WINTER 2009 ISSUE 226

link

The magazine for people with hydrocephalus and spina bifida

Have wheels & travelled

Your Voice event review on page 25

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ability beyond disability
TM

Your Voice presents

Have a Lifestyle of Leisure

Date and venue:

Saturday 14 March 2009

Holiday Inn
Cardiff Bay
Cardiff

Book NOW

£35 includes: workshops, lunch & refreshments.

The delegate rate is being subsidised by Your Voice

About this event:

This event is to be run as a regional event, with people from throughout Wales attending. Disability Sport Wales will attend showing what leisure pursuits are available in Wales.

It is also hoped to have Wales Paralympians there and for them to share there experiences in being involved in Leisure in Wales.

For further information and to register your interest contact:

Mark Harris
ASBAH House
42 Park Road
Peterborough PE1 2UQ
Email: markh@asbah.org
Telephone: 01733 421322

association for
spina bifida
hydrocephalus
ability beyond disability

Registered charity no.249338

To read more about Your Voice see page 25

link

the lifestyle magazine for people with hydrocephalus and spina bifida

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Association for Spina Bifida and Hydrocephalus • Registered charity number 249338

Gill Winfield writes

Welcome to *Link* 226, the first edition of 2009. I hope you all had a great Christmas and New Year and are managing to stick to any New Year resolutions you made.

The *Link* team made a resolution to continue to produce a magazine that our readers find informative and interesting, so please help us by keeping your news and ideas coming in.

This issue updates you on the new publications and information sheets the ASBAH team has been working on. With a new adult book, a children's activity book and revamped ante-natal leaflet, there's certainly something for everyone.

We have a round-up of the new people who've recently joined the organisation, a report about the recent AGM and a review of the last Your Voice event, 'Have Wheels Will Travel', which was held, for the first time, in Leicester.

The supplement this time is part two of Adult Issues, with features on how to get the most out of your holiday, advice for disabled parents and a look at relationships.

There's a bumper fund-raising section to say thank you to some of the many people who have been hard at work raising much-needed funds.

We also meet service user Peter Clarke and his wife Susan, who talked to us about how Peter's NPH affected family life.

So hopefully there's plenty between these pages to interest you.

Gill Winfield
Marketing and Communications Manager
gillw@asbah.org

Patron:
HRH The Duchess of Gloucester GCVO

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

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National Centre, 42 Park Road, Peterborough PE1 2UQ

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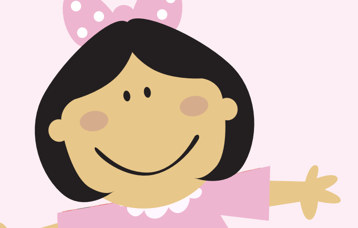


Leaflets 2U

spina bifida hydrocephalus

First point of contact

Hydrocephalus Spina Bifida

0845 450 7755
helpline@asbah.org

As part of our ongoing publicity drive to make more professionals and service users aware of our helpline and advisory services, ASBAH is taking part in a pilot project in the new year.

Leaflets2U, who provide a leafleting service to GP practices, are now trialling an online service where health professionals can order free leaflets from different organisations and have them delivered, in batches of 25, to pass on to service users.

ASBAH has produced a new leaflet giving a brief guide to the helpline and how callers can access all our services through it.

Symposium report published

Following its well-attended symposium on management of pregnancy when a CNS anomaly (including spina bifida) is diagnosed, ASBAH has produced a report. The eight-page document summarises the proceedings of the symposium. It also identifies problems with the current ad hoc system; describes the patient experience; and gives examples of good practice and possible solutions and suggestions to provide better management of this difficult area of antenatal care.

ASBAH aims to use the report, entitled 'Symposium on Management of Antenatally Diagnosed Congenital Abnormalities of the Central Nervous System', to raise awareness of the issues by sharing them with the relevant professional bodies and seeking their comments.

It is also hoped that the National Institute for Clinical Excellence (NICE) will take the report into consideration, and any further recommendations from the appropriate Societies and Royal Colleges, in drawing up guidelines for antenatal management of diagnosed congenital abnormalities.

Flour Fortification campaign spreads across Europe

Campaigners from across Europe and Eurasia gathered in Romania to further their efforts to achieve the mandatory fortification of flour with vitamins and minerals, particularly folic acid.

Delegates representing the medical, nutritional and regulatory communities attended the second European Regional Flour Fortification Consultation in Bucharest in October.

The three-day conference was organised by the European Food Safety Authority and Flour Fortification Initiative (FFI) partners who are working to make the fortification of flour standard practice.

> It was great to see so much enthusiasm for flour fortification from the millers, the families of disabled children, and doctors and scientists who were there in Bucharest.

More than 100 people attended the event to determine their next steps for delivering micronutrients through flour fortification.

The first day of the conference featured research that supports the value of fortifying flour. Presentations were made by several speakers including ASBAH's Chief Executive, Andrew Russell, and Dr Joan Morris from the Wolfson Institute of Preventative Medicine.

While folic acid is best known for its role in preventing neural tube birth defects, Helene McNulty with the Northern Ireland Centre for Food and Health of the University of Ulster, also noted that new research shows that adequate folic acid levels may reduce heart disease and stroke.

Following the presentations, participants met in small groups based on geographic regions to identify the biggest challenges they face.

A concern voiced frequently in Europe is that consumers want a choice about whether their food is fortified.

Andrew Russell said: "As we saw in Bucharest, there's a golden opportunity for primary prevention of spina bifida right across Europe, which our government should also grasp here in the UK, where so much of the research was done.

Andrew Russell

"It was great to see so much enthusiasm for flour fortification from the millers, the families of disabled children, and doctors and scientists who were there in Bucharest.

"Many disabled children suffered terrible deprivation under the old communist regime in Romania, but today the Romanian government is determined to do the best they can in their health and education services.

"Primary prevention is about promoting healthy pregnancies and avoiding the dilemma of abortion as far as possible."

Introducing ASBAH's new Vice President:

Danny Mills

Footballer Danny Mills will work even more closely with ASBAH after agreeing to become Vice President.

Danny, who has played for England, Norwich City, Leeds, Charlton Athletic and Manchester City, has been involved with the organisation since 2003, when he launched ASBAH's Helpline Appeal on GMTV.

Thanks to his fundraising efforts the Appeal funds got off to a flying start. Since then Danny has continued to work for ASBAH by raising money, supporting awareness campaigns and making personal appearances at events.

Danny told *Link*: "I felt very proud and honoured to be asked to be Vice President for ASBAH and I was delighted to accept the role."

ASBAH's Chief Executive Andrew Russell said: "We are so pleased that Danny has agreed to become a Vice President of ASBAH and will build further on his great commitment to children and adults with spina bifida and hydrocephalus"

> **I felt very proud and honoured to be asked to be Vice President for ASBAH and I was delighted to accept the role.**

Danny became involved with ASBAH after he and his wife Lisa experienced first-hand the need for a dedicated information service after suffering the loss of their third child, Archie.

A routine scan 20 weeks into Lisa's pregnancy revealed that Archie had spina bifida and hydrocephalus so severely that he would not survive

Danny said, "When we found out about Archie we didn't know what to do or who to turn to for support and advice.

"We didn't know about ASBAH or its team of experienced advisers who could give us all the information we needed."

Danny wanted to make it easier for other families in the same difficult situation to contact ASBAH and offered his support to kick start the helpline fundraising appeal.

Since then his wide-ranging support has included making a dream come true for young fan, Michael Jones, who has hydrocephalus.

Michael desperately wanted a replica football shirt but due to his hydrocephalus the 'off the peg' versions wouldn't fit over his head. Danny came to the rescue getting a shirt specially made for the delighted youngster.

More recently, Danny was part of the ASBAH team at the SEB bank's mammoth fundraiser, at Bisley Shooting Ground.

SEB Bank selected ASBAH as its charity of the year and the sole beneficiary of this year's annual clay pigeon shooting event.

Danny spoke to the 400-strong audience at the after-shoot dinner and his personal experience and dedication assured everyone of the value of ASBAH's work and helped to swell the bids at the evening auction.

Andrew Russell added: "Danny has led our appeal to fund the Helpline, using his many sporting and business contacts, and he is enthusiastic to do more."

Meeting Ade Adepitan

Meeting Boris Johnson and Lord Sebastian Coe

Gareth Picken in Beijing

Gareth Picken was centre stage at the Paralympic Games handover performance in Beijing on 17 September.

Popular children's TV programme, Blue Peter, took Gareth, aged nine, and his family, from Cheltenham to Beijing for an incredible once-in-a lifetime opportunity, after he won the 'Postcard to Beijing' competition earlier in the year.

Watched by millions worldwide, Gareth and his hero, former Paralympic basketball star, Ade Adepitan, guided the famous London double decker bus into the Bird's Nest Stadium and welcomed the world to London as part of the closing ceremony.

Meeting Dame Tanni Grey-Thompson

For the eight days he was in Beijing, Gareth spent his time between rehearsals giving interviews; holding daily skype sessions with his school back home; watching the sporting action; visiting the sights of Beijing, including the Great Wall and Forbidden City, and even sampling local delicacies such as scorpion and snake!

The fun didn't stop there; since returning home Gareth has become something of a local celebrity, making various appearances and giving talks around Gloucestershire, as well as receiving personal invitations from Lord Sebastian Coe and MP Tessa Jowell to visit them in London.

Gareth's Mum, Nici Picken, said: "Where do I begin? It was a fantastic trip – the experience of a lifetime. Gareth was not fazed one bit and loved being at the centre of the action in front of all those people."

Blue Peter viewers have been able to watch a behind-the-scenes film of Gareth's amazing experience since the new series began on 23 September 2008.

In training for London 2012

Young athletes are training hard after being inspired by the recent GB successes at the Beijing Paralympics.

Britain won a total of 42 gold, 29 silver and 31 bronze medals at the Beijing 2008 Paralympic Games to finish an impressive second in the medal table.

Now the British Paralympic Association (BPA) is preparing for the London Paralympics in 2012 which will take place from 29 August until 9 September.

BPA Chief Executive Phil Lane said that hosting the Paralympics in London will bring long-term social and sporting benefits including disability awareness and improved accessibility and visibility.

He said: "This will give elite disability sport an even higher profile encouraging new talent into sport."

"Winning the Games will provide improved and accessible sport and leisure facilities in the capital and other regions.

"Great Britain is passionate about paralympic sport. The movement was born here, at Stoke Mandeville, so it feels as if the Paralympic Games are coming home."

He added: "Paralaympic athletes in this country will enjoy a greater number and consistency of sports competitions between now and 2012 as new facilities are built and events, like the hugely successful recent Paralympic World Cup, are used as test events for the Games.

Sebastian Coe, Chairman of the London Organising Committee of the Olympic Games and Paralympic Games, said: "Our vision is to use the Games to inspire change and change attitudes towards people with a disability. We look forward to welcoming paralympic athletes to the UK in 2012."

Appeal for athletes

***Link* would love to hear from any athletes with spina bifida and/or hydrocephalus who are in training for the 2012 Paralympics.**

Whether you've set your sights on a medal or would be happy to secure a place in the squad, please get in touch at the usual *Link* address.

Rosemary has just returned and has sent Link some pictures of her trip and conference presentation

Spreading the ASBAH message in Japan

Senior medical adviser, Rosemary Batchelor, travelled to Japan to speak to health professionals about ASBAH and its vital work.

She addressed delegates at a two-day conference, discussing puberty and sexuality in girls, in late November.

The invitation followed a recent visit to ASBAH by three Japanese nursing professors who were keen to learn more about sexuality and menstruation in girls with spina bifida, for their new research project.

After visiting ASBAH, the nursing professors went on to the Chelsea and Westminster Hospital in London where they met with Dr Richard Morgan, who runs the country's only holistic treatment clinic for adult patients with spina bifida and/or hydrocephalus.

Professor Yoko Noda was so impressed with what she learned that she asked Rosemary to attend the conference at Gifu University's Medical and Nursing School. The meeting was attended by 150 Japanese delegates including doctors nurses and therapists.

Before setting off, Rosemary told *Link*: "It will be a very interesting experience on a number of levels.

"Until recently, the Japanese seem to have had a very different attitude to disability to those in the Western world. For example, I believe antenatal scanning was only introduced as routine over there eight years ago.

"Now there seems to be a great deal of interest in our research into spina bifida and hydrocephalus so my visit will be the perfect opportunity to forge new relationships.

Now there seems to be a great deal of interest in our research into spina bifida and hydrocephalus so my visit will be the perfect opportunity to forge new relationships.

"I will also promote the work of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB) so hopefully Japan will become involved with this organisation too."

Rosemary added that during their visit to ASBAH, she gave the three nursing professors copies of the Below the Belt book.

"The response has been amazing," she explained, "everyone seems to be so enthusiastic about it and already it has been translated into Japanese.

"I'll be taking some copies of *Link* and the Disability, Pregnancy & Parenthood International's (DPPI) magazine out with me to show what other publications are available in the UK."

Updated information sheets

Two ASBAH information sheets are currently being updated to make them more relevant to today's service users.

The revised Normal Pressure Hydrocephalus (NPH) and Antenatal Screening fact sheets will be available in the New Year.

Senior medical adviser, Rosemary Batchelor, who is handling the rewrites, said: "The NPH information sheet is old and the update is long overdue.

"Changes in screening procedures meant that the frequently-requested Antenatal information sheet also needed reworking."

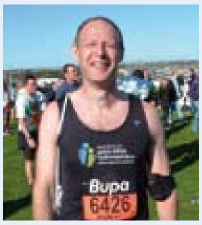
The alphfetoprotein (AFP) test at 16-18 weeks of pregnancy is no longer offered as routine as it was found to give too many false positives.

Rosemary added: "These days the emphasis is on good screening to diagnose abnormalities.

"This ties in with one of ASBAH's research projects, which Professor Paul Griffiths is doing in Sheffield. He is looking at the results of MRI scans versus ultrasound scans in pregnant women whose unborn child has spina bifida.

"MRI is becoming more available antenatally when a potential problem with the baby has been detected"

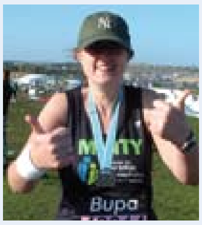

L to R: Karen Robinson, Diane Lestrange, Tracy Rodgers

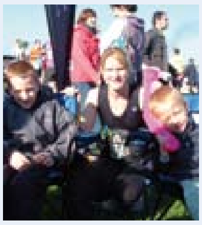

Jon Tibke


L to R: Harry Trenholm & Riina Vaht


Nurses on the run


L to R: Ellie Valentine & Helen Arnold


Claire Minter (Minty)


Rebecca Clayton (centre) and her two sons Joshua & Toby

Record number represent ASBAH in Great North Run

An incredible 42 people represented ASBAH in this year's BUPA Great North Run - the highest number to-date.

The courageous team joined 50,000 other runners on 5 October to take part in the world's biggest half marathon.

This year, triple Olympic gold medallist, Chris Hoy, double Olympic gold medal winner, Rebecca Adlington, and former Prime Minister, Tony Blair, were at hand to get the race under way.

While the rest of the country suffered downpours, the sun shone on the competitors as they completed the 13-mile course from Newcastle to South Shields.

Despite the gruelling task, the day was clearly enjoyed by all who took part. There were smiles all round at the finish line, not to mention brightly coloured wigs, tutus and nurse outfits which were also donned by ASBAH representatives on the day.

Although sponsorship money is still being collected, an amazing £6,600 has already been raised.

We need your old mobile phones!

ASBAH is appealing for people to send in their old and unwanted mobile phones which can be turned into cash.

Greener Solutions, which recycles mobile phones, pay ASBAH for every working phone and even pay 50p for each non-working phone sent in.

There are about 50 million mobile phone users in the UK, and it is estimated that the average person will replace their handset once every 18 months.

Less than 20% of all unused mobile phones in the UK are currently recycled and estimates suggest that close to 90 million phones are hiding in drawers and cupboards across the UK.

These phones and batteries contain toxic substances harmful to the environment when released into the air, earth or water. By sending them in *Link* readers will help to protect the environment as well as raising valuable funds for ASBAH."

To request a freepost envelope for your phone, contact Cerys on 01733 421329 or email her at cerysl@asbah.org

RUN for ASBAH

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

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

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

association for
spina bifida
hydrocephalus
ability beyond disability

Registered charity no. 249338

Tia Goldsmith

Adam & Tia Goldsmith

Charity auction raises a bundle

Guests at a charity auction held at Charlton Football Club took away some awesome prizes raising a super £4,500 for ASBAH in the process.

The auction was held in the Millennium Lounge of the Football Club and was attended by more than a hundred people.

The evening consisted of an auction and two raffles; one for adults and one for children. Lots of tickets were sold, and it's no wonder - the prizes on offer were fantastic.

These included; A holiday to Las Vegas, Early Learning Centre toys, restaurant vouchers, a family Pontins holiday, beauty treatments, wine, family tickets to Legoland, Madame Tussauds and The London Dungeon and cinema tickets, to name just a few.

> **It was so helpful to meet her and we have developed a good relationship which has helped us to come to terms with this diagnosis.**

Teresa Goldsmith from Eltham, London, organised the event. Her daughter, five-month-old Tia, was diagnosed with spina bifida, during pregnancy, and hydrocephalus after she was born.

Teresa wanted to raise money for ASBAH because of the tremendous support and advice the family has received since the diagnosis.

She commented: "I was amazed when ASBAH sent one of the regional advisers to visit us in our home. It was so helpful to meet her and we have developed a good relationship which has helped us to come to terms with this diagnosis. Now we feel confident that we can cope with what the future brings."

The prizes were all donated by local companies after Teresa sent letters out explaining why she wanted to raise money for ASBAH.

She was surprised at the generosity of some of the companies, many of which said they would be happy to support any future events. "I even received a personal call from a company MD who knew someone with spina bifida and really wanted to help," said Teresa.

Teresa received a lot of help from friends and family. Husband Steve took control of the auction and raffles with the help of Teresa's sister Debbie. Debbie also catered for the event with help from friends Carlie, Jamie, Lynn, Maxine and Taylor. Family friend Catherine worked hard and kept the children entertained all evening with face painting.

The children, including Tia's big brother Adam, got stuck in and did their own bit to raise money by drawing portraits of guests on to paper plates and selling them.

Teresa would like to say a very special thank-you to all of her family and friends. Teresa said: "We are truly grateful for their continued love and support. Without their help this event would never have taken place."

Well done to Teresa and the gang for organising such a successful evening.

Spencer runs up cash

An inmate from Dartmoor Prison made the headlines for all the right reasons when he ran a full marathon to raise money for ASBAH.

Spencer Ash, whose four-year-old-son, Henry, has spina bifida, completed a gruelling 26 miles running on a treadmill in the prison's gym to raise £147.

Spencer, who was sponsored by fellow inmates and prison staff, presented a cheque to ASBAH adviser, Lynne Young, at a handover event which was featured in the local newspaper, The Tavistock Times.

Geoff Steps Out for ASBAH

Geoff Thacker from St Mary Bourne in Andover, Hampshire, has raised more than £600 for ASBAH after walking 15 miles from St Mary Bourne to Winchester.

Geoff, who has spina bifida, has had 12 operations on his back, legs and feet.

"I am now able to walk relatively easily and I therefore felt I should do something for those children with the same condition who have not been as fortunate as me," said Geoff.

His friend, Sarah and dog Carla joined him on the trek. At one point during the journey the trio took a wrong turn, adding four miles on to their journey, undeterred they finished the walk at around 8:30pm after nearly 12 hours of walking.

Ten countries in seven days

In September, Ian Hulme and Keri Hulme-Webb, along with their ten-year-old son Rhys and four-year-old daughter Olivia, who has spina bifida and hydrocephalus, drove across ten European countries in seven days to raise funds for ASBAH.

Taking part in the Landy Rally™ they passed through Belgium, Luxembourg, Germany, Switzerland, Liechtenstein, Austria, Italy, the French Alps, Andorra and across a number of remote tracks in the Spanish and French Pyrénées, stopping only to pitch up tents and camp each night.

Keri, who navigated whilst Ian drove, said: "On the first day we started driving at 9.30am and didn't stop until 4 o'clock the next morning! It was incredibly tiring and very hard at times but definitely well worth it.

"We enjoyed it all, but the best part had to be the Stelvio Pass in the Italian Alps, the scenery was breathtaking. We had to wind our way down through 48 hair pin turns and some of the roads had sheer drops of 1500 metres.

"We drove together with eight other teams, chatting across the radios, the camaraderie between us all was fantastic," added Keri.

To top it all off, the family surpassed their fundraising target of £1,000 and have raised over £1,600 for ASBAH.

Festive run brings in cash

Student Ceri Parker is hoping to raise £275 following his valiant efforts in the annual Port Talbot Reindeer Run.

Ceri, who is studying Psychology at Swansea University, is currently collecting donations in memory of his young nephew.

Sion, who was born with spina bifida and hydrocephalus, died four years ago when he was just 18 months old.

Ceri has since raised money for ASBAH as a thank you for the help and support his sister received.

He completed the 10K race in 57 minutes 50 seconds, despite injuring tendons in his foot at the 3K mark.

He said: "I felt that I had to carry on because I was trying to raise money for such a good cause – otherwise I would have quit.

"The support my sister received from ASBAH was very helpful so I wanted to repay that by helping to raise much-needed money so ASBAH can help other families in the same position."

Ceri Parker

Pedal Power

A team of cyclists donned their helmets and pedalled their way around a slippery course to raise £1,900 for ASBAH.

In previous years, ASBAH's Ian Morley has organised the annual Megacycle event, with great success.

Unfortunately this year there were fewer people applying to take part and the event had to be cancelled.

But Peterborough's Jon Kelly had participated in the Megacycle event three times in the past and really enjoyed the experience so when he heard that the Megacycle would not be going ahead he decided to organise his own 'Mini-megacycle', which was held on 7 September.

Jon formed a team with 20 of his colleagues, at Business Management Software, and their friends and families.

Most of them had participated before and were keen to do it again.

As there were fewer cyclists than in previous years, it was decided that the Mini-megacycle would last 12 hours rather than the usual 24, but the course would follow the usual circuit of cycle paths through Peterborough's Ferry Meadows Country Park.

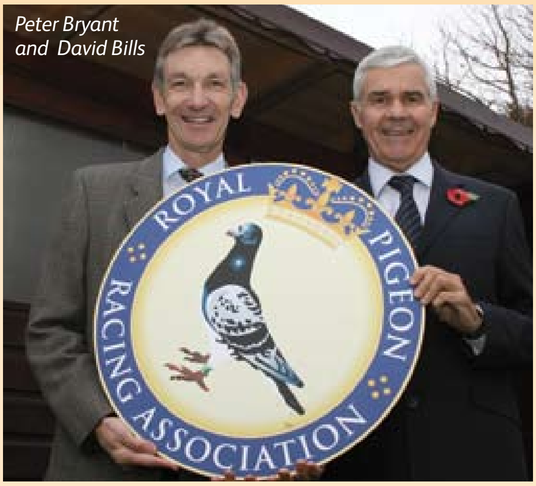
The rain came down throughout the day which made the ground much more challenging for riders, but that didn't dampen spirits and there was a great atmosphere.

Jon said: "I was very disappointed when I heard that there were not enough takers for this year's Megacycle as it is such a fantastic event, which is why I decided to put something together myself.

"I am so pleased that I did. It was a great day and I'm very happy that we have raised over £1,900 for this deserving charity."

STAR supporters

Royal Pigeon Racing Association


Peter Bryant and David Bills

The Royal Pigeon Racing Association (RPRA) has been supporting ASBAH for over a quarter of a century, and to-date has raised nearly half a million pounds!

1973 saw the beginning of an annual RPRA event - the British Homing World Show - now in its 36th year.

These days, the event attracts crowds of more than 20,000, who turn out to view the pigeons on display, visit trade stands and see the trophy presentations for the year's races.

The first event was held at Doncaster Racecourse and the RPRA decided from the outset that profits from the event should go to charity.

A granddaughter of one of the stewards at the Racecourse had spina bifida and he suggested that the money raised should be donated to ASBAH.

In that first year £3,600 was raised for ASBAH, and significant sums have been donated every year since, making them ASBAH's largest single donor.

Peter Bryant was appointed General Manager of the RPRA in 1999 and he has maintained the special relationship with ASBAH.

Peter has visited ASBAH in Peterborough many times and attended ASBAH's 40th Anniversary event, and met service users, including young Gareth Picken (pictured left).

Peter has recently retired from the post of General Manager but will continue to work with both the RPRA and ASBAH, and he will be attending the forthcoming 37th British Homing World Show in January.

Reflecting on his time as General Manager, Peter said: "I am proud to have been associated with ASBAH, a charity that I have upmost respect for. It has been a pleasure to raise so much money for such a worthy cause and we will continue to maintain our relationship even though I am in a different position."

David Bills is taking over from Peter as General Manager at the RPRA. He told *Link* that the RPRA will continue to support ASBAH in future. In fact the RPRA have set a target to raise half a million pounds by 2010.

David commented: "RPRA values its links with ASBAH and their involvement in the annual show. They were one of the original charities to receive support from us and that is a testimony to the strength of feeling the Association has for the charity. Our members really appreciate the recognition from ASBAH as this helps to promote our sport."

Aidan serves up £400 for ASBAH

Seven-year-old Aidan Fincham has raised £400 for ASBAH by hosting a charity lunch in his Church Hall.

Recruiting the help of his mum, who cooked 60 jacket potatoes for the event, Aidan prepared a range of delicious toppings for the lunch, including grated cheese and chilli with meat donated by his local butcher, Mr Macken.

Aidan, who received a special certificate from his Beavers group for all his hard work, told *Link* why he wanted to hold the event: "My dad has hydrocephalus and I wanted to tell people about his shunt.

"I made posters and told my friends and my family that I was having a lunch in our Church Hall to raise money for ASBAH. Lots of people had not heard of it.

"Some of our neighbours could not come but they still gave me money and bought marmalade and raffle tickets."

ASBAH would like to say a huge thank you to Aidan for raising such a fantastic amount of money and helping us to make people, in his local community more aware of spina bifida and hydrocephalus.

£1400 raised in five-day sponsored walk

Four friends from the Weavers Arms in Bulkington, Warwickshire, have raised more than £1,400 for ASBAH after completing a mammoth five-day sponsored walk.

Tom Murphy, 60, Peter Scott, 55, Jeff Squires, 53 and Vaughan Heath, 53, walked the length of Hadrian's Wall to raise the money, covering a distance of 84 miles between Walls End, Newcastle and Bowness on Solway.

The foursome presented their cheque to the landlady of the Weavers Arms, Cynthia Gilbert and councillor Jeff Clarke, chairman of the borough council's licensing committee, who accepted the money on behalf of ASBAH.

Tom said: "I wanted to do the walk for a challenge. It never started off as a charity event but chatting over a beer we decided to raise a few quid for ASBAH."

Linda's line

I recently volunteered to help out with the Surrey ASBAH street collection and it was a real eye opener I can tell you.

I discovered a number of things, including how easy it was to help (sitting down for a few hours holding a tin isn't exactly hard work), how different people react when they see you with a tin (many donations came from the elderly, some having mistakenly thought we were the British Legion), and where the best places were in the High Street (not 25 metres downhill from my friend James, who always collects more than everyone else put together as he has better accessories – more on this later).

There are also some very strange rules about street collections - for example collectors have to be 25 metres or more apart. Why? Is it dangerous to have two disabled people sitting close together?

The other rule (which is equally bonkers) is the one about not rattling the tin. How else are you supposed to grab people's attention? Call me old-fashioned but shouting "Oi granny!" across the High Street doesn't seem very polite.

Due to the rather chilly weather, I decided (on medical grounds of course) that I would have to jiggle my fingers to keep the circulation going and unfortunately the tin moved around a bit, shaking the money in the tin. Hey ho.

It was actually very interesting watching the responses of the general public as they scooted past my collecting tin.

Some people pretended that they hadn't spotted me, whilst still trying to see what the colourful ASBAH display was all about on the table behind; this trick of being invisible was quite a novelty as I am normally very good at attracting attention (even though it is mostly unwanted).

Some came over to talk to me, and one man asked if I could play the violin or accordion!

Other people had the cheek to actually fumble in their bags or pockets pretending to look for coins until they were safely out of the target area.

I smirked to myself at those going up the hill, as they would have to repeat the experience 25 metres further on where James was lurking outside Woolworth's with the ultimate accessory – his wheelchair.

In matters of fundraising it is no holds barred and if you've got it, flaunt it! Those who didn't have wheelchairs had to rely on other tactics, including sporting an ASBAH cap or bringing along an adorable kiddie in a cute hat (well done Jim!). I was beginning to wonder whether bringing along one of the guinea pigs might have attracted more attention but knowing my luck Roger would have widdled on some unsuspecting member of the public.

In all we raised a little under £200 – not bad for a morning's work, and hopefully by the time we do this again we will have the new logo on the tins and we won't get confused with the British Legion.

And for the benefit of the old gentleman in the tweed cap, no I don't play the violin, accordion or any other portable instrument!

New ASBAH book tackles adult issues

ASBAH is adding to its growing list of publications with a new book for adults.

The book, yet to be named, is being co-ordinated by senior medical adviser Rosemary Batchelor and has been written by six other ASBAH advisers.

The 32-page book follows on from the success of the teenage publication, Below the Belt, and will help adults with spina bifida to address many of the issues they face in daily life.

The A4-sized booklet will be packed with useful information and practical advice to help improve their quality of life.

Diane Owen

It will cover a wide range of topics including continence, skin care, hydrocephalus, depression, the menopause, prostate problems, driving, diet and exercise, osteoporosis and ageing.

Rosemary said: "There is a real need for a comprehensive book like this. Below the Belt was very well received around the world and we think that this book will be as, if not more, sought after.

"We want it to be a comprehensive guide but the difficulty we are finding is that we have too much information to fit in.

"The various chapters have been written by different medical and local advisers, who each have their own area of expertise."

The book is being sponsored by Hollister Limited, a healthcare company which provides the Advance range of intermittent catheters.

Diane M. Owen, Global Senior Marketing Manager, Continence Care, told *Link:* "For over 85 years, Hollister Inc. has lived the mission of developing products and services which provide dignity to those using our products.

"Sponsoring education material development, such as the new adult book, is one example of Hollister's dedication in this area. This type of education supports Hollister's focus to make a difference in the journey of life."

The ASBAH advisers involved with the book are: Linda Knight, Angela Lansley, Naomi Marston, Elizabeth Miers, Paula Thompson and Gill Yaz. Your Voice and Jackie from the Helpline have also had input.

Adult issues - part 2

In the last issue of *Link* we turned our attention to adult issues, but as there simply wasn't enough space to cover all the relevant topics, we're covering some of the remainder this time.

You'll find information and advice on holidays, with a checklist giving you ideas to think about before you go plus details of ASBAH's new Shunt Passport (on the Codman partnership pages).

There are personal stories from Chris Quinn and Ian Driscoll, who had two very different holiday experiences.

We also take a look at issues facing disabled parents and how they can ask for extra support – if they need it – from social services.

If there's anything you think we've missed out, or you'd like to tell your story, please get in touch at the usual *Link* address.

Contents

Help available for disabled parents

It isn't easy being a parent, and life can be more difficult if you're a disabled parent.

The charity Disability, Pregnancy & Parenthood international (DPPi) has put together a leaflet giving guidance about how to approach social services for help.

A spokesperson said: "If you need practical support in your parenting role, don't be afraid to ask for help."

It is your right to ask social services to discuss your needs with you and to talk to you about the sort of support they can offer.

Adults with a disability in England and Wales are entitled to an assessment of their needs by social services under the Disabled Persons (Services, Consultation and Representation) Act.

If you would like a needs assessment, call your local social services department and ask to be put through to someone in the relevant team such as physical disabilities or learning difficulties.

If you feel that the children and families team should be involved, you need to talk about this when you first contact social services.

The DPPi also recommends that you prepare well for the assessment. Spend some time thinking about the things you need help with in detail and write these down.

During your assessment, it might be suggested that your children are "in need" and that the children and families team should assess them.

If you do not feel that involving the children and families team is appropriate, be clear about this to the person assessing you. If you are well supported, your children's needs will already be met by you without the need for support services from the children and families team.

After the assessment the assessor should send you a copy of your assessment in a format that you can access, so that you can agree what has been said. The assessor should then discuss with you what support can be provided.

If a package of support is agreed, this should be written up in a care plan and, again, a copy sent to you. Any support agreed can be arranged by social services or they could give you a direct payment. A direct payment is a sum of money that you use to arrange your own support.

Disability, Pregnancy & Parenthood international (DPPi)

A UK based registered charity, controlled by disabled parents, which promotes better awareness and support for disabled people considering, during and after pregnancy and as parents.

The comprehensive Needs Assessment Guide costs £3.50. For more information go to: ***www.dppi.org.uk*** or contact Disability, Pregnancy & Parenthood international

National Centre for Disabled Parents, Unit F9, 89-93 Fonthill Road, London. N4 3JH.Telephone: 0800 018 4730.

Elaine’s a model mum

Elaine Kedwards always planned to have children. “It was never a question of if,” she laughed, “it was more a case of when I had children.”

The mother, from Sutton Coldfield, always knew that her mobility problems would make the role a tougher one, but her positive attitude and willingness to adapt are helping her enjoy every minute of motherhood.

Elaine has spina bifida and Charcot-Marie-Tooth disease (CMT), a neurological disorder which affects the nerves that carry information to and from the spinal cord, causing weakness and loss of sensation in the limbs.

She has always used a wheelchair but until three years ago, was able to walk very short distances.

“Unfortunately the CMT, which is a progressive disease, got worse, “she explained, “but hopefully it has reached he point where it deteriorate any further.”

At the age of 18 she had genetic counselling at Birmingham Women’s Hospital where Elaine was reassured that there was no reason why she shouldn’t have a healthy pregnancy.

And after marrying Nathan in June 2006 she paid a visit to her GP for folic acid supplies to improve her chances of a healthy pregnancy.

“Just two weeks later I was pregnant,” Elaine said. “I felt very well throughout and the only downside was that I had to stop taking my bladder control medicine, which meant I had to nip to the loo every ten minutes.

“It was a very happy time although I did sometimes wish that I had someone in a similar situation to talk to.

“Ben was born by caesarean section because he was facing the wrong way and refused to turn.

“I felt well and recovered quickly although it was a couple of weeks before I could push myself around and I had to be careful when I transferred myself because that uses the stomach muscles.”

She said the past 17 months since Ben’s arrival have been incredibly happy ones.

“I think he was a little slower to walk than he perhaps would have been because I spent a lot of time playing on the floor next to him. In other areas, such as speech, he is much more advanced.

“Everyone has noticed how helpful he is when he is with me. He knows to pass toys to me if they are out of my reach and if I’m trying to get down on to the floor he will move his things out of the way.”

Elaine, who returned to her position as business co-ordinator at the Ministry of Defence on a part-time basis, says she has been lucky in having fantastic support from her mother and husband Nathan.

She said: “Mum comes round every morning to look after Ben while I’m at work, which is a huge help. Then while she’s here she will pop some washing on or do the hoovering.”

Elaine told *Link* that the key to successful motherhood if you’re disabled is being able to adapt and find ways to overcome any hurdles.

“There’s no right or wrong way to be a mum,” she said. “If you are disabled you just need to stay positive, be open minded and ask for help if you need it.”

Help from REMAP

Elaine contacted the REMAP charity to see if a special sling could be designed so she could carry Ben when he was a small baby.

The unique organisation is a network of volunteer engineers and craftsmen who make one off aids for disabled people – free of charge.

Elaine said: “Two people from the charity visited me at home to see exactly what I needed. They designed a fantastic sling which enabled me to carry Ben and push my wheelchair around. It was wonderful.”

REMAP works through a nationwide network of dedicated volunteers who use their skills to design equipment to help people with disabilities to achieve independence. The charity has 85 panels across England, Wales and Northern Ireland helping more than 3000 disabled people each year.

To find your nearest REMAP panel go to ***www.remap.org.uk*** or telephone 0845 130 0456.

KEY POINT

- **Mum with mobility problems finds ways to adapt**
- **Looking at relationships**

Building relationships will enrich your life


John Naudé

Social isolation can be a problem for many disabled people whether they live with their parents or independently.

But getting out and about, making new friends and dating are experiences which should be open to everyone, whatever their disability.

Many people, able-bodied and disabled alike, find it difficult to make friends. Shyness, hang- ups about the way they look, or past rejections, are all contributing factors. Some disabled people may be used to over-protective parents talking for them in social situations.

Sometimes these difficulties have their roots in the condition, for example, some people with hydrocephalus who find relationships difficult.

But, as with most things, talking to people and making friends is habit forming – the more you do it, the easier it will become.

The Rev John Naudé, vicar of the Church of the Good Shepherd, Crookhorn, Hants, was a former ASBAH counsellor and adviser.

John, who has spina bifida and is a wheelchair user, said: "Everyone forms relationships on a variety of levels - from people you know only to say hello to, people you pass the time of day with, family, friends, and then the romantic and physical relationships with partners.

"Thankfully attitudes towards disabled people are changing and there are more positive images of disabled people in the media than ever before.

"TV programmes showing disabled people in relationships are more common, which helps to make the public more open and accepting.

> **Thankfully attitudes towards disabled people are changing and there are more positive images of disabled people in the media than ever before.**

"Friendships flourish if you meet someone with whom you share a common interest – that's a great starting point for a conversation. Think about your interests and join a relevant club," he added.

"Don't sit back and wait for other people to strike up conversation. It isn't easy taking the initiative to begin with but it will get easier with practice.

"If you get knocked back don't give up. No-one likes being rejected but don't let it stop you having another go.

"There are several online dating sites and chat rooms for disabled people which are other ways of getting to know new people. Personal ads in the *Disability Now* magazine appeal to others.

"If you do go down this route, I would advise anyone to be truthful about their disability from the start, and to be careful. Don't give out any personal information and if you arrange to meet anyone, make sure you take a friend along."

Learn to like yourself

During his time with ASBAH, John worked with service users, helping them to develop their self-confidence.

He said: "Having self-confidence and good self esteem generally means that a person finds it easier to make new friends.

"You have to come to terms with who you are and what you are – just the same as any able-bodied person has to.

"Many people get too caught up in what they think society thinks is attractive. If you look around, very few people actually look as if they've stepped off the pages of a magazine.

"It is important to like yourself for who you are. People may initially judge you on what you look like but once they get to know you a little better then they see the person, their honesty, their humour... attributes that are far more important than looks.

"It is these attributes which make you attractive and make people want to be with you.

"I often tell the story of when I saw a tall, blonde and very attractive woman who was with a short, fat and rather unattractive man. She was clearly in love with him because of who he was, not what he looked like.

"Learning to make the best of yourself will boost your confidence. Good personal hygiene, flattering clothes that fit, a hair style that suits you. Take pride in your appearance and you will feel better about yourself and be more confident.

"Take ownership of your body and become familiar with what it looks like. Many disabled people are so used to other people caring for them that they become disassociated with their own bodies.

"Everyone has flaws and they are part of what you are. Learn to like yourself and you will find that others like you too."

Holiday Checklist

Going on holiday? Lucky you. But make sure your trip goes smoothly by taking a few extra precautions.

ASBAH adviser Gill Yaz has come up with a holiday checklist to help you plan ahead.

1 Make sure you inform your travel insurance company of all your health conditions and check that the policy meets your needs (see our feature on travel insurance in *Link 223* p20) If holidaying in Europe, don't rely on your EHIC card - it won't provide enough cover so you'll still need proper insurance – ASBAH's helpline has a list of insurers who provide cover for people with spina bifida or hydrocephalus, and their fellow travellers.

2 Don't forget, some activities (like drinking alcohol) might mean your insurance won't cover you for accidents. And if you do have a drink, drink a glass of water for every drink of alcohol.

3 Ask your neurosurgeon for a CD-Rom of your latest MRI/CT scans in plenty of time before your holiday, (there may be a small charge for this), also take your Shunt Alert card with you.

4 If you are flying, make sure your airline knows all about your particular needs, especially mobility, and arrive at the airport in plenty of time. Think about how you will manage the toilet etc during the flight. Consider using flight stockings and drink plenty of water during the flight. Keep your medicines in your hand luggage so they are close at hand and you are less likely to lose them.

5 Get a note from your GP or pharmacist detailing what non-prescription medicines you take, and take a copy of your prescription for other medicines.

6 Take extra continence supplies, and if possible divide them between two separate pieces of luggage, in case one gets delayed or lost.

7 Use bottled water to lubricate catheters etc. and drink plenty of water. If holidaying in the UK take a Need-To-go card, available from the Helpline, or a Radar key for the loo. A Radar loo directory can be useful too.

8 Sometimes different food and drink might upset your stomach so take some medicine with you just in case. In hot countries, avoid salads, or fruit with the skins on unless you know it's been washed in clean water and don't buy meat-based food from street-side sellers.

9 Wheelchairs can be tricky to use in sand; some places hire caterpillar tracks, or have special beach wheelchairs and wooden ramps over the soft sand. Radar has access information on many holiday resorts.

10 Look at Tourism for All's website for more information **www.tourismforall.org.uk**

Have fun!

A taste of adventure

***Link* reader Ian Driscoll enjoyed his first independent holiday so much that he's already planning another.**

Last year Ian, 38, from Eastbourne, decided to take a break with a friend, rather than going away with family.

The pair chose their destination carefully because Ian, who has spina bifida, needed wheelchair-accessible accommodation. His friend also has a disability although she is able to walk for short distances.

Ian said: "Neither of us drive so we were reliant on my mother to take us in her car, which is why we didn't venture too far."

They booked self-catering accommodation, in Selsey, with John Grooms Holidays, (now called Livability Holidays) who provide a wide range of accessible holiday accommodation for people with disabilities.

"It was quite an adventure for us both," said Ian. "We had a great time getting out and about and I loved the sense of freedom from doing our own thing.

"But what neither of us had considered were the stresses of constantly being with someone. Although we had been friends for more than ten years, the holiday was the first time that we had spent a long spell in each other's company."

But Ian and his friend are now planning a holiday at Butlins in Bognor Regis in May.

He said: "We went to Butlins a couple of times during our stay in Selsey and thoroughly enjoyed ourselves. The entertainment was good and everything you need is on one site if you don't feel like going further afield. Now we're looking forward to spending a few days there."

For more information about Livability Holidays (formerly John Grooms Holidays) go to:
www.livability.org.uk

For more information about Butlins breaks go to:
www.butlinsonline.co.uk

Lynn Kirkman visits the Brandenburg Gate

Lynn's German experience

Link reader Lynn Kirkman, from Warwickshire, took time out from her role as part-time administrator with the Connexions service, to enjoy a holiday in Germany with The Disaway Trust.

The Trust is a registered charity that has been organising group holidays with physically disabled people aged between 16 and 80 since 1981.

The disabled person pays for the cost of the holiday, with a carer paying around half price.

Here Lynn, who has spina bifida and hydrocephalus, writes about her experiences of her eight-night trip.

I went to Rheinsberg in Germany where we stayed at the HausRheinsberg Hotel Am See. The hotel was specially built so disabled people could go independently or with a group.

This year I enjoyed a lovely holiday in Germany with the Disaway Trust. I had been on two previous holidays to Disneyland Paris and Florida with the Trust, so I knew what to expect.

Each disabled person has their own carer for the week – mine was Sue, who was with her husband Rod but you can provide your own carer if you wish.

This time I went to Rheinsberg in Germany where we stayed at the HausRheinsberg Hotel Am See. The hotel was specially built so disabled people could go independently or with a group.

All the bedrooms and public areas were all very accessible and all the doors were automatic. The other lovely aspect of this holiday was its position by a lake.

On our first morning we had a Welcome Meeting when we were introduced to all the members of the group, the committee members and nurse. We then had the rest of the day to explore the hotel and surrounding area.

A few of us met up at the Cafe Tucholsky for lunch. Later on in the day I had some quiet time to watch the Opening Ceremony of the Paralympics.

Tuesday we went on a day trip to Berlin. We were supposed to meet a tour guide in Berlin who was going to show us around Berlin, but the hotel had a phone call to say that the tour guide would not be there as he was ill. Luckily for us we had Brendan, a fluent German speaking carer, and between Brendan and the Coach driver they gave us a tour around Berlin.

We stopped at a railway station for lunch. My carer had to give her passport in to a kiosk in return for a key that opened the disabled toilets as our Radar keys do not open German disabled toilets. We then made two more stops to see the Brandenburg Gate and a Cathedral.

There was plenty to do all week. We enjoyed walks around the lake, skittles, a boat trip, plus days out to the nearby towns of Waren and Neuruppin.

Saturday was our last day and after packing, Sue and I went for a quick look around for souvenirs to take home. Just before we left for the airport I gave a small "Thank you" speech to all the carers and committee members. I finally arrived home at 1.45 am after leaving the hotel at 2pm the previous day.

I really did enjoy this holiday. The Hotel's position beside the lake was beautiful and the rest of the group were very friendly and I had a very nice carer. I'd certainly recommend the Disaway Trust.

For more information log on to:
www.disaway.co.uk

Holiday accommodation – make sure it really is wheelchair-friendly

Stuart Quinn (centre) with his brother and father, Chris.

Link **reader Chris Quinn discovered to his cost that when it comes to booking a holiday, it isn't enough to accept claims that a hotel is wheelchair accessible.**

Chris, from London, booked a week's holiday on the Costa del Sol for his family, which includes son Stuart, 35, who has spina bifida.

The family takes a summer holiday each year so Chris knew the importance of checking that the accommodation is wheelchair-friendly.

He went online and booked the holiday with a well-known tour operator, highlighting that one of the group used a wheelchair.

Chris said: "Prior to travel we had concern that the booking details were wrong and phoned the tour operator several times, repeating every time that we needed suitable accommodation.

"When we arrived at the hotel there was a ramp into the reception area and a lift to the rooms. Unfortunately, most other areas were virtually inaccessible.

"Stuart's wheelchair wouldn't fit through the bathroom door so I had to carry him into the room and dismantle and reassemble the wheelchair for him.

"There were steps leading down to the restaurant so we had to wait until a member of the hotel staff could take us round the back – which was very dark – and in through another entrance."

The swimming pools, which had looked so inviting on the website, were on differing levels – all with steps which couldn't be negotiated by a wheelchair.

"It was hopeless," Chris said. "We finally managed to get hold of a holiday rep who gave us a UK telephone number to call. The tour operator tried to find more suitable accommodation but apparently there was none to be had in that area of Spain.

He added: "The holiday was a disaster. Stuart needed my help to get into a bathroom every time he needed the toilet or to get to the restaurant. He is an independent man, used to his freedom, so he found it very frustrating to keep asking for help.

"When we returned home I fired off a letter of complaint. The tour operator apologised but the attitude was, well you're home now, move on."

Chris eventually began legal proceedings to try and get a refund and after almost a year, the company made an out- of-court settlement.

"During the confusion over the booking confirmation, I had taken the operator's name and made a note of the time of the call. So when the tour operator denied any knowledge of these requests I was able to provide telephone bills that married up with my calls.

"It didn't stop them being obstructive though. We still had to take them to the brink of a court appearance."

He advises anyone booking a holiday for a wheelchair user to speak directly to a holiday company rather than booking online.

"Ask about access and the dimensions of rooms and doorways," he suggested. "Make a note of the name of the person you are dealing with and the date and time you spoke to them. Keep copies of all letters and emails you send or receive too, so if you do need to make a complaint on your return, then you have all the facts at your fingertips.

"We were unlucky to have a bad experience and nowadays I don't accept the term 'wheelchair accessible' at face value."

> **...anyone booking a holiday for a wheelchair user needs to speak directly to a holiday company rather than booking online.**

KEY POINT

- **Chris Quinn offers advice after holiday problems and how to deal with them**
- **Ageing research study: what are the effects?**

Research study: Looking at the effects of ageing with spina bifida and hydrocephalus

The ageing process has a significant impact on the lives of people with spina bifida and hydrocephalus, and more support from healthcare professionals is needed to improve quality of life, according to a recent research study.

Compiled by West Midlands area advisers Geraldine Long and Jenny Green, the study looks in detail at the effects of ageing with spina bifida and hydrocephalus, from both a physical and psychological perspective.

In May 2007 Geraldine and Jenny organised a conference for service users, their carers and professionals. The conference covered a number of topics relating to spina bifida and hydrocephalus, but one of the key issues highlighted was the ageing process. Connect, a group of adult service users in the West Midlands, had a lot to say on this subject and had prepared material about their personal experiences for consideration at the conference.

Reflecting upon the conference, Geraldine and Jenny realised that whilst they had gathered a lot of information throughout their time working as advisers, a combined total of 40 years, they had no quantifiable data or factual information that could be used to justify the strength of feeling surrounding this issue. There was also a strong feeling amongst service users that they were not being asked about their feelings.

The first step was put together a short questionnaire. 180 service users, aged over 35, agreed to fill in this form with complete anonymity, and the response was good, with 42 respondents agreeing to participate in a much more in- depth study. A 13-page questionnaire was then developed, the results of which have been published in a report; *Journey into the Unknown*.

The questionnaire focused on four topics; general health, mobility, hydrocephalus and continence. Participants were asked a series of straightforward questions, which was followed by a further question that asked them to state how this made them feel.

As expected, the results show that many of the participants feel misunderstood by healthcare professionals who don't seem to understand their condition. As a result, many service users say that they have accepted that there is little that can be done to help them to cope with the daily challenges that ageing with the conditions bring, such as suffering with pain and feeling lonely.

Geraldine and Jenny are pushing their study into many different avenues. Geraldine said: "We feel that it is very important for us to share this information with as many people as possible to promote interest in these issues."

Journey into the Unknown has given an insight into the views of adult service users living in the West Midlands. Jenny has high hopes for what the study might lead to in the future: "We hope that the study will act as a trigger to encourage further research into these conditions, and focus attention on what it means to live with their symptoms."

Journey to the Unknown is available on the ASBAH website: **www.asbah.org**

Main conclusions:

- The majority of participants experienced skin problems, such as pressure sores, as a direct result of their condition
- Weight problems, including eating disorders, are extremely common and are attributed to poor mobility
- More than half of participants experienced depression
- Shunts are a real cause for concern, and participants expressed a desire for regular screening
- Mobility is significantly affected with age, and people who had once had upright mobility as a child are now full-time dependant on wheelchair users
- Most of the participants use medication for pain regularly
- Continence issues are a major problem, and for many participants this leads to unhappiness and/or depression

Participant comments...

"My doctor said; 'It's ok to have a headache, it won't do you any harm'."

"It's an uphill struggle, but I have to get on with it."

"Health workers rarely seem to understand my disability."

"Unless you ask for help, it is never offered."

"I worry about going out as I can't trust my continence management."

ASBAH's activities reviewed at AGM

This year's ASBAH AGM was held in the John Foster Hall at Leicester University and was combined with the annual staff training event to give Local Association representatives the chance to meet up with ASBAH staff.

On the agenda was a series of short presentations by ASBAH services staff. These gave an insight into a number of topics including; the day to day work of medical advisers, the scope of calls handled by the ASBAH Helpline, and an update on the transition and employment project.

Andrew Russell, ASBAH's chief executive, presented a report that highlighted the key activities, events and projects of the last year.

Andrew stressed that the front-line support and advisory service would remain a priority for 2009. He also recognised the success of ASBAH's Helpline, now in its third year of operation, which has been vigorously publicised and now deals with many thousands of enquiries each year.

Around 80 per cent of these enquiries are dealt with immediately, with the remainder referred on to appropriate services including ASBAH advisers.

Another topic that Andrew highlighted was ASBAH's continued communication with the government.

ASBAH has developed a relationship with the government and frequently liaises with its departments regarding many policy issues, in areas including; social care, education and health services, as well as on important topics such as the primary prevention of spina bifida through the vitamin folic acid.

The Association is used to standing on its own feet financially but faces particular challenges in the present economic downturn. It is therefore developing new fundraising approaches to address these new obstacles. These include internet shopping and sponsorship by companies through initiatives such as 'charity of the year' deals.

User involvement, through the forum "Your Voice", has continued to develop, with a number of exciting new developments coming to fruition throughout 2008, including; a new website, a newsletter, and two high-profile conferences organised by its members, with more to come in 2009.

Andrew said that this would be his last AGM as chief executive and listed some of the key future challenges for ASBAH, including pressing for improvements in inclusive education for disabled children and working for better transition support for children as they approach adulthood.

He told the gathering: "People with spina bifida and hydrocephalus are living longer, and generally experience a better quality of life these days, but far more progress is needed."

He was confident that the Association would preserve its status as the foremost national voluntary organisation in its field thanks to the dedication of everyone involved in its work, including trustees, local members and professional staff. Andrew thanked the honorary officers and all contributors for their commitment throughout another successful year.

Caroline Bowditch

Caroline Bowditch

In the afternoon session guest speaker Caroline Bowditch talked about society's expectations of disabled people and how she had successfully challenged the expectations others had for her by becoming a dancer and choreographer.

Caroline is a 'Dance Agent for Change'. Through her work in this role Caroline is able to open up opportunities for other people to try dance, with the aim of allowing these people to challenge the limited expectations that they feel society has placed upon them, in much the same way that Caroline has herself.

Caroline's presentation, titled 'Unknown Expectations', was both entertaining and thought provoking. In it she explained how other people's expectations can: "make us, shape us and break us." Caroline explained her own family history, and the challenges that she faced because she is a disabled person. Caroline who was diagnosed with brittle bones when she was 11 months old originates from Australia. No other families in the region of Australia where they lived had a child with the same disability - the nearest known was 400 miles away. Caroline's mother felt very isolated, and had no expert knowledge of Caroline's condition but was determined to make Caroline's life the best it could be.

Aged five, Caroline went to a special school in Melbourne where the expectations of her teachers was patronising, for example, sex was never discussed, as if it was not an option for Caroline. Caroline dreamt of one day perhaps becoming a speech therapist, an ambition that was not shared by the school, who didn't expect her to go to university.

Helped by her mother's attitude of how to facilitate her daughter's wishes rather than play safe and not take any risks, Caroline was able to exceed those childhood expectations. Caroline left home, went to university, fell in love, got married, become a genetic counsellor and, on moving to England, finally got a job in dance, something she had had a passion for since childhood.

Caroline would like to see people being happy in the skin they are in. She believes that dance can help with physical and mental wellbeing by helping to overcome pain and health issues which can sometimes stop disabled people from living fulfilling lives. Caroline's presentation urged disabled people to reconnect with their bodies, expect more of themselves and of others.

If you want to find out more about dance opportunities and enjoy the benefits this could bring visit www.communitydance.org.uk - the website of the Foundation for Community Dance. Here you will also be able to download their newsletter 'Potential'.

Keeping in touch with you

Users of ASBAH's website can now sign up to be kept informed on matters of interest to them.

By registering your details and email address, ASBAH can build up a confidential database and keep members up to date with news and forthcoming events.

Marking and Communication manager Gill Winfield said: "A list like this will give us more opportunities to interact with service users and ensure they're the first to know about new initiatives, future events, latest publications etc..

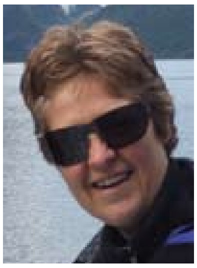
"It will be a useful resource for *Link* too. If we are planning a special feature or supplement we often struggle to find people with the relevant experience to talk to us.

"We know the people are out there but sometimes it isn't easy tracking them down.

"A simple email letting readers know what will be in the next issue and asking if they would like to contribute will save us so much time and will improve the content of *Link*."

New Faces at ASBAH

ASBAH would like to welcome the new faces that have joined the team in recent months.



Geraldine Whittle has been appointed as area adviser for South Yorkshire, East Riding of Yorkshire, North & North East Lincolnshire, Hull and Wakefield. Geraldine comes from a teaching background and has previously worked with children with special needs (language and communication problems) and wheelchair users.

Bryn Roberts is the latest area adviser to join the team in North Wales. He has been appointed on a full-time basis and is working out of the office at Parc Menai, Bangor, Gwynedd. Previously, Bryn was a development officer with Ynys Mon Social Services. He has also worked in the voluntary sector as a welfare rights adviser and for the Job Centre. He is a wheelchair user with both spina bifida and hydrocephalus.

Jackie Pridmore is a new helpline operator. Before joining the helpline team Jackie previously worked at Lloyds TSB, as a call centre operator at Royal & Sun Alliance Insurance and also spent time as a support worker for children with autism.

"I was delighted to be offered the position. I'm really looking forward to continuing the good work of the team, as well as learning new skills along the way. It certainly promises to be a challenging experience," said Jackie.

Catherine McCurry joins the Northern Ireland team as education adviser. Catherine brings a wealth of experience to this position, and she believes that working as an education adviser will provide the opportunity to use all of the various skills she has gained throughout her career.

Catherine began her career as a teacher in a mainstream post-primary school in Belfast and later became a senior teacher in a secondary school. Whilst teaching, Catherine developed an interest in working with children with special needs and social and behavioural issues. This led to her becoming a principal at a special needs school.

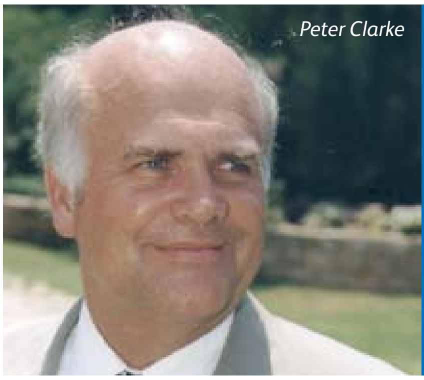
Catherine has also worked at the Educational Library Board and spent three years in a research post. She also has a counselling diploma.

Catherine has been in the post for ASBAH for a few months now. She said: "I enjoy the multi-layered aspect of my work as an education adviser. The work load is varied and draws upon all of my skills."

"I have heard great things about ASBAH from the people I have worked with so far, and I am enthused by the positive outlook of the service users. I am looking forward to continuing this good work."

Another new face has been appointed in Northern Ireland. **Irene Kean** has taken up the position of area adviser. Irene will work three days a work, based at the Belfast office.

ASBAH bids a fond farewell to **Maria Morris**, ASBAH Wales' Regional Secretary. Maria will be starting work with the North Wales Police as a translator in January 2009. Elin Ifan, ASBAH Wales' Regional Manager, would like to congratulate Maria on her new job. Elin said: "Maria has worked diligently for us for six years, and she will be sorely missed by all the team, both for the consistently high standard of her work, and her calm and cheerful attitude to any challenge thrown in her direction!"



Peter Clarke

Living with Normal Pressure Hydrocephalus

Peter Clarke was fitted with a shunt in July this year after being diagnosed with normal pressure hydrocephalus. Peter's quality of life had slowly deteriorated since he had experienced early symptoms such as neck and head pains in 1993, to an extent where he could barely go out of the house.

Here Peter, 59, and his wife Susan, talk to *Link* about their experiences and how NPH has affected their lives.

Peter's story

"I had meningitis at the age of 24, which may be where my problems stemmed from. I suffered head and neck pains on and off but I just took a few tablets and got on with my life.

When I was divorced at the age of 40 I was busy bringing up my two daughters and working in the Police. I didn't really have too much spare time to dwell on how I was feeling.

Looking back it was a nightmare really. I couldn't understand what was happening to me.

The symptoms slowly became worse through the 90s. My balance and memory weren't good and I was in a lot of pain. Eventually I lost a lot of the feeling down the left side of my body and I was pensioned off 18 months before completing 30 years' service.

I had been back and forth to the GP and was eventually referred to a neurosurgeon. Although I had scans and was given different medication, I still became progressively worse.

I would say that I am a strong person so to some extent I learned to cope with the loss of memory, poor balance and double incontinence.

Looking back it was a nightmare really. I couldn't understand what was happening to me and the doctors didn't seem to know either.

My wife Susan, who I married nine years ago, was wonderful, but she doesn't always express her feelings so I did worry that she resented being tied down by an invalid.

My daughters were wonderful too, particularly Andrena who lives close by. Nothing was too much trouble for her.

My condition was finally diagnosed after I came across the ASBAH website. I read the NPH information and called senior medical adviser, Rosemary Batchelor. She referred me to area adviser, Elizabeth Miers, who put me in touch with the Walton Centre in Liverpool.

On July 25 I was shunted and as soon as I came round from the operation I immediately realised that the intense neck pain I'd suffered for so many years had gone.

I feel much better, although I know it will be a slow process and I will probably never regain all the feeling in my left side.

But the relief at knowing about the condition is immense and I feel reassured that I am finally being treated."

Susan's story

"Peter's memory problems were probably one of the biggest issues for us. After taking early retirement through his ill health, Peter became steadily worse.

His memory deteriorated even further and he had continence problems too, all of which, understandably, affected his moods.

Peter's personality changed and he became very moody and agitated. It sometimes felt like I was living with a stranger.

Peter's personality changed and he became very moody and agitated. It sometimes felt like I was living with a stranger. Thankfully, he was able to be left alone so I could continue working part-time.

Living with someone whose memory is poor is a strain and I would lose patience sometimes, and then felt very guilty later on.

When Peter was finally diagnosed with NPH it was just a huge relief to finally find out what was wrong with him and to get specialist support from the hospital and ASBAH adviser Elizabeth Miers.

But as we found out more about the condition that brought up different concerns regarding the treatment and what can go wrong.

Since Peter had the shunt fitted in July we have both noticed a gradual improvement in his memory and continence. He's also much brighter and feels more positive. For the first time in many years we can look forward to the future."

Peter's area adviser Elizabeth Miers was delighted to be able to offer help and support to Peter.


Elizabeth Miers

She told *Link*: "Peter's story shows so clearly the impact that NPH has on not only the person with the condition but their whole family.

"When Peter was seen by a neurosurgeon who understood his condition, he was at last given the treatment he had needed for many years.

"It is wonderful that having a shunt fitted can relieve so many symptoms almost immediately - symptoms that make everyday living so difficult and are so similar to those of dementia.

I rang Peter when he was home from hospital to ask how he was feeling. He said it felt like a miracle - long may that miracle continue."

KEY POINT

- How NPH has affected Peter and Susan
- Making travel abroad less daunting with a Shunt Passport

Shunt passports will take the stress out of overseas travel

ASBAH is producing a new Shunt Passport to make overseas travel less daunting for those with hydrocephalus.

Carrying this passport will help to allay their fears about obtaining emergency medical treatment abroad.

The passport will contain information about hydrocephalus including symptoms of shunt failure, just like the shunt alert cards currently available in English.

There will be space in the Passport for the individual to write important information about themselves, including the type of shunt they have and when it was fitted, the name of their local hospital and neurosurgeon, along with contact details.

This information will be included in six of the most common languages, including Spanish and French.

At the back of the passport will be a sticky pad to hold a CD Rom showing the individual's shunt scan.

Helpline manager, Linda Lewis, said: "We hope that service users thinking about travelling overseas will apply for one of these new Shunt Passports

"Carrying one will help to reassure them, and their families, that if they are involved in an accident or are taken ill, the relevant information will be on hand for the medical professionals."

The shunt passports will be available via the helpline for a small fee. Telephone: 0845 450 7755 for more information.

hydrocephalus action

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

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

Survey success for helpline

spina bifida
hydrocephalus
helpline
0845 450 7755
Local Rate Call

Since June 2006 ASBAH's Helpline and Information Service has become the first point of contact for service users.

The team has handled thousands of enquiries, providing support on all aspects of spina bifida and hydrocephalus to parents, carers, individuals and professionals.

If the Helpline manager Linda and operators Dawn and Jackie can't answer the questions themselves, they will provide access to medical and educational advisers or support at a local level.

To fulfil the requirements of the funding criteria by the Big Lottery Fund, Linda, asked the Telephone Helplines Association (THA) to design and conduct a survey of callers to assess the level of service they were providing.

Linda said: "Until now we have only conducted surveys internally, so we organised an external survey to ensure we are completely transparent in what we do."

Key results

- *98 per cent said it was easy to contact the Helpline*
- *72 per cent rated the expertise and knowledge of the person they spoke to as very high, with 20 per cent rating them as high*
- *68 per cent were calling on behalf of someone else*
- *63 per cent obtained the Helpline number from a health professional at the hospital or as part of an information pack given to them at the hospital.*
- *82 per cent of callers were female.*
- *The whole sample group would recommend the helpline to someone else who needed the service.*

The survey, conducted between March and June this year, confirmed that the Helpline is achieving all its original aims and ASBAH is delighted with the overwhelmingly positive response from those questioned.

> **The survey, conducted between March and June this year, confirmed that the Helpline is achieving all its original aims...**

Linda said: "We have heard unofficially that the results of our survey were the best the THA has ever had.

"We are delighted and very proud to know that we are doing such a good job and are making a positive difference to people's lives.

"Now it is vital we keep the momentum going and find ways to reach out to more people and continue to develop our service as far as we can. Our team has attended a wide variety of training covering topics such as depression, benefits and bereavement, and we will continue to look for new topics where development opportunities are available".

She added that the survey was also useful in highlighting details about the people who use the Helpline.

Linda added: "It was interesting to learn that 90 per cent of callers described themselves as White - British, Irish or Other.

"We learned that this figure is representative of the general population based on the 2001 Census when 92.1 % were described as white. From the sample group a slightly higher proportion of callers described themselves as of Asian origin but no-one described themselves as Black – Caribbean, African or Other.

"We aim to reach all ethnic communities and hope this article will encourage anyone out there needing information or support related to the conditions to contact us.

A spokesman for the THA said: "The caller survey confirms the Helpline is delivering the appropriate service for its client group and the sample group stated tremendous praise for the work of the helpline workers.

"There were a vast array of positive comments on the skills and professional telephone manner of the helpline workers.

"The Helpline is delivering the appropriate combination of services and has the flexibility to respond to each individual caller's need."

What the surveyed callers said...

"I am reassured knowing that somebody's there. It's good to be able to speak to an Association that understands the condition."

"If it hadn't been for the Helpline I wouldn't be seeking a second medical opinion right now and I wouldn't have someone accompanying me to a Benefits tribunal. I feel I now have some chance of getting what my son deserves."

"Reassurance, knowledge and information has given me comfort and I know we can deal with the condition."

"I'll approach things differently because I have more knowledge - it will help my son because I will be able to put more forward to represent him."

Have Wheels, Will Travel

Delegates were full of praise for the latest Your Voice event - Have Wheels Will Travel - which had a packed programme focussing on mobility and travel.

The group, which spent the weekend at Leicester's Marriott Hotel, listened to a range of presentations aimed at whetting their appetite for getting out and about.

The two-day event organised by Your Voice committee members Carole Armour and Mary King, included talks on Dogs for the Disabled, the rights of the disabled traveller, cycling and motability.

Maggie Pickard, from the Extend organisation, spoke about the benefits of exercise and encouraged the audience to try out a few simple stretches during her presentation.

Inspiration to travel also came from Geoffrey Wright who gave a talk on his fundraising John O'Groats to Land's End trip by mobility scooter.

Paul Manning, YV committee member and current chair of the committee gave a presentation on planning train and coach travel with tips for a smoother journey.

Organiser Carole said: "The weekend went very well and we were pleased to get some very positive feedback.

"We were expecting 20 delegates and nine carers but unfortunately three people pulled out through illness. We were very pleased to see several new faces and more people with carers attended than on previous weekends."

She added: "This was the first time we have held an event at this venue and everyone found the hotel to be very comfortable and accessible and the staff helpful."

The next YV event will be held in South Wales and based on the themes of lifestyle and leisure. Full details will be posted on the Your Voice website www.yourvoicegroup.org and you can find out more below.

What they thought...

"We gained a greater understanding of working dogs for the disabled".

"The speaker made it a very friendly atmosphere and gave some very simple and cheaper alternatives to gyms".

"Moving story about scooter ride".

"It was interesting to hear about his own experiences and the love of his hobby".

"Very knowledgeable speaker who knew his subject".

"The workshops were not long enough."

Your Voice presents

Open to all adults (aged 18 and over)

Celebrating Diversity

Date and venue:

Saturday 18 April 2009

Forum
Greenwich

Book NOW

£35 includes:
workshops,
buffet lunch & refreshments.

The delegate rate is being subsidised by Your Voice

Proposed content:

- Medical Issues - around spina bifida & hydrocephalus
- Helpline - how and when to use it
- Advisers - who they are what they do
- Know your rights - DDA
- Have your say - Discussion session
- Your Voice - who we are and what we do

Plus entertainment

For further information and to register your interest contact:

Mark Harris
ASBAH House
42 Park Road
Peterborough PE1 2UQ
Email: markh@asbah.org
Telephone: 01733 421322

association for spina bifida hydrocephalus
ability beyond disability

Registered charity no.249338

Your Voice event: 'Have a lifestyle of leisure' see inside front cover for more details

Coloplast - Working in partnership with ASBAH

For a complimentary sample or for further information, please call our customer care team at Charter Healthcare on Freephone 0800 132787.

A new family of catheters

Over the years, Coloplast has worked extremely closely with healthcare professionals and catheter users to develop a truly unique and user-focused range of intermittent catheters.

Coloplast's innovative SpeediCath range aims to be simple, discreet and convenient. With features that provide you with complete peace of mind.

SpeediCath

The SpeediCath packaging contains a small amount of saline solution, keeping the whole catheter constantly lubricated.

There is no more fiddling about in public toilets, preparing the catheter with water and waiting for it to be ready before inserting it. All you need to do is take the catheter out of the packet and use it instantly, confident it is fully lubricated and safe to use.

SpeediCath is also clinically proven to create less friction than other catheters on the market, such as the Lofric® and InCare® Advance Plus products, when withdrawing the catheter from the body after use. This means less trauma to your urethra and less likelihood of long-term complications for you.

SpeediCath Compact

Launched in 2004, SpeediCath Compact was designed specifically for women. It is the height of discretion - no bigger than a lipstick, it fits neatly into a handbag or pocket.

Again, the all-in-one packaging contains saline solution to keep the catheter lubricated and ready-for-use at anytime. Built into the design is a large grip handle to allow hygienic use and to minimise any risk of touching the catheter and picking up a urine infection.

SpeediCath Complete

Coloplast's latest addition is SpeediCath Complete - an all-in-one solution, combining a SpeediCath Catheter and 1 litre urine bag, designed to give you the freedom to catheterise anytime, anywhere.

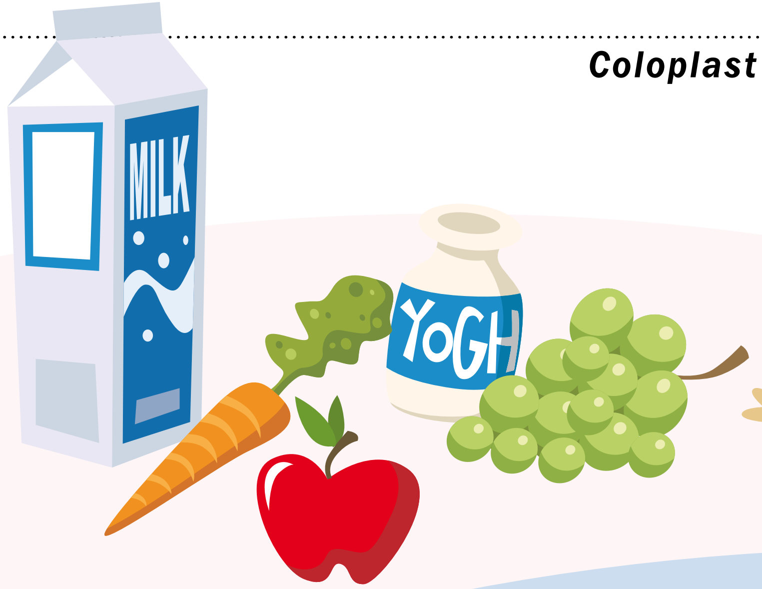
Like all SpeediCath products, SpeediCath Complete needs no pre-soaking, which allows you to use the product anywhere. A neat insertion guide allows you to use the catheter without touching it, again minimising the risk of urine infections. When it is appropriate the bag can be emptied using a tear strip, which ensures a clean non-drip procedure.

SpeediCath has the solution for all your Intermittent catheter needs!

For a complimentary sample or for further information, please call our customer care team at Charter Healthcare on Freephone 0800 132787.

KEY POINT

- A new range of catheters
- New activity book helps children learn how to manage their continence



New activity book for young service users

A new activity book, the Big B & B Book (Bowel & Bladder), which is aimed at 5 – 8 year-olds, will be launched in the spring.

The eight-page publication, sponsored by Coloplast, will have a section where children can fill in their own continence routine, word searches and a multi-choice quiz section, all aimed at helping them understand the importance of their continence management.

Easy-to-understand advice on diet is included and at the back of the book will be four daily routine charts for the children to complete.

Marketing and Communications manager Gill Winfield said: "This new book will provide simple information about continence issues in a fun, appealing format, with lots of activities young children will enjoy doing.

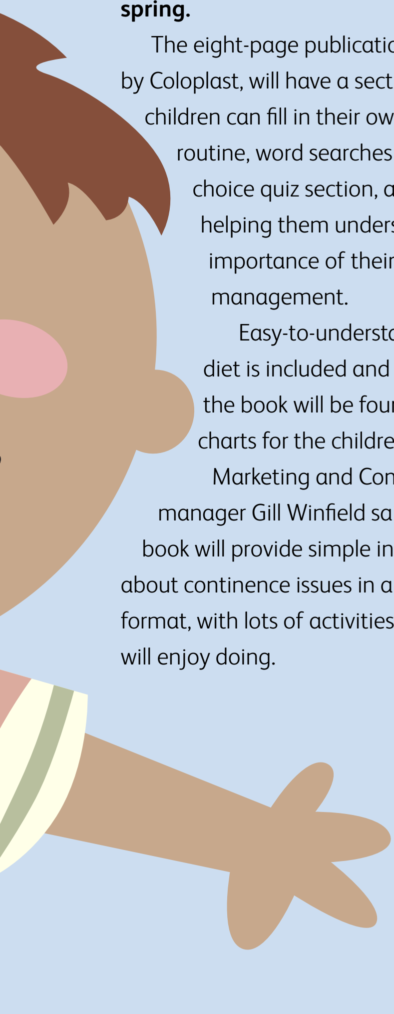
"By learning more about continence young children will take ownership of their own routine."

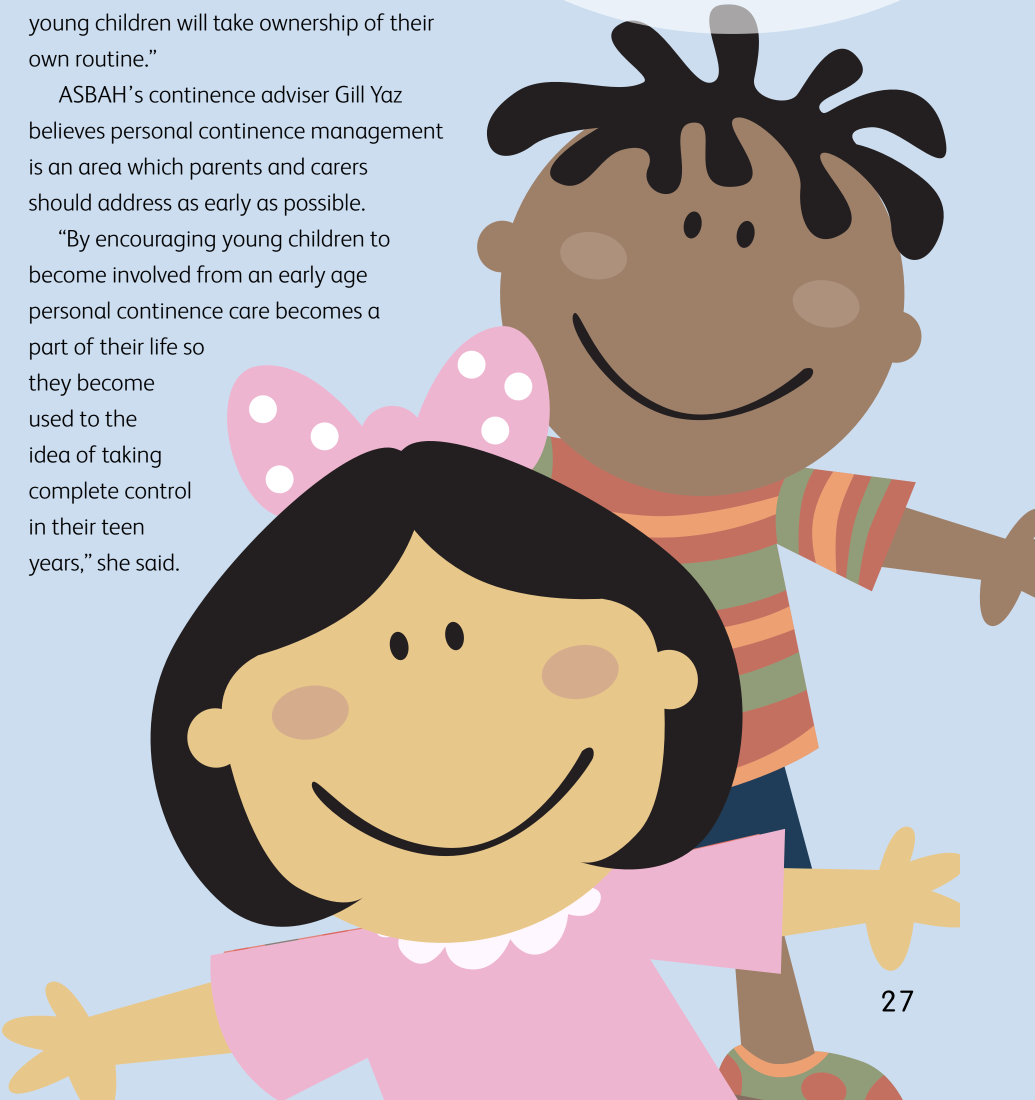
ASBAH's continence adviser Gill Yaz believes personal continence management is an area which parents and carers should address as early as possible.

"By encouraging young children to become involved from an early age personal continence care becomes a part of their life so they become used to the idea of taking complete control in their teen years," she said.

Coloplast is proud to work with ASBAH and sponsor this unique booklet, giving children the opportunity to interact and have fun, while they learn about their bowel and bladder continence.

Sue Frost, Coloplast Medical Product Manager - Bowel Management Urology and Continence Care Division





Diary dates

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

Dunstable Support Group

For people with spina bifida and/or hydrocephalus and their carers. Meets: 1–3pm, usually on the second Monday of each month.

Where: Disability Resource Centre, Poynters Road. Dunstable.

When: Dates for 2009:

12 January
9 February
9 March
30 March
11 May

Please come whenever you can. While there is no crèche, young children are always welcome.

Contact: Valerie Bottoms on 01582 757745

Eastern Region Local Association Forum Meeting

Speaker, Gill Winfield, Marketing and Communications Manager.

When: Saturday 4 April 2009, 11.00 am start.

Where: ASBAH House, Peterborough, PE1 2UQ.

Lunch and parking provided. All welcome.

For further details contact the Eastern Region Office on 01733 421309, or *email ero@asbah.org*

Suffolk / Norfolk Spina Bifida / Hydrocephalus Support Group

This group for adults with spina bifida and/or hydrocephalus and their carers meets every two months. Parents of teenagers with spina bifida and/or hydrocephalus are also very welcome. There is ample parking and disabled access at the hall. Do come and join us for tea/ coffee and a chat. Area adviser Val Meyer-Hall attends meetings whenever possible

Where: Roydon Village Hall, High Road,
Roydon, Nr Diss, Norfolk.

For further details please contact Margaret & Alan Twyford on 01728 860916 or by email ***twyfords@aandmtwyford.plus.com***

Northern Region York Drop-in 2008

Where: Low Moor Community Centre, Bray Road, Fulford. York. YO10 4JG.

When: Second Wednesday each month –
14 January, 11 February, 11 March, 8 April

Time: 10.15am – 12 noon.

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

North and West Yorkshire Drop-In sessions 2009

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

Where: ASBAH House North, 64 Bagley Lane,
Farsley, Leeds. LS28 5LY.

When: First Tuesday of every month;
6 January, 3 February, 3 March, 7 April.

Time: 10am – 12 noon

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

Your Voice presents:

Have a lifestyle of leisure

Location: Holiday Inn, Cardiff Bay
Date: Saturday 14 March 2009

Celebrating diversity

Location: Forum, Greenwich
Date: Saturday 18 April 2009

Contact Mark Harris on 01733 421322 or email ***markh@asbah.org*** for information on all Your Voice events.

Please e-mail the editor (Link@asbah.org) with dates of your events for the next issue of Link by Friday 20 February 2009, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.

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.

Holiday lets

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

ISLE OF WIGHT ASBAH - HOLIDAY BUNGALOW

Wheelchair-accessible bungalow, sleeps six. Open-plan lounge/kitchen, wetroom. Site facilities. Local heated accessible pool. Beautiful area. Transport advisable.

Details and rates: Sylvia Griffiths,
3 Western Road, Shanklin, Isle of Wight PO37 7NF
Tel: 01983 863658, *www.iwasbah.co.uk*

ROPERS WALK BARNS, MOUNT HAWKE, TRURO, CORNWALL

Single storey accessible barn converted to a high standard. Visit Britain Mobility Level 3A & 4* Quality ratings. Sleeps 4/6 + cot. Short level walk to village, close north coast, 8 miles Truro.

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

PRESTATYN, NORTH WALES

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

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 20th February 09

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

ASBAH offices

ASBAH
42 Park Road
Peterborough PE1 2UQ
Tel: 01733 555988
Fax: 01733 555985
Email: *info@asbah.org*

ASBAH EAST
42 Park Road
Peterborough PE1 2UQ
Tel: 01733 421309
Fax: 01733 555985
Email: *ero@asbah.org*

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

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

ASBAH IN WALES
4 Llys y Fedwen,
Parc Menai, Bangor,
Gwynedd LL57 4BL
Tel: 01248 671 345
Fax: 01248 679 141
Email: *wro@asbah.org*

ASBAH N. IRELAND
PO Box 132
Cushendall
Belfast BT44 0WA
Tel: 0845 450 7755
Email: *niro@asbah.org*

ASBAH's area advisers provide advice and support to families and individuals, working with them to answer queries and resolve practical issues on an ongoing basis.

Emma McKeever & Belinda Williams

We're here for you

Emma McKeever

If you've ever picked up the phone and dialled the ASBAH Helpline to ask for help or advice then you may well have been put in touch with one of ASBAH's area advisers who pick up referrals from the helpline.

Two of these advisers are Emma McKeever and Belinda Williams, who work proactively to help and advise ASBAH's service users.

Emma McKeever has worked for ASBAH for four years, in the South East Region, and her patch encompasses Buckinghamshire, Berkshire and South Oxfordshire.

"The main part of our role is supporting families and individuals. It's a very varied role advising families and individuals on issues related to spina bifida and hydrocephalus," said Emma, who was previously a paediatric nurse before joining ASBAH and now works from home three days a week. "I have young children so working from home is great.

"My day starts with checking my emails and picking up referrals which I receive from the central helpline. I then follow these up and speak to the people directly. This will mean arranging visits to see them in person.

"I also make a lot of visits to schools to assess issues and to help teachers to understand the conditions," she explained

> **Spending face-to-face time with service users to provide reassurance and practical solutions to their issues is at the core of the area adviser's role**

Emma finds the work varied and relishes the challenge of dealing with a wide variety of issues. "These include education, employment and benefits issues. We also work with service users on obtaining funds and grants," she said.

"While there's no such thing as a typical day for us the work equates roughly to a 50/50 split between making visits to service users and carrying out paperwork and administration," explained Belinda Williams who works as an adviser covering Hampshire, Dorset, Wiltshire and the Isle of Wight.

Belinda works for ASBAH two days a week, combining the role with looking after her three children and working part-time as an occupational therapist.

She told *Link*: "Many of my skills as an occupational therapist come in really useful for my work with ASBAH especially when working with service users with hydrocephalus."

Spending face-to-face time with service users to provide reassurance and practical solutions to their issues is at the core of the area adviser's role, according to Belinda.

"The work I do is especially varied. One day you can be in a school carrying out a training session for teachers. The next day you will be visiting a service user in their home helping them with a housing issue," she said.

This diversity of the caseload is also what Emma enjoys about her job, as she explained: "There's no such thing as a

KEY POINT

- **Meet two ASBAH area advisers**
- **Directory of local associations and contact details**

typical day. We deal with a wide range of issues and cases. In the morning you can be speaking to an older person with normal pressure hydrocephalus and in the afternoon speaking to a mother whose baby has been newly diagnosed."

One other role of an area adviser is to foster and maintain links with other organisations.

Belinda said: "I have recently become involved with a new group. This is the Hampshire Neurological Alliance, which aims to work to improve services through links with Social Services and healthcare providers like Primary Care Trusts."

For Emma the best part of the job is the interface with service users and encouraging efforts to support them.

"I particularly enjoy working with children and setting things up. Recently we have had fantastic results from a survey we carried out about setting up a support group which we hope to carry forward."

Contacting ASBAH

NATIONAL OFFICE:
ASBAH, ASBAH House,
42 Park Road, Peterborough,
Cambridgeshire PE1 2UQ
Helpline: 0845 450 7755
Fax: 01733 555985
Email: helpline@asbah.org

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

Northern ASBAH Affiliated Local Associations:

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

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

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

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

SUNDERLAND
Mr J Pounder
42 Gowanburn
Fatfield, Washington
Tyne & Wear NE38 8SG
Tel: 0191-415 1725

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

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

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

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

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

ASBAH Eastern Affiliated Local Associations:

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

HERTS AND SOUTH BEDS ✓
Mrs Jennifer Hammond
28 Gladeside
St Albans, Herts AL4 9JA
hamrock@supanet.com

LEICESTERSHIRE ✓
Lenore Hardy
62 Malham Way
Oadby,
Leicester LE2 4PT
Tel: 0777-2220563

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

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

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

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

ASBAH Southern Affiliated Local Associations:

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

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

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

SOUTH THAMES
Mrs M Harrison
24 Hawthorn Rd
Dartford
Kent DA1 2SB

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

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

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

ASBAH South West Affiliated Local Associations

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

ASBAH West Midlands Affiliated Local Associations

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

DUDLEY & WOLVERHAMPTON
Mrs Lorna J Wootton
14 Leveson Road
Wednesfield,
Wolverhampton
West Midlands
WV11 2HF
Tel: 01902-738724

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

ASBAH WALES OFFICE:
4 Llys y Fedwen,
Parc Menai, Bangor,
Gwynedd LL57 4BL
Tel: 01248 671 345
Fax: 01248 679 141
Email: wro@asbah.org

ASBAH Wales, Affiliated Local Associations:

LLANELLI
Mrs Anthea James
61 Westland Close
Loughor
Swansea SA4 2JT
Tel: 01792-428004

MID WALES ✓
Mrs Pat Edwards M.B.E
Llawrcoed Uchaf
Llanbrynmair
Powys
SY16 7AF
Tel: 01650 521325

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

ASBAH NORTHERN IRELAND OFFICE:
Graham House
Knockbracken Healthcare
Park, Saintfield Road,
Belfast BT8 8BH
Tel: 028 90798878
Fax: 028 90797071
Email: niro@asbah.org

ASBAH Northern Ireland Affiliated Local Association

NORTHERN IRELAND
Veronica Crawford
667 Antrim Road,
Belfast
BT15 4EG
Tel: 028-9077 0420

OTHER ASSOCIATIONS

SCOTTISH SBA
Chief Executive:
Mr Andrew Wynd
The Dan Young Building
6 Craighalbert Way
Cumbernauld
Tel: 01236 794500

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

CHANNEL ISLANDS
Mrs Joy Thomson
Belles Roches Cottage
Vallee des Vaux
St Helier
Jersey CI
JE2 3GB
Tel: 01534 -732295

✓ ***Upholds the quality standards of the ASBAH Local Association Compact***

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