the brain to drain away excess fluid.

People will respond to the operation in different ways and while most people find their health improves, the level of this improvement will vary.

For a more detailed explanation of NPH go to the ASBAH website www.asbah.org

To buy a copy of ASBAH's "Living with Normal Pressure Hydrocephalus" information CD contact the ASBAH helpline on 0845 450 7755 or visit www.asbah.org to order online.



Case studies

Ageing with Spina Bifida:

In April this year, Cheryl Wilton from Staffordshire celebrated her 60th birthday. We caught up with her to find out a bit more about what it is like to age with spina bifida.

“As I have grown older, I feel I have also grown happier. Ageing with spina bifida for me has helped me develop a particularly positive outlook on life. As I’ve got older, I’ve definitely become more optimistic. I always try to see the good side of people, situations and life in general. I think this has made me a very contented person.

“The other good thing about getting older and having a condition like spina bifida is the progress which has been made in medicine. There have been advancements which have helped me, the most notable one being the introduction of super pubic catheters - when I was fitted

In terms of physical effects, I think I have been quite lucky as I haven’t experienced the usual mobility problems able-bodied seem to do as they grow older.

with mine it changed my life.

“As far as negative aspects of getting older with spina bifida go, I don’t feel I have experienced any major negative effects.

The only pessimistic things I can think of are to do with other people’s perceptions of spina

bifida. Many people hold quite a negative stereotype about people with spina bifida and I think this comes from how the media portray the condition and people not being educated about conditions like this.

“In terms of physical effects, I think I have been quite lucky as I haven’t experienced the usual mobility problems able-bodied people seem to do as they grow older. Many older people seem to have problems with their hips and knees but because I use a wheelchair, my hips and knees aren’t under as much strain as they would be if I was walking around all day.”



Cheryl Wilton

As is the case with many people, Cheryl has experienced hard times in her life: “My father died when I was 15 so my mother looked after me throughout my childhood.

When I was 46, she passed away. Her death was particularly hard for me as she had always been my main care giver.

“I also experienced problems with my foot a few years ago and as a result had to have it amputated but, as with any cloud,

there are always silver linings; I now have a wonderful assistant who visits my home every day to give me a hand with cooking, cleaning and generally looking after both myself and the house. I also have a strong network of friends who continually prove a source of inspiration and companionship.”

As the years pass by for Cheryl, she is starting to take things easier, enjoying pastimes such as playing cards and scrabble and watching TV, especially comedy shows and soaps. Spina bifida has not stood in the way of growing old gracefully for Cheryl.

Ageing with Hydrocephalus:

When Nick Manning was diagnosed with hydrocephalus in 1995, he was concerned that he could lose his job as Senior Bird Keeper at Chester Zoo.

He was on sick leave for many months during the next three years, until his fifth shunt finally seemed to do the trick.

Nick was delighted to return to the job he had done since leaving school – looking after and breeding the variety of birds at the famous zoo.

Caring for almost 200 species of bird ranging from penguins, storks and flamingos, to parrots, birds of prey and cranes was a way of life for Nick.

But in 2002 the back pain he had

A programmable shunt was adjusted to minimal pressure, and my hydrocephalus hasn’t really troubled me since then.

suffered from for more than 25 years became debilitating and after numerous scans he was shocked to hear that he had spina bifida occulta.

Despite two operations the pain

increased and he became less mobile. Two years later Nick had to hand in his resignation.

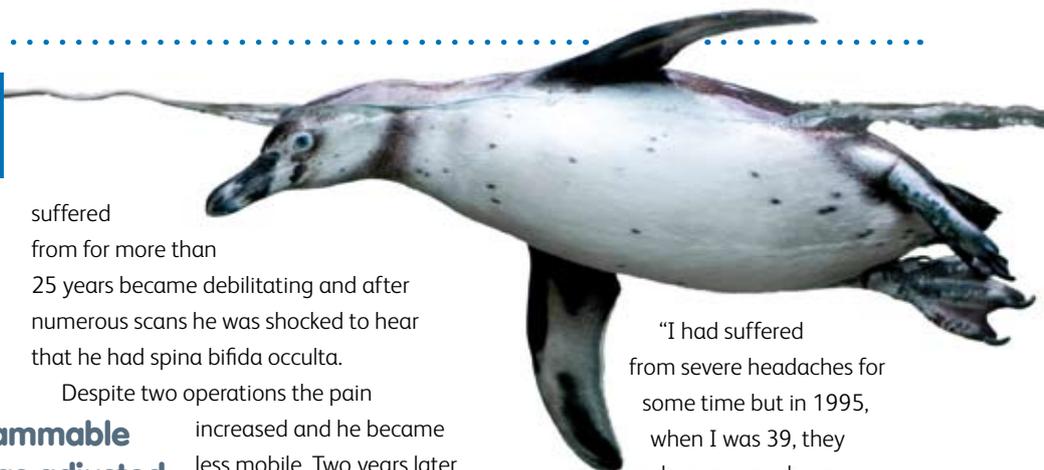
He said: “I had been so ill from the hydrocephalus that when I began to feel better after the fifth shunt, I really thought things would get back to normal.

“I had meningitis when I was just one year old and the doctors thought that was when the problems started.

“I had suffered from severe headaches for some time but in 1995, when I was 39, they became much worse.

“The first two shunts didn’t work and the fluid built up very quickly. In 1997 I had three more shunts within three months. The final one, a programmable shunt was adjusted to minimal pressure, and my hydrocephalus hasn’t really troubled me since then.

“But although I was obviously really ill for much of those two years, I remained positive and the operations didn’t really



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bother me. I was just keen to get better and back to work."

Life returned to normal for Nick and wife Eunice, who mans the switchboard at Chester Zoo.

But fate struck again seven years later when Nick was diagnosed with spina bifida.

He said: "I had been in agony for so long that I knew something was really wrong with my back. The pain was centred in my lower back with shooting pains down my legs.

But no-one, apart from my osteopath really took me seriously. My GP referred me to a psychologist for six months because they thought that the problems were in my head because I didn't really want to return to work."

When Nick finally underwent surgery it was discovered that the lower vertebrae weren't fixed and were rubbing against his spinal cord. He had a bone graft and plates were fixed either side of his spinal column to keep the vertebrae in place.

He said: "I was back on my feet the following day and the pain didn't seem too bad. But things quickly deteriorated and soon it was as painful as it had ever been. The operation was successful in that if I hadn't had it, I would be paralysed by now.

"I tried to return to work but it was so physical that there was no way that I could continue with my job."

The couple still live in their cottage near Chester Zoo where Nick can still enjoy listening to the sounds of the birds and the animals he loves.

And while he is in continual pain and has difficulty moving around, Nick continues to care for his six noisy parrots and is involved in a falcon breeding programme.

Often the living room, where he now sleeps, is a temporary home to incubators hatching out chicks. "Birds have been my life. I'd be lost without them," he said.

What they thought...

"Overall it was very good"

"The balance of info and breaks was just right."

"Thanks to all the organisers and speakers"



Ageing Disgracefully the Your Voice way

Members from the Your Voice user group got together in Birmingham for the 2007 summer event, Ageing Disgracefully

Twenty people from around the country attended the event organised by Michael Bergin, Lisa Cain and Paul Manning who brought in a variety of speakers to cover medical and well-being topics.

The visitors arrived at the hotel on the Friday evening for dinner and a welcome meeting, where they learned more about the planned programme of events.

The Saturday schedule packed in five talks ranging from A New Revolution in Bowel Management (see page 25) and Healthy Eating (see page 18) through to The Ageing Bladder (page 16) and Rosemary Batchelor's Keeping it all Together presentation. Each was followed by a question and answer session.

"We tried to gather a wide range of speakers," explained organiser and Your Voice chair Lisa Cain. "So hopefully there was something for everyone."

There were plenty of breaks for coffee and a buffet lunch during the day which concluded with Michael Thompson's Easy and 1, 2, 3 art demonstration.

His landscape painting, created using just three colours, was raffled off after the session, with lucky Jeannette Prentice scooping the prize.

Following another three-course meal the delegates were left to their own devices. Some went to the cinema while others enjoyed a drink in the hotel bar.

But there was no time for long lie-ins on the following day. The Sunday programme kicked off at 9.30am with a talk by Maggie Pickard from the Extend organisation about the benefits of exercise (see page 19). She even encouraged the audience to try out a few simple stretches during her presentation to get their circulation going.

Yvonne Davies from the Birmingham Citizens Advice Bureau followed with a talk about the different benefits available and advised on how to make a claim.

The event ended with a Your Voice information and feedback session with organisers Michael and Lisa, followed by lunch.

Michael, who first became involved with Your Voice in December when he was elected to the YV Committee, said: "Organising an event like this does take a great deal of work, but it was worth it because everyone seemed to enjoy themselves.

"Hopefully they all learnt something which will help them in their day to day lives too.

"There was a very positive response to all the speakers which was very encouraging. If just one person says thank you then it is all worthwhile."

Lisa and Michael were also delighted that the event, which was oversubscribed, attracted six new people who hadn't attended a Your Voice event before.

Don't miss your chance to attend the Your Voice autumn event – 'Moving on up'. Turn to page 24 for full details.

Don't miss your chance to Move On Up!

BOOK NOW!
Places are going fast!

Your Voice members are being offered the chance to pick up plenty of advice on independent living at the next weekend event.

Bookings are now being taken for 'Moving On Up', which will be held in Mortimer, near Reading on 2 – 4 November.

The weekend away will take place at the Wokefield Park Hotel. The cost for delegates will be £95, which includes two nights' accommodation, breakfast and buffet lunch plus evening meals on Friday and Saturday.

Barbara Robinson, Policy Officer (Your Voice) said: "The Your Voice events are always very informative and give members a great opportunity to get together. We hope they won't miss this opportunity for a great weekend away."

The provisional list of speakers includes:

- **Paul Gamble**
Assistant Director, Habinteg – Housing Options
- **Wendy Gross**
Information manager, National Centre for Independent Living
- Direct Payments, individual budgets employing & working with personal assistants

- **Liz Dunscombe**
From Credit Action - Budgeting
- **Chris Turner**
Chief Executive, Reading Citizen's Advice Bureau - benefits available while living independently
- **Caroline McAleese**
From Action for Advocacy - Advocacy support

There will also be input from YV members/disabled people giving a more personal perspective on issues like experience of direct payments.

Places at the last Your Voice event were quickly filled so make your reservation now by contacting Barbara Robinson on barbarar@asbah.org or call 01733 421322.

“The Your Voice events are always very informative and give members a great opportunity to get together”

Your Voice presents

Moving On Up!

Come along and pick up lots of advice on independent living

Open to all adults (aged 18 and over)

Date and venue:

Friday 2nd November to Sunday 4th November 2007

Wokefield Park Hotel
Mortimer
Nr Reading

Reserve your place NOW

£95 delegate rate including two nights accommodation, breakfast and buffet lunch. Evening meals on the Friday and Saturday only.

The delegate rate is subsidised by Your Voice

Discussion points and speakers on:

- ➔ Housing options
- ➔ Individual budgets employing and working with personal assistants
- ➔ Benefits and living independently
- ➔ Advocacy support
- ➔ Budgeting
- ➔ Personal perspectives from disabled people

Details of the precise content to be confirmed

For further information and to reserve your place contact:

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



Registered charity no.249338

Improved Bowel Management



Speaker Sue Frost, a medical product manager with Coloplast, gave a talk

about a new approach to bowel management at the Your Voice weekend.

Sue, who was a bowel nurse specialist for 17 years, said she was delighted at the enthusiastic response from the audience, particularly considering the sensitive subject matter.

Her presentation was followed by a lively question and answer session. While many were happy to speak up in front of the audience, others had a quiet word after the event.

In the world of bowel management there haven't been any technical developments for many years.

There are various methods which people who have spina bifida will be familiar with, such as manual evacuation, enemas and laxatives.

So this is why the Peristeen Anal Irrigation from Coloplast, which was launched in April this year, is proving popular.

It is a purpose-designed system for anal irrigation – and it's the first system which is available on prescription.

Peristeen is a way of emptying the lower bowel and is used to prevent faecal incontinence, constipation or simply as a method of bowel management.

It has been specially designed to make it portable and easy to use, which gives independence and confidence to the user. It's also time-saving - taking on average 30 minutes to perform every other day.

It can be used by people with a variety of bowel problems, but in clinical trials with spinal injured patients, the Peristeen

system reduced faecal incontinence and constipation and improved the quality of life.

Sue said: "We have received so much positive feedback from users, who say that the system has really enabled them to improve their day to day bowel management.

"I know that faecal incontinence is something which is a huge worry to many

people who rely on bowel management. Using this new method gives their confidence a huge boost and improves their quality of life immensely."

But Sue advised: "Before using the Peristeen system you must be assessed by a qualified health care professional to ensure it is appropriate for you.

You will then be taught the method by the health care professional in order to obtain the best results."

And while Peristeen is becoming more widely known, if you or your health care professional would like further information, you can call Charter Healthcare on 0800 132787.

Before using, the Peristeen system you must be assessed by a qualified health care professional to ensure it is appropriate for you

Blood donor guidelines to be investigated

ASBAH is investigating National Blood Service (NBS) guidelines which do not allow people who have shunts to donate blood.

Roger Bayston, Associate Professor, School of Medical and Surgical Sciences at the University of Nottingham and Chair of ASBAH's Medical Advisory Committee says that the Guidelines contain a number of exclusions that people with spina bifida and/or hydrocephalus need to be aware of.

He believes that in some cases the guidelines might be based on inaccurate information and might need to be rewritten.

Link spoke to Ruth Greenaway from NHS Blood and Transplant (NHSBT), who said: "People with indwelling shunts are asked not to donate blood".

Dr Bayston is studying the official guidelines and will investigate the reasoning behind them. If necessary, ASBAH will then discuss the position with the various authorities involved including the Department of Health and the UK Blood Transfusion Service (Donor Selection).

Meanwhile, if *Link* readers have experienced any difficulty donating blood (or bone marrow) and would like to share their story, please write to the Editor at the usual *Link* address.

Case study

Jeff Lawrence donated blood for more than ten years, happy to play a part in the life-saving scheme.

But that all stopped in 1998 when a doctor at a donor session discovered that Jeff has a shunt.

Jeff, from Conover near Shrewsbury, explained: "I was actually in the process of donating blood when a doctor spotted my walking sticks and asked why I used them.

"I explained that I had hydrocephalus and immediately the needle was removed from my arm and I was told that people with shunts can't donate blood.

"It was the first time this had ever been mentioned to me and I was pretty angry."

Back at home Jeff contacted the National Blood Service (NBS) to be told that this rule was part of the UK Blood Transfusion Service (UKBTS) guidelines.

"So I phoned up and spoke to the NBS haematology department to ask if there had ever been anything wrong with my blood and if my donations over the years had been used," he said. "I was told that my blood was fine and yes, my donations had been used.

"I wasn't happy about it but rules are rules so I didn't feel there was much else I could do. But it is a shame because I have had several operations over the years and have needed blood transfusions. People's donations of blood helped me and I was keen to help others in return."



Latex allergy – know the facts

Latex, a natural rubber, has been used to make medical gloves and other commonly used products for over 100 years.

Latex allergy was first recognized in the general population in the late 1970's. Since that time it has become a major health issue.

People who have long term exposure to latex gloves or medical products containing latex are especially at risk.

Long term or cumulative exposure is seen in people who undergo repeated surgeries or medical procedures from early in life.

Many children and adolescents with spina bifida are sensitive to latex, and current research has shown a clear association in children with spina bifida who have had several surgeries.

In spina bifida, neurosurgery or bladder and bowel surgery, diagnostic tests, and medical examinations are the main reasons for the intense and constant exposure which leads to increased sensitivity to latex.

Shunts are never made of latex but people who have had multiple revisions may develop a latex allergy due to exposure to latex in the operating theatre.

Yet many people are still completely unaware of the risks.

Symptoms of latex allergy

When the immune system detects latex proteins, a range of reactions ranging from mild to severe can start within minutes or hours.

Mild reactions include: skin rashes, hives, flushing, itching, nasal, eye or sinus symptoms. These can progress quickly and unpredictably to a severe reaction.

Severe reactions include: coughing, wheezing, bronchospasms (asthma), or life threatening anaphylaxis and shock.

Reactions to certain foods including potatoes, tomatoes and bananas are also associated with latex allergy.

Diagnosis

The condition should be suspected in anyone who exhibits allergy symptoms after an exposure to natural rubber or implicated foods.

It should ALWAYS be suspected in people with spina bifida and anyone experiencing even mild symptoms should consult their GP.

Diagnosis is made on the basis of the outcome of the medical history, which includes food allergies, physical examination, and blood and skin tests.

Treating latex allergy

The most effective way is to avoid latex completely. A primary step in avoidance is awareness. Household and medical items that are made of latex (natural rubber, not synthetic rubber), should be removed from the home and medical environment.

People who are at risk of latex allergy or have had a reaction should inform all medical and other community professionals with whom they interact, so they can remove latex products from the environment.

Be prepared

If you have had a mild or severe reaction to any latex product, or have food allergies, it is important to:

- **Wear a medic-alert bracelet or necklace**
- **Carry an epi-pen (portable, injectable epinephrine)**
- **Carry non-latex gloves**

It is also a good idea to notify community professionals of your health risk, and avoid any environment where you may come into contact with products containing latex.



Case study

Mother Anne Harper knows only too well the dangers posed by latex allergy.

More than 20 years ago her son Michael, now 41, was diagnosed with the condition which nearly killed him.

Michael, who has spina bifida, and his family had to change their whole way of life to make sure that he didn't come into contact with the material again.

Here Anne, from Hertfordshire, tells her story.

"Michael had three very bad reactions to latex during hospital stays and he had to be resuscitated each time.



Michael Harper

The first couple of times it was put down to his poor condition, but on the third occasion the surgeon believed that Michael had a rare allergy and sent a blood sample to a Professor in Hammersmith.

The tests revealed that Michael was extremely allergic to latex, an allergy which very little was known about at the time.

While Michael was recovering in hospital we had to go through our house from top to bottom removing anything which may have latex in it.

That ranged from shoes which had rubber soles to the simple things like erasers, balloons and elastic bands. It was a huge job at the time, but it had to be done because his saturation level was so high. Michael was so allergic that even skin contact would bring him up in large red swellings.

We also had to get a latex-free wheelchair for Michael, which wasn't easy 20 years ago. Social Services didn't provide specialist wheelchairs in those days so we had to pay for it ourselves. It was a huge outlay but it had to be bought.

It was a very worrying time to begin with and we were very anxious for Michael, but it does become a habit and with a little care life can go safely on."

For more information about latest allergy read the new Latex Allergy information sheet downloadable from the ASBAH website www.asbah.org

demonstrating more understanding *

We are a leading law firm who specialise in investigating Hydrocephalus and medical issues surrounding Spina Bifida claims.

Medical issues are often highly complex as well as daunting.

If you have concerns regarding medical treatment you have received then please contact **Anthony Fairweather** (Law Society Clinical Negligence Panel Member) for a free consultation

on **0117 916 9352**

or email: afairweather@clarkewillmott.com

Diary dates

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

Eastern Region Local Association Forum Meeting

Date: Saturday 13 October 2007
 Time: 11.00 am start
 At: ASBAH House, 42 Park Road, Peterborough PE1 2UQ
 Lunch and parking
 Speaker: Linda Lewis Help Line and Information Manager.
 More information contact the Eastern Region Office on: 01733 421309

Southern Region TIME FLYING BY Employment information day

Date: Thursday 25th October - Friday 26th October
 Venue: The Selsdon Park Hotel Addington Road South Croydon Surrey CR2 8YA

Due to spaces being limited, it is essential you contact your adviser or Naomi Marston on: 01959 534154 or email naomim@asbah.org

Your Voice presents: MOVING ON UP

Date: 2 - 4 November 2007
 Venue: Wokefield Park hotel, Mortimer, Nr Reading
 Cost: £95
 Bookings are now being taken for the autumn event. The cost for delegates includes two nights' accommodation, breakfast and buffet lunch plus evening meals on Friday and Saturday.
 Places at the last Your Voice event were quickly filled so make your reservation now by contacting Barbara Robinson on barbarar@asbah.org or call 01733 421322.

Northern Region Tethered Cord and Chiari

A talk by Mr. Neil Buxton, Consultant Neurosurgeon, Walton Centre for Neurology and Neurosurgery and Alder Hey Hospital Liverpool.
 Date: Thursday November 8 2007
 Time: 1pm
 Venue: Greenbank Sports Academy (Rathbone Room), Greenbank Lane, Liverpool L17 1AG.
 For further details contact Asbah Northern Region office on 0113 255 6767.

Northern Region York Coffee Mornings

Venue: Low Moor Community Centre, Bray Road, Fulford, York YO10 4JG
 Time: 10.15am - 12 noon
 Dates: The second Wednesday of every month: 10 October 14 November

Please e-mail the editor (link@asbah.org) dates of your events for the next issue of *Link* by Friday 23 November 2007, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.

Holiday let

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

ISLE OF WIGHT ASBAH - HOLIDAY BUNGALOW

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

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.

On the move

Becki Ellison was the girl who captured the hearts of viewers of BBC 1's Lifeline programme 21 years ago.

Donations to ASBAH flooded in when Becki, aged just four, appeared on screen alongside presenter Sarah Greene.

Becki's Mum Jan wrote in to *Link* after reading other people's mobility experiences in the last issue, to share Becki's story with others.

She said: "I was moved by the supplement and think it is so useful for new parents to read about other people's mobility issues.

"Becki has had ups and downs, plus a lot of learning by experience, but I know that when she was a child I was always very interested to hear how others deal with certain matters.

"Becki is getting married next March, a day which is going to be very special for everyone and one that she well deserves."



Becki's story continues overpage

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 23rd Nov 2007

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

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Becki's story

Becki's first few months were very much like any other baby's, until her peer group began to sit and crawl. We worked hard to help her and she managed to sit up at the age of nine months.

Just before her first birthday our ASBAH area adviser asked if Becki would like to try out a SHASBAH trolley. It was amazing. She instinctively turned the wheels and started moving around the living room.

Two months later she received her first full-length callipers (from chest to feet) to be used for standing only. For two hours a day she stood reading books, completing puzzles and generally being amused by me.

It became a chore but she soon progressed into walking callipers with special shoes and a walking frame.

Becki took her first steps just before her second birthday. What a day that was. She was crying, I was crying, but the effort had all been worth it.

Walking was always difficult for Becki but she persevered until the age of 15 when she found that she could get round much quicker in her wheelchair.

Becki is now 25 and every five years has a new wheelchair under the voucher scheme. She has never regretted her time walking or having manual wheelchairs which have given her the strength and stamina to do all the things she has wanted to do.

Next year Becki is getting married. He only regret is that she can't walk down the aisle. The days of callipers are unfortunately behind her. But her special day will be truly memorable, and we wish her and her partner every success in their new life together.

Olga de Wit from the Netherlands...

the white coat on wheels

Bubbly medic Olga de Wit made the decision to use a wheelchair for her ward work two years ago to enable her to devote her energies to her patients.

Olga, who has spina bifida, graduated in neuropsychology after five years at the University of Maastricht.

She then began her medical training, which involved four years study in Amsterdam followed by a two year internship at Groningen Hospital in the north of the Netherlands

It's been a tough training programme for Olga, who is now in her final year at Groningen, but it is work she clearly loves.

She told *Link*: "Using a wheelchair leads to a lot of funny - and not so funny - remarks but it gives me the energy to be able to do my internship and research.

"I have a responsibility towards my patients to be able to listen to their stories and treat them.

"If I can't think or listen because I am too tired from standing, I can't help them in the way they deserve.

Olga, 29, added: "When I started medicine I got another view on spina bifida and disability. To begin with I didn't do any work with spina bifida patients, but I learned about

the body in a different way than as a patient.

"My work with people with spina bifida really started when I was appointed research assistant at a rehabilitation project in Utrecht studying adolescents with spina bifida."

Using a wheelchair leads to a lot of funny - and not so funny - remarks but it gives me the energy to be able to do my internship and research

During this time Olga was very active as president of the workgroup for spina bifida/hydrocephalus (whose members are both parents of and people with spina bifida/hydrocephalus) of the Dutch patient-organisation for people with a disability (BOSK).

In recent years she has been involved with several spina bifida and hydrocephalus research projects which have given Olga a different perspective into the conditions.

She gained valuable experience working on the ASBAH-funded Stevenson Project run by the Department of Psychology at the University of Southampton, which among





Contacting ASBAH

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other things, studied the self-esteem and behaviour of children with spina bifida.

Last year, when Olga moved to Groningen to start her final internship, she did additional research into spina bifida, this time with a child neurologist who specialises in the condition.

"I don't know yet where I will end up, but hopefully I will get a job where I can help other people with spina bifida or other chronic diseases or disabilities," Olga said.

"But I hope that my personal experiences of spina bifida coupled with my professional education, will give me the ability to make a difference to the lives of my patients."

But wherever Olga ends up, the future looks bright and very busy for the young medic. 2008 is set to be a particularly memorable year, for as well as qualifying as a doctor; Olga is looking forward to marrying boyfriend Edward in March.



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Local Association secretaries requiring changes to this list should contact:

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