WINTER 2006 ISSUE 218

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LiNK

The magazine for people with hydrocephalus and spina bifida

Festive fun for Sarah and Zac

40 ASBAH
1966-2006 Challenging the future
Association for Spina Bifida and Hydrocephalus

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Peter Farrall writes

Well here we are in the frantic run up to Christmas again. ASBAH's 40th anniversary year has been a hectic one, that's for sure, but it has flown by incredibly quickly.

In this, the last issue of 2006, we take a look back at some of the highlights of our 40th anniversary, and include the last in our popular series, 40 This Year.

Thank you to everyone who has sent in articles, letters and messages of support. There has also been a terrific response to our request asking for people to send in their stories. Unfortunately we haven't space to include everything, but we do keep your information on file and may approach you in the future if we need case studies.

ASBAH receives many queries from people with shunts who are anxious about dental treatment because they are unsure about the need to have antibiotics before having dental treatment. You'll find all the answers to your questions on page 25.

Also on the medical side we talk to a service user about his experience of depression and look at what you can do if you are affected by depression too.

On a more cheerful note you can read about the two successful Your Voice events on pages 16 and 17. If you'd like to join the YV committee you'll find details about the forthcoming YV elections there too.

With best wishes for a happy Christmas and a prosperous New Year.

Best wishes,
Peter

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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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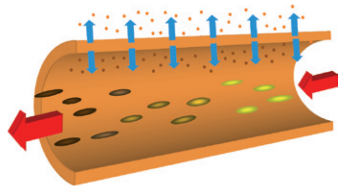


Antibiotics and dental treatment
(see p 25)

Life begins at 40

Andrew Russell

Today we know far better the needs and challenges for people with spina bifida and/or hydrocephalus, than we did 40 years ago, mainly because the voice of disabled adults has been added to those of parents, who founded ASBAH. Most subjects are out in the open!

But it's one thing to be aware, and quite another to achieve change. Believe all the "spin" and we can all pack up and go home; but the reality at home for many disabled people is still beset by frustrations, poor services, limitations, and worse. We need to see an open, accessible, inclusive society with far more opportunities for disabled citizens. Not just on paper.

The triumph is that, distilled from these experiences, ASBAH today has a 40-year fund of expertise based on the wisdom of our members and service-users.

Our mission must be to use that better to bring real changes in policy, priority and attitude. Our only assets are people, and their support, willingly given, and that is as striking today as it was when ASBAH was set up.

So the aims are there, the people are there, and as the saying goes - Life begins at 40!

Andrew Russell

Andrew Russell
Chief Executive

Spina Bifida Hydrocephalus
HELPLINE
0845 450 7755

40 not out

Well what a year! A time for celebration and reflection after 40 amazing years.

The anniversary year was the perfect chance to look back at the organisation's early days and how, from its humble beginnings, ASBAH developed into the pro-active professional organisation it is today.

For many the anniversary celebrations were a time to remember loved ones no longer alive, while others celebrated the medical advancements which have improved the quality of their lives.

The year proved a real focus to reflect on past achievements and drew support from people from all walks of life.

We were also able to launch our much-needed Helpline and Information Service thanks to a large grant from The Big Lottery.

Now, as 2006 draws to an end, ASBAH, thanks to the efforts of thousands of its supporters, can look forward to continuing its valuable work to improve the lives of thousands of individuals and families affected by spina bifida and hydrocephalus.

Link celebrates with our final two 40 year olds in our anniversary year...

Michael Savings

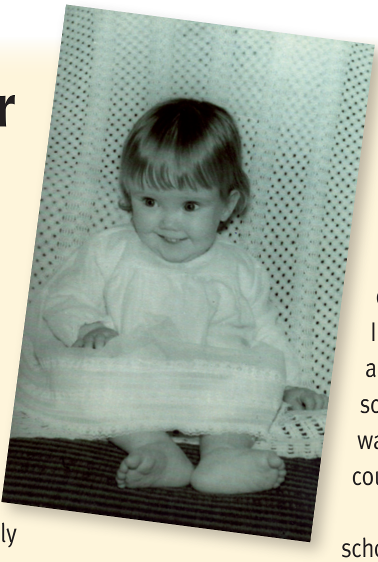
Michael Savings from Swanley in Kent, celebrated his 40th birthday on 1 July.

'Life begins at 40' they say, but for me, 'life begins' is a phrase which I have used many times in my life as I have entered new phases and overcome different health related challenges.

Obviously the first time 'life began', was 40 years ago, when I born in Swanley, Kent,

Andrea Parker

Andrea Parker was born with spina bifida and hydrocephalus on 21 July 1966 to young parents who had barely heard of the conditions.



With ASBAH in its infancy, there was little support available for families affected by spina bifida, and as Andrea revealed, “they simply had to get on with it.”

Andrea, from Rugeley in Staffordshire explained: “It must have been very difficult for them when I was born. Mum and Dad were 20 and 23 years old at the time, and didn’t have a clue that I had spina bifida until I was born.

“But they brought me up to think of myself as able-bodied because, after all, I’m like anyone else, I just happen to use a wheelchair.”

Andrea attended mainstream school until the age of 13, when “some bright spark decided that I would be better off at a school for the disabled.

“Until then I’d been very happy at school and fitted in quite well with the other children. I wasn’t happy about moving schools but there was little we could do.”

Following school Andrea attended several colleges, studying on a variety of courses from dress making to secretarial. Today she works four days a week at the Nuffield Unit, an employment preparation centre in Lichfield, doing “everything and anything.”

> **I’m like anyone else, I just happen to use a wheelchair**

But despite the many initiatives fighting for equality for disabled people, Andrea believes that since she was a child, people’s attitudes have barely changed.

She told *Link*: “I think disabled people are still shunned, and many able-bodied people still don’t know how to treat us.

“Even today if I’m with my mum, people will say, “does she want a cup of tea?” or pat me on the head. Just because my legs don’t work as they should my brain isn’t affected! But I don’t let their ignorance affect me.”

Andrea moved out of the family home 11 years ago, after deciding that the time was right to make her own way.

She recalled: “When I told my parents of my decision my Mum started to cry, but I explained that it was natural progression and I had to learn to become more independent.

“I only live a quarter of a mile away so I see my parents at weekends and I phone everyday. Mum and I are so close. We get on so well, she really is my best friend.”

with hydrocephalus and spina bifida. The challenges came thick and fast right away, and, after having my spine closed a couple of days after birth, I had a shunt fitted at 10 days old. In those days attitudes towards children with spina bifida and hydrocephalus could be quite negative and my mother recalls being told ‘not to expect too much’ either for me or from me. I am happy to say that I have proved everyone wrong on both counts and, 23 operations later, I have been told that I must be something of a medical miracle as I have managed to get through so many periods of ill health.

As a child I struggled with my mobility and found sticks and callipers difficult to get on with. I went to school and enjoyed maths and swimming and got on with life, but perhaps strangely, I felt ‘life began’ when at 18, following major heart surgery, I decided to use a wheelchair permanently. Suddenly a whole new world opened up – I could get around and I took up wheelchair dancing (yes, you did read that right!), wheelchair archery and even passed my wheelchair proficiency test. Life was great and I whizzed around everywhere – even taking a cruise around the Mediterranean on the QE2.

I’d call myself happy go lucky, an optimist, and reckon I’ve a good sense of humour too. I think a lot of it can be put down to the unwavering love and support I have had from my mother Joan and my father Peter – we never allowed problems to get us down and took pleasure from simple things like a visit to dad’s allotment or a trip to the swimming baths. Mum and I are facing a new challenge at the moment as we learn to live without my father, who passed away last month – it’s very hard and we miss him terribly, but we’re a good team, always pulling together in the same direction and dad wouldn’t have wanted us to fall apart. We’re survivors, full of hope for the future and my glass... is always half full.”

Sign up to something big

ASBAH is backing the Every Disabled Child Matters (EDCM) campaign and it hopes *Link* readers will do the same.

EDCM is a three-year campaign to put disabled children and their families high on the political agenda, so that no party can ignore the needs of disabled children.

The three main political parties have already given verbal support to the campaign but to turn words into action it needs the support of those most affected - disabled children and their families and carers.

The campaign is being run by four organisations, including the Council for Disabled Children and the Special Educational Needs Consortium - ASBAH is a member of both.

ASBAH is asking the Government to take action on many matters that are relevant and important for children with spina bifida and hydrocephalus.

disabled
Every Child Matters

For example, EDCM wants a minimum entitlement to family support and short break services; all schools to ensure full access to every aspect of the life of the school for disabled pupils; all education and childcare professionals to receive training to ensure they have the skills to meet the needs of disabled children.

ASBAH has been pushing for progress on many of these issues, but as part of this much wider campaign families have an important part to play.

Your support matters and you can easily get involved by just signing up to the campaign – they want 10,000 individuals to do so by December, including parents, carers, professionals, disabled children and young people.

To find out more: visit the EDCM website at: ***www.edcm.org.uk*** or telephone: 020 7843 6448.

March of the penguins

The Cooper family usually selected holiday destinations where they could have relatively easy access to a neurosurgical unit, in case their son Tas, who has hydrocephalus, needed treatment.

But after 16 years without needing a shunt revision since it was first inserted when Tas was three months old, his consultant gave the family the green light to explore further afield... so they took him at his word.

Parents Brian and Rosemary booked a once-in-a-lifetime trip to Antarctica, to give Tas, 16, and their other children, Kyle, 14 and Beth, 12, first-hand experience of the coldest, driest, windiest, highest, most isolated continent in the world.

The family sailed from Ushaia in Tierra del Fuego in Chile to the Antarctic peninsular, spending five days in Antarctica.

Brian said: “Drake Passage, 1000km of open Southern Ocean south from Cape Horn, is unavoidable when visiting the Peninsula and it lived up to its stormy reputation.

“But after the two-day crossing we arrived, going ashore once or twice every day at different locations, chosen for their wildlife, historical interest and sheer beauty.

“We learned to recognise the four different species of penguin which colonise the area, the other seabirds, seals and whales.

“At one spot on the shoreline the thermal activity was just sufficient to warm the water for the hardier ones to bathe. Imagine swimming in the Antarctic with icebergs floating around. Tas was in there with the other two children.

“So despite hydrocephalus we have been able to enjoy one of the world’s last great wildernesses. Where there are no cars, no hotels, no Coke and where the impact of humans is insignificant. It was wonderful.”

Maternity Alliance folds

The Maternity Alliance charity closed in December 2005 but there are alternative sources for families needing help and advice.

For advice and information on employment related issues - contact Working Families on:

- Helpline phone number 0800 013 0313
- ***www.workingfamilies.org.uk***

Maternity Alliance Publications can be purchased from the National Childbirth Trust charity:-

- at ***www.nctresources.co.uk***, or
- by calling 0870 112 1120 (office hours), or
- by e mailing your request to ***shop@nctsales.co.uk***

An ASBAH Helpline spokesman said: “We have previously referred people to the Maternity Alliance as no one else had their breadth of knowledge.

“They also did really good free study days including some for disabled parents and were active campaigners and lobbyists for the rights of pregnant women and new mothers. It is sad that funding problems meant the organization had to fold.”

Carers, don't be unsung heroes... know your rights

This year's Carers' Rights Day on Friday 8 December aims to raise awareness of the needs and rights of the estimated six million carers in Britain.

The day, now in its seventh year, is organised by Carers UK, the voice of anyone providing unpaid care to an ill, frail or disabled family member or friend.

A spokesperson for the charity said: "Carers give so much to society yet they experience ill-health, poverty and discrimination because they provide care.

"Carers UK campaigns to end this injustice and we will not stop until people recognise the true value of carers' contribution to society and get the practical, financial and emotional support they need."

Carers' Rights Day aims to increase the take-up of benefits available to carers and their families. While there are no firm statistics on the take up of carers' benefits, it is estimated that £660 million of benefits go unclaimed each year.

Another key focus for the day is to ensure carers know their rights. Every year, more than 2 million people become carers for the first time and they need straightforward information about entitlements.

Access to practical support can also be vital in maintaining carers' health and well-being and can help to ensure that they are not isolated and socially excluded.

This might include time off, help with lifting and bathing, equipment or adaptations to the home or access to leisure activities for their disabled son or daughter.

Carers – the facts

1. *One in eight (1 in 8) adults are carers... around six million people*
2. *Carers save the economy £57 billion per year, an average of £10,000 per carer*
3. *Over 3 million people juggle care with work*
4. *The main carer's benefit is £46.95 for a minimum of 35 hours, equivalent to £1.34 per hour*
5. *1.25 million people provide over 50 hours of care per week*
6. *People providing high levels of care are twice as likely to be permanently sick or disabled*
7. *Over 1 million people care for more than one person*
8. *58% of carers are women and 42% are men*
9. *By 2037 the number of carers could have increased to 9 million*
10. *Every year over 2 million people become carers*

For more information about Carers UK and Carers' Rights Day check out the website at **www.carersuk.org**, contact: Carers UK, 20-25 Glasshouse Yard, London EC1A 4JT. Tel: 020 7490 8818 or email **info@carersuk.org**

Warren sets his sight on new horizons

Globe-trotting Warren Tofts is working flat out to pay for his next adventure.

Link readers may remember reading about his exploits on his solo trips to several African countries last year.

Since then Warren, who has spina bifida and uses a wheelchair, has travelled to Moscow and Beijing, and most recently Israel and the Palestinian territories in February where he visited several holy places and even swam with dolphins.

He said: "I didn't experience any safety issues and the access for disabled people was the best I've ever seen on my travels. It was certainly as good as in the UK."

But instead of a holiday, this time Warren plans to work abroad on a community-led initiative in Peru.

He told *Link*: I recently discovered a wonderful opportunity to make a real difference overseas, by working side-by-side with local people on community projects."

He plans to be a volunteer with Cross-Cultural, a not-for-profit volunteer organisation and a registered charity in the UK, that offers a programme placing volunteers in countries such as Brazil, China, Costa Rica, Ghana, Guatemala, India and Peru, working with children with severe learning difficulties

Warren added: "All Cross-Cultural Solutions programmes are run solely by volunteer contributions, and volunteers have to pay for each 12 -week programme, including all meals, lodging, and travel medical insurance.

"I need to save or raise £2754.00, and that doesn't include the airfare to Peru, so I am hoping to do some fundraising to help pay for the trip!"

For more information about the scheme log on to **www.crossculturalsolutions.org.uk**

Cover story

Sarah Bousetta, aged 5, her mum Laura and brother Zac get into the festive spirit at Notcutts Garden Centre in Solihull where they met Santa.

Gary's Great Walk

One man's hill is another man's mountain – or at least that's how the saying goes. But for one man, Gary Walker of Reigate in Surrey, that hill came in the form of the Great Wall of China, which he walked to raise funds for ASBAH.

He spent seven days – for up to seven or eight hours per session – trekking the wall in the name of charity and raised £371 for ASBAH in the process.

Gary, whose wife has hydrocephalus, spent three Sunday mornings training for the adventure.

He told *Link*; "You could say there were a lot of ups and downs while we were walking, and some of the hills were particularly challenging, but overall it was a great experience."

Fancy a Flutter?

If you like to buy a lottery ticket each week, why not try your luck on the Monday Lottery which allows online lottery players to choose which of the featured registered charites should benefit from their lottery ticket purchases.

monday
THE CHARITIES LOTTERY

ASBAH has already benefited to the tune of £18,000 from two of five draws planned for this year.

The range of charities, both big and small, get 30% of every ticket sold - more than five times what they receive from National Lottery tickets.

ASBAH is one of the featured charities in the games for weeks commencing Monday 16 January and Monday 3 April.

If you want to play Monday the Charities Lottery visit ***www.playmonday.com*** to register.

Musical evening hits the right notes: *The Shipley Musical Union Male Voice Choir were in fine voice at a special charity night. John Wills, a regular ASBAH fundraiser, and the choir raised £172 with the event, in memory of Andrea Winterburn.*

ASBAH's coffers have been boosted by £3,000 thanks to the generosity of the Women's India Association of the United Kingdom.

The group have been fundraising for the past 12 months and the money has been divided between a range of charities in India and the UK.

Neena Dugal, charity co-ordinator of the Association, presented the cheque to Helen Dow, project co-ordinator (fundraising), at the group's AGM at the Court House Hotel in London.

Helen said: "We are very grateful for the Association's continued support. The money donated will be put towards the running of ASBAH's Helpline."

Look out for Star Supporter Jaynie Phillips in the next issue of *Link*. Jaynie, Manchester's very own superwoman, has taken part in six tough races in her bid to raise funds for ASBAH... and she plans to do it all again next year. Read her story in *Link* 219, out in March.

Pedal power drives Tim to £630 target

Super cyclist Tim Hess chose ASBAH as his nominated charity when he planned a 250-mile ride from Cardiff to Holyhead.

Tim, who undertook the mammoth trek last year with his father, aimed to do the ride alone this time… in less than 20 hours.

He was looking for a charity to support and heard of ASBAH when he bought a bike from someone whose daughter, Amy, has cerebral palsy and hydrocephalus

Tim, who lives in Sheffield, cycled the route in less than 18 hours over three days, with two punctures, one new wheel and three days of rain.

He reached the seafront at Holyhead on Day Three at 9pm where his loyal wife Helen was waiting. Tim completed the journey two hours ahead of his target.

Tim said: "Helen also completed quite a challenge- waiting for me on the side of the road at destinations across Wales, often with no thanks!"

"We celebrated by eating chips and drinking a beer in the centre of Holyhead – one of the most enjoyable meals ever!"

Jane enjoys the flight of her life

Super skydiver Jane Lawrence fell to earth from 13,000 feet to raise funds for ASBAH.

Jane, from Heanor in Derbyshire, decided to raise money for ASBAH which has helped Jessica, the 18-year-old daughter of Jane's best friend, Kay Hallam.

She said: "Jessica has spina bifida and over the years I've seen the good work that ASBAH does. I was 40 this year and as it was ASBAH's 40th anniversary, I thought it would be a good time to raise some money."

Jane, who is a home help, raised an impressive £828, but insists that although she did the jump, the fundraising was a joint effort between her, her boyfriend and friend Kay.

"Everyone was very generous," she said. "Heanor Gate School, which Jessica attended, also donated £250, which was a huge boost."

But Jane said that although she initially had a few nerves, after the training course she was looking forward to the skydiving experience.

She did a tandem jump strapped to an instructor which also gave her more confidence.

"It was a fantastic experience," Jane said. "As soon as we touched down I wanted to do it all over again."

No mountain is too high for Dawn

Congratulations to fundraiser and supporter Dawn Helsby, who has raised almost £350 for ASBAH by climbing Ben Nevis.

Dawn, who has spina bifida occulta, reached the summit along with her father Mike Healy, husband Ben, Father-in-law Nic Helsby, Aunt and Uncle Linda and Tony Window and, last but by no means least…the intrepid mountaineering family dog Pebbles!

Dawn says she kept going largely due to 'fibs' told by uncle Tony, who climbs the mountain twice a year, who kept telling her "not far to go now" many, many times on the long journey up to the top!

Dawn told *Link* that it took 10 hours to complete the challenge – four and a half going up, and five and a half coming back down again – by which time her hips were causing her quite a bit of discomfort.

And if Dawn's achievement isn't enough to report, she tells us that her father suffers from diabetes and angina and had a stroke seven years ago. What a determined and dedicated family – well done to you all.

The Defence Academy of the UK combined fun and fitness to run up a generous total for ASBAH. The organisation, based in Shrivenham, near Swindon, arranged a 10km Fun Run attracting 120 competitors of all abilities.

The first runner home, Capt Steve Cadywald, crossed the line in a speedy 36 mins 21 seconds. Funds were divided between three charities – ASBAH, Macmillan Cancer and the Soldiers, Sailors, Airmen and Families Association (SSAFA).

Richard put his best foot forward

ASBAH Chairman Richard Astle ran up an impressive £1,100 for the charity's funds after tackling the Great Eastern Run.

Richard was so impressed with ASBAH's many fundraisers that he set himself a tough challenge – to run the annual half marathon and collect more than £1,000 in sponsorship.

Richard, who took part in half marathons in 2002 and 2003, said: "If I'm not training for an event I won't run. I really need an incentive to get me going.

"The previous half marathons I've run have been spring events, which meant I had to train during the cold, dark months, which wasn't much fun.

"This time I did my training throughout the summer months, when the warm, light evenings meant I could run through the countryside rather than in a small loop around the village."

He was delighted to complete the distance in 1 hour 42 minutes at the Peterborough-based run on 15 October, finishing 486th out of 2000

He said: "The only thing I could think of as I finished the run was how on earth does anyone go on from this to run a marathon. Thirteen miles is a long way! Still all in a very good cause and I would like to thank my many supporters who help me to raise so much money for ASBAH."

charity made easy
justgiving.com

Signing up to JustGiving.com brings in even more funds

As *Link* went to press, 25 fundraisers are listed on ASBAH's page on the popular Just Giving website.

These online fundraising pages are one of the easiest and most efficient ways to collect donations.

Anyone collecting for a charity registered with Just Giving can create a page giving details of their charity event, with messages and pictures.

Friends and family can then sponsor them by credit or debit card from anywhere in the world.

The website which was launched in 2001 has become popular with fundraisers and donors alike... particularly since it automatically reclaims 28% in Gift Aid on UK donations, helping fundraisers to collect even more cash.

For more information about some of our hard working fundraisers log on to **www.justgiving.com/asbah/raisemoney**

Sanja challenged by the British 10K London Run

Well done to Sanja Karanovic who rubbed shoulders with many of the world's finest athletes when she took part in the British 10K London Run back in July this year.

Sanja described what it felt like to be in the race: "I was nervous before the race but I needn't have worried, as soon as I got started I became totally focused on completing the course. It was exhausting and sometimes I felt I wouldn't be able to finish, but I did and I'm really pleased to have raised funds for ASBAH."

ASBAH's Great North runners


Justin Phillips


Alexander Rusden


David Mallen


Dianna Capstick & Jon Tibke


John Paul Reay & Danielle Lindley


Jude Blakemore


Malcolm Henderson


Marie Bacon


Myles O'Donnell


Phillippa O'Donnell


Left to right: Ronnie Bowers, Phillip Heeks, Wes Fuller

ASBAH's valiant runners turned out in force to join the 50,000 field taking part in the 2006 Great North Run.

This year's event attracted 24 people keen to tackle the 13.1 mile course to raise much-needed funds for ASBAH.

They put themselves through the paces alongside elite athletes and celebrities including commentator John Motson, TV presenter Carol Vorderman, actress Amanda Burton, and actor Jimmy Nail.

Supporters turned out in their droves to cheer the runners along the way and to add to the party atmosphere, The Red Arrows provided a spectacular aerial salute as they passed over the famous Tyne Bridge.

ASBAH's events fundraiser Ian Morley was there on the day with his wife Val, a regular ASBAH volunteer, and Joan Pheasant from Northern Region, handing out drinks and giving moral support.

The team also included Anne Walton, a retired ASBAH adviser from Tyneside and her husband Reg – two more regular volunteers ASBAH relies on at this annual event.

Ian said: " It is always a delight to meet our runners at the end of this event.

"Although most are in an exhausted state they are always willing to have a chat and pose for a photo. The majority of these fantastic people actively look for us at the end of the run."

Caroline tackles the three peaks

ASBAH Adviser Caroline Cashman's fundraising has reached 'new heights', as her latest activity involved taking part in the gruelling Three Peaks Challenge.

In just 24 hours, Caroline, local adviser for Hampshire, and nine companions had to climb the UK's three highest mountains, starting with Ben Nevis.

Caroline completed the challenge back in July this year, but has only just thawed out – she recollects: "We experienced torrential rain, horizontal snow, high winds and an almost total lack of visibility at times, so yes, it certainly was a 'challenge'.

"I don't think I have ever been so cold and wet – putting my feet back into wet socks and boots at 4am on the final day must have been the lowest point, but there was an amazing camaraderie amongst the climbers as we urged each other on to the finish.

And at the end, instead of a nice hot bath and a good night's sleep in a local hostel, "we got in the car and drove straight back to Hampshire" said Caroline!"

What a superstar you are Caroline – and £2,500 was raised for ASBAH too, so very well done and thanks to you and the rest of the climbing team.

Summer of Fun

ASBAH youngsters had the time of their lives at a fun-filled four-day Summer Experience funded by the Four Acre Trust.

The group of 12 – aged between 12 and 17 years - travelled to The Keppleway Project in the Lake District, keen to try out a whole host of exciting new activities.

They had a busy programme of sports sessions with the chance of canoeing on Lake Coniston, tree climbing and abseiling, archery and team challenges.

The evening sessions included indoor games such as table tennis, pool and board games, and craft sessions.

Joan Pheasant, manager of ASBAH North, who organised the event, told *Link*: “The youngsters had a wonderful time. It was a great experience for them. Many of them conquered their fears and achieved far more than they thought they would.

“This was partly due to the team support and the excellent instructors who encouraged and helped each individual through every activity.”

She was helped by ASBAH’s Moira Foggo and Julie Turnbull, plus a team of eight occupational therapy students who volunteered to work as “buddies” for the youngsters.

Joan added: “Our thanks go to the Four Acre Trust, which funded the course, the excellent staff at the Keppleway Project and the occupational therapy students – without their help the Summer Experience wouldn’t have been able to take place.”

What the youngsters thought...

“I loved being there. The activities were excellent.”

“It was brilliant. There was a really good mix of activities and free time.”

“The disco was brilliant.”

“It was the best experience of my life.”

“The centre could cater for all levels of disability.”

Apply now for Family Weekend

The Family Weekend 2007 will be held on the 23, 24, 25 March in the Isle of Wight.

The weekend is open to families with a child with spina bifida, hydrocephalus or BIH who is aged 6 or under on the 1st February 2007. Cost per family is £75 plus cost of ferry.

Due to the very long waiting list there are a limited number of places available. Ask your adviser for further information and/or an application form, or contact Shelley at National Office - ***shelleyg@asbah.org*** or telephone 01733 555988.

Please note that places are not allocated on a first come first served basis, but are dependant on laid out criteria.

Helpline gets off to a flying start

Helpline patron Danny Mills meets operator Annie Kilsby

ASBAH's Helpline and Information Service was launched in June this year and to date an estimated 900 calls, plus over 200 e-mails have been logged by Helpline manager Linda Lewis and her team of two Helpline operators, Dawn and Annie.

The helpline aims to offer a sympathetic ear and practical advice and support on all aspects of spina bifida and hydrocephalus, as well as acting as a referral medium, passing requests for help to area advisers where available or directing callers towards other voluntary and statutory organisations who may be able to assist or to ASBAH's specialist medical, education and continence advisers.

LOTTERY FUNDED

Linda described the first few months of the Helpline service: "It's been really hectic because we really had to hit the ground running – the two operators initially started on a job share basis and at the moment this is working well to service clients' needs."

As the weeks and months have passed, patterns of call categories have emerged – for instance, an estimated 40 per cent of calls relate to medical issues, whilst many others phone to request shunt alert cards.

To raise awareness of the Helpline, a wide range of healthcare professionals such as GP's, midwives, paediatricians, neurological clinics, diagnostic centres and ante-natal clinics were sent information in July, inviting them to request leaflets for the general public to access. The response has been phenomenal and responses are still flowing steadily in months later.

Linda continues: "Perhaps the most interesting finding when summarising calls to the Helpline to date, is the high proportion of callers with children or family members aged 40 plus, who are making contact for the very first time, having only just discovered that ASBAH is there to support them. This is largely attributable to the new leaflets and shows that there are many, many more people who we can reach out to if they only become aware that we are there.

"We've learned a lot since we started and every call we take helps prepare us even more for the next one. What I really enjoy is being able to point someone in the right direction to enable them to get the help they need – that's what makes the job worthwhile – making a difference."

ASBAH's Helpline can be called on 0845 450 7755 Monday to Friday, between 10am-4pm, at local call rates.

DER NOW • ORDER NOW • ORDER NOW • ORDER NOW • ORDER NOW • ORDER NOW • ORDER NOW • ORDER NOW • ORDER N

Christmas Cards

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

ASBAH
1966-2006 Challenging the future
Association for Spina Bifida and Hydrocephalus

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

Wintry Scene

Flowers

Penguins

Hat

ASBAH Order Form
Christmas Cards

Please send me:	Qty	Price	Total (£)
Penguins		£2.50 plus p&p	
Flowers		£2.50 plus p&p	
Wintry Scene		£2.50 plus p&p	
Hat		£2.50 plus p&p	
Christmas card (postage and packing) - £0.82p per pack			
Total order *(inc. postage and packing)*		£	

Payment

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

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

Or

☐ VISA ☐ Mastercard/Access

Card no. ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

Start date ☐☐☐☐ Expiry date ☐☐☐☐

Signature ____________________

Mr/Mrs/Miss ____________________

Address ____________________

____________________ Postcode ____________

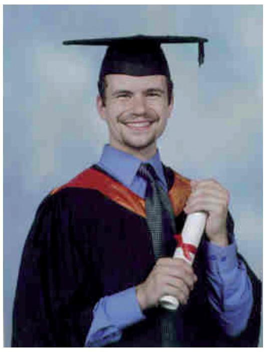
Telephone ____________________

Please send the completed order form together with your payment to:

ASBAH, 42 Park Road, Peterborough PE1 2UQ

Registered charity no. 249338

James Weavin



Congratulations to James Weavin who graduated from Aberystwyth University in July with a degree in Marketing and Business Management.

James, from Halesowen, West Midlands, was born with congenital hydrocephalus and had shunts fitted when he was 8 months and 10 years old.

Proud mother Wendy said: "Thankfully James's mental and physical capacity has not been affected by his hydrocephalus, although when he was younger he did suffer with severe headaches. But he was always very brave and never let his condition get him down.

"James underwent seven operations as a child, which gave him a normal quality of life. For this we are eternally grateful."

Joanna Clyne

***Link* readers may remember Joanna Clyne, who featured in the Autumn 2005 issue, talking about her experiences at University.**

Joanna graduated from the University of Bolton in the summer after achieving a 2.1 BA (Hons) in Human Resource Management and is now studying for an MA in the subject.

Joanna, who aims to work within the training and appraising side of human resources, said: "The University has always been very helpful. I have always had an assistant who helps me by accompanying me in lifts and carrying my books and bags, which meant that I can concentrate on my academic studies rather than worrying about how I'm going to manage to get around the building.

"If you are in a wheelchair it shouldn't prevent you from achieving your full potential. It's all about forward planning."

degree success

In the next issue of *Link* we'll be featuring an education section. Among the special features will be an in-depth interview with Ben Edwards, who will talk about the highs and lows of university life.

Sarah Williams

Sarah Williams enjoyed university so much that she's gone back to study for a Masters Degree.

Sarah, 22, who has spina bifida and hydrocephalus, told *Link* about her experience: "My course at Kent University was English and American Literature and History and I really enjoyed the whole experience of meeting new people, learning and the best part of it was being able to live independently – it really boosted my confidence.

Sarah, from London, added: "I ended up with a 2:1 which I am very pleased with and my Masters course on the History of Propaganda is proving to be stimulating and challenging – we have some lively debates in seminars.

"I'd like to go on to do a teaching course and possibly teach history or English at A level – and I'd recommend university to anyone – I'm having a great time."

Ben Edwards

***Link* reader Ben Edwards has begun his Barrister training after graduating from Exeter University.**

He achieved a 2:2 LLB Law degree and is now studying for his Bar Vocational Course at the Inns of Court School of Law, London.

Ben said: "I was just one mark away from gaining a 2:1, but they wouldn't give it me. I was a little disappointed with it, but it is how you use your degree that counts.

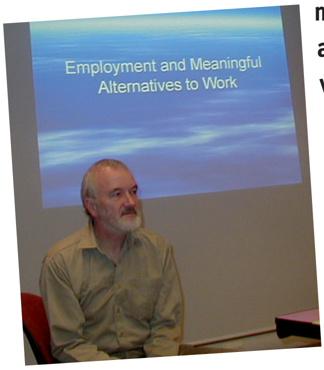
"Considering the problems I had before GCSE's and A Levels I feel I have done well to get this far.

"My goal is to become a very successful barrister, specialising in criminal law. I have aspirations to become a judge, maybe the Lord Chancellor one day, but that is possibly out of my reach!

"But who knows. I could be the first hydrocephalic person to become a major cog in the Judiciary."

Weekend away to consider work options

To work or not to work? That was the question posed at the recent Your Voice weekend which aimed to help people make choices about paid and voluntary work.



The event, held at the Novotel in Leeds, was attended by 21 Your Voice members, keen to learn more about many employment issues.

The weekend attracted eight inspiring speakers who covered a range of pertinent topics, all aimed at providing information to people who were considering their work options.

These included talks about confidence building and how to write an effective C.V. Others gave advice about work experience and training opportunities, culminating with information about Benefits, employment rights and support in employment. There was also a session on doing voluntary work.

Your Voice (YV) Policy Officer, Barbara Robinson, said: “The YV committee has again worked hard to provide a full and informative weekend event which was well received by the delegates.”

One of the Your Voice delegates, Claire Tushingham, from Chester, told *Link*: “I have had a few health problems over the last two years so taking a job would be quite difficult for me. I was very interested to learn more about voluntary work which is a more flexible option.”

Claire, who has spina bifida and hydrocephalus, added: “The weekend was fun and very informative. I learnt a lot about Benefits and what options are open to me. It was a surprise to find that there is a lot of help and support available if you know where to look.”

> **I was very interested to learn about voluntary work which is a more flexible option.**

Samantha Johnson from London also found the weekend event useful, and it whet her appetite for more Your Voice events.

Samantha said: “The talks were really interesting because they provided a lot of information that I wasn’t aware of before and I enjoyed hearing other peoples’ experiences about going out to work.

“I also made some really good friends. The venue was great – a relaxing environment with helpful, friendly staff.”

Your Voice elections

Deadline for applications is Friday 15 December.

The Your Voice National Committee is looking for new members to join its ranks.

The Committee has 15 places which are open to anyone with spina bifida and/or hydrocephalus who is aged 18 years or over.

Members of the group meet up to six times a year in a fully accessible venue and are invited to spend three years in position.

In addition to the regular meetings they also communicate individually or in small groups over the telephone between the main meetings.

If you do gain a place on the committee your expenses to attend the meetings can be claimed for and will be reimbursed to you after meetings in accordance with ASBAH’s Expenses Policy.

Any personal support needed whilst attending a meeting will be organised and paid for by ASBAH. Alternatively, if members prefer to bring a support worker with them, any reasonable expenses will also be paid for that person.

> **Members of the group meet up to six times a year in a fully accessible venue and are invited to spend three years in position.**

Applicants who are unfamiliar with this type of work should be reassured that the most useful and important thing they can bring to the group is their

r all in Wales

Your Voice members from around England and Wales enjoyed a weekend of fun and fitness as part of the group's on-going event programme.

This year's event, based at the Jane Hodge hotel, near Cowbridge, attracted 21 members from ASBAH's adult user group, keen to improve their fitness levels and enjoy a new sport.

The weekend, billed as "Be A Sport for Leisure and Pleasure" was aimed at inspiring members to try out a new sport in a relaxed and supportive environment.

And with taster sessions in wheelchair sports including basketball, tennis and badminton, plus hand cycling, there was no excuse not to have a go.

When everyone had worn themselves out after all the activities, they sat back and enjoyed talks on subjects including nutrition and the British Disabled Flying Association.

One satisfied customer said: "It was brilliant fun. I got moving very quickly and I surprised myself at being able to do it."

experience of being a disabled person.

If you are interested in joining the National Committee you need to complete an application form together with a few words on why you would like to get involved, what skills or experience you think you can bring to the group, and what you would like to get out of the group.

If ASBAH receives more than 15 replies there will be an election to see who joins the committee.

The write-ups sent in with applications will then be sent to everyone on the Your Voice mailing list so that they can vote for who they would like to be elected to the group.

If we do not receive more than 15 replies, applicants will be automatically asked to join the committee and will be invited to the first meeting, due to be held in the New Year.

To obtain more details about the work of the group and an application form contact Barbara Robinson at ASBAH House. Tel. 01733 421322; email ***barbarar@asbah.org***

Deadline for applications is Friday 15 December.

Your Voice websites ready for launch

ASBAH's two exiting new websites are ready to go live and open up a new world for hundreds of people around the country.

The Your Voice and YV Youth sites have been designed and are currently being reviewed by the Your Voice committee and a group of ASBAH teenagers in Liverpool before they finally go live.

Both sites will feature a variety of information on living with spina bifida and hydrocephalus, medical advice, how to contact ASBAH for help, and useful links to other relevant websites.

But perhaps the highlight of the websites for many users will be the Forums, which will bring together people with spina bifida and hydrocephalus.

Secure registration systems will be in place to ensure that only registered people will be allowed to participate in the forums.

Under 18's hoping to use the Forum on the Your Voice Youth website will need to obtain permission from their guardian before they can use the message boards.

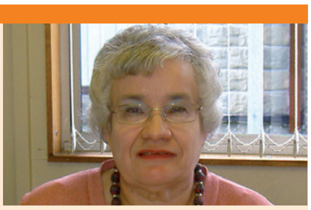
Peter Farrall, Director of Communications and Marketing said: "Increasingly more and more people are turning to websites as their primary source for information. We were keen to ensure that in addition to the main ASBAH website there was a separate site for the growing Your Voice group.

"Whilst details of new YV events will still be found in *Link* –they will also be featured on the new YV site together with other useful information. The interactive forums give people the opportunity to discuss common interests and make new contacts within the safe environment of the Forum."

For teenagers the YV Youth site, which is being trialled in the Merseyside area, thanks to a grant from Barclaycard, offers a site dedicated to teenagers needs and where they can talk to others with the same condition as themselves. The information on the sites will be tailored for a younger audience and with relevant topics such as bullying, driving, moving towards independence, careers etc.

Peter added that it is hoped that the trial site can be extended nationally in 2007.

Career advice from Christine



Christine Helliwell was one of the speakers at the recent Your Voice "To Work or not to Work" event.

Link caught up with Christine to learn more about her inspirational story.

There's nothing more inspiring for someone about to enter the working world than meeting someone who has succeeded against all odds to have a successful career. Christine Helliwell from Brighouse, West Yorkshire is a shining example of triumph over adversity.

Christine, who has spina bifida and has had three major operations in the last twelve years, has still managed to notch up an impressive working record of over 43 years, and that's after gaining O Levels and a Bachelor of Science degree – not bad for someone who didn't start school until the age of ten and a half because healthcare professionals said she couldn't be educated!

Christine is one of life's 'givers', always wanting to help others, whether that's improving disabled access at her local church or raising money to help the Brownies and Girl Guides via the Trefoil Guild. So it was no surprise that Christine was happy to give up some of her free time to speak to delegates at the recent Your Voice event.

Christine gave a talk about Gaining Employment and in particular, shared some sage advice about Access to Work, recounting her own experiences to illustrate the significant benefits available.

The installation of a lift at her place of work, the provision of specially made protective shoes, a private toilet to help reduce infections due to lowered immunity, a special chair on wheels and help with transport, have all made Christine's life easier and provided her company, A.H. Marks of Wyke near Bradford, with an employee who is rarely off sick and has a great deal to offer the firm. Funding for these vital adaptations has been provided both by Access to Work and the company itself.

Christine Helliwell from Brighouse, West Yorkshire is a shining example of triumph over adversity.

On the subject of obtaining funding, Christine advised that employees should apply for Access to Work funding as early into a job as possible, as a greater proportion of funding is met by Access to Work within the first year of employment – a significant factor to consider, especially if a person is joining a small organisation who may not have access to large budgets to pay for adaptations out of company funds.

Finally, Christine reminded delegates that when considering the potential loss of benefits as a result of taking a job, people should take heart, as Disabled Tax Credit can compensate amply.

Shropshire group gets back to nature

A Shropshire ASBAH group made the most of the glorious summer weather with a trip into the countryside.

The get-together, at the Secret Hills Discovery Centre in Craven Arms, attracted many families from the area, keen to meet up and have fun.

They spent the afternoon strolling through the meadows surrounding the exhibition centre and enjoying the summer sunshine.

The event was organized by Joan Carter and Elizabeth Miers, the ASBAH area adviser.

Jean Clayton, one of the group members, told *Link*: "It was a beautiful day and we were able to spend time outside chatting and walking. Joan, Elizabeth and other members organized a quiz sheet, raffle, bingo and refreshments. We also helped the children to spot fish, toads, frogs and dragonflies in the ponds.

"Everyone was really friendly and it was a very happy occasion. Everyone involved would like to thank Joan and Elizabeth for their hard work in making our day out one to remember.

Flying Scholarships up for grabs

If you would like to apply for a Flying Scholarship for the Disabled, act now. The closing date for applications for 2007 is 5 January 2007.

One of the successful 2006 applicants, Kim Buckingham told *Link*: "I saw a documentary about Flying for the Disabled about 10 years ago, and thought at the time that flying a plane is something I would love to do.

"But it wasn't until a few months ago that I thought about it and looked it up on the internet. I downloaded the forms and sent them off, and the next I knew was I had been invited to a three-day interview. So it just proves that it's always worth applying."

For an application form contact Sue Whitby, FSD Director, Douglas Bader House, Horcott Hill, Fairford, Gloucestershire. GL7 4RB or telephone 0870 800 1942.
Email ***info@toreachforthesky.org.uk***

Full details about the scheme and a preliminary application form are on the charity's website ***www.toreachforthesky.org.uk***

And don't forget to mention that you heard about Flying Scholarships for the Disabled in *Link!*

More help at hand for the South West region

New area adviser Ann Gillard has been welcomed with open arms by service users in the Somerset area, which has been without an adviser since 2004.

Ann, a physiotherapist, joined ASBAH on September 18, and is settling in well to her new role, covering the South West, including Bristol and Bath, and the fringes of south Gloucestershire, Dorset and Wiltshire.

She had the chance to meet other ASBAH advisers and staff at the annual adviser residential in Leicester before tackling the challenges of her new position.

Ann said: “My first main task is to write to service users on our database to introduce myself as the area has been without an adviser for some time.

“But several calls have already been passed on to me by the Helpline, so there’s plenty to keep me busy until people start contacting me direct.”

Ann Gillard

Update on... Cross Border Initiative

In the summer issue of Link we told you about the European funding worth £120,000 that ASBAH helped secure, to benefit young people with spina bifida and hydrocephalus from both sides of the Irish border.

The Cross Border Initiative will provide training leading to qualifications as well as courses and workshops to help participants learn essential life skills and boost their self esteem.

Julie McGrory

The project has since taken a step forward with the appointment of Julie McGrory who commenced her role as Cross Border Project Worker in October.

Julie told *Link*: “Now I’m in post, we can crack on with much of the preparation for the courses and workshops which, all being well will start in February next year. We’re involved in an active recruitment drive at the moment to raise awareness of the places available and the training will very much depend on the participants and their individual needs.

“Our aim is to provide a tailored approach to ensure that each young person gains the maximum benefit from the initiative, whether they are keen to learn about photography, money management, self care and hygiene or sports.”

Julie added that they were also hoping to assist with transport for the participants.

She concludes: “We’re really excited about this project and hope that it will provide the young people with something they haven’t had access to before – as well as the actual training, we will also act as a referral service, so that youngsters can make contact with other agencies, to keep the momentum going and lead them on to even greater challenges.”

If you know of a young person aged around 18-25, living in the North West area of Ireland, including the council areas of Coleraine, Limavady, Derry and Inishowen in County Donegal, who would benefit from careers advice and preparation for employment through the project, contact Julie McGrory on ***Julie.mcgrory@gmail.com*** or call Julie on 00353 866002929.

Cerys joins the team

ASBAH new girl Cerys Long is relishing the challenge of boosting ASBAH’s funds in her role as donor development officer.

Cerys, who joined the fundraising team on 9 October, is keen to use her marketing and sales skills to build and develop the existing support base of donors.

Cerys, who previously worked as a sales rep for a food distribution firm, said: “Although I am now working in a totally different field, this job allows me to combine my sales and marketing skills to promote a very good cause.

“Everyone has been very helpful and friendly, helping me to settle in very easily. I think the biggest change for me is working in an office. As a sales rep I was constantly on the road. My office was my car!”

Cerys Long

PIPPA ON TARGET

Congratulations to Pippa Britton who scooped a prestigious silver medal at the 2nd European Grand Prix Invitational Event in the Czech Republic.

Pippa, who was forced to take time out this year due to an operation to correct her scoliosis, was delighted to come second in both the ranking round and in the individual competition at the summer event.

She missed out on a medal in the following European Championships, finishing in 5th place.

But Pippa said: "I shot well, equalling the existing World Record for the 50 metre distance and I was also part of the GB ladies team who managed to set a new World Record in the team ranking round, so I wasn't too disappointed."

Following the busy summer months Pippa spent two weeks at a training camp in China, to sharpen her skills for the next round of competitions. We wish her every success in her future events.

Love is in the air for David and Maria

Sweethearts David Clare and Maria Hives are enjoying wedded bliss 12 years after meeting through the Liverpool Echo's Heart to Heart column.

The couple from Croxteth Park who both have spina bifida, tied the knot at an emotional ceremony at the city's Devonshire Hotel.

But their road to the altar has been a rocky one as Maria, 31, has undergone a series of life-threatening operations during the past ten years.

She said: "To be honest I wondered if I'd ever see the day. But David's been brilliant and has always been there for me."

A failed kidney transplant left Maria, a wheelchair user, seriously ill in 1996 and four years later she was diagnosed with a brain tumour, which was benign.

Last January she had 13 operations in two weeks after complications during another kidney transplant.

But the couple put all that behind them when they married, surrounded by family and friends.

David, 39, said: "It was a brilliant day. Apart from a few minor hiccups such as the wedding car breaking down, everything went to plan.

"The best part of the day was the ceremony itself. I was nearly in tears and I'm sure Maria had a tear in her eye too. It was wonderful. No-one could have asked for a better day."

Artist's tribute to young asylum patient

We having called to our Assistance a **Surgeon and Apothecary** and having personally examined **William Joseph Shakespeare**, a Pauper, and being satisfied that the said **William Joseph Shakespeare** is a **Idiot** and a proper person to be taken charge of and detained under care and treatment hereby direct you to receive the said **William Joseph Shakespeare** as a Patient into your **Asylum**.

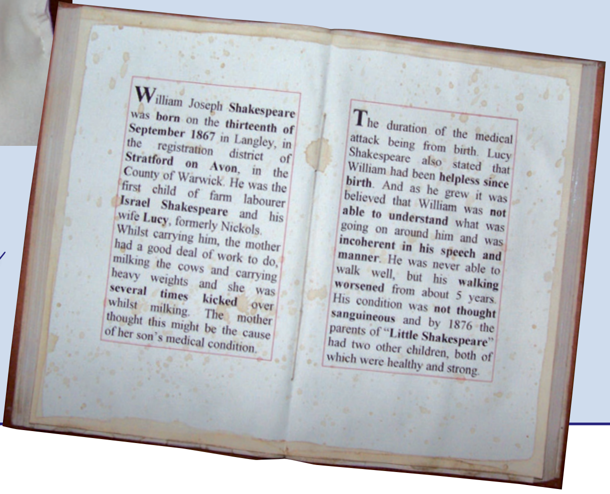
Signed : Clergyman of Henley in Arden &
Officer of Stratford on Avon

ORDER FOR THE RECEPTION OF PAUPER PATIENT
William Joseph Shakespeare (c)

A Warwickshire artist hopes her recent exhibition will put the record straight about a young child with hydrocephalus who was committed to a Victorian asylum.

After reading the casebooks of the Warwick County Lunatic Asylum, artist Carol Ballard uncovered the records of a child called William Shakespeare.

He was admitted to the asylum at Hatton, near



William Joseph **Shakespeare** was **born** on the **thirteenth of September 1867** in Langley, in the registration district of **Stratford on Avon,** in the County of Warwick. He was the first child of farm labourer **Israel Shakespeare** and his wife **Lucy**, formerly Nickols. Whilst carrying him, the mother had a good deal of work to do, milking the cows and carrying heavy weights and she was **several times kicked** over whilst milking. The mother thought this might be the cause of her son's medical condition.

The duration of the medical attack being from birth. Lucy Shakespeare also stated that William had been **helpless since birth**. And as he grew it was believed that William was **not able to understand** what was going on around him and was **incoherent in his speech and manner**. He was never able to walk well, but his **walking worsened** from about 5 years. His condition was **not thought sanguineous** and by 1876 the parents of "**Little Shakespeare**" had two other children, both of which were healthy and strong.

Somerset rider gets the bit between his teeth

Young Rowan Ford is no stranger to rosettes and trophies – in fact he's got a whole stack of them in his bedroom.

The lively 11-year-old from from Draycott, near Cheddar in Somerset, joined the Wookey Hole Riding for the Disabled Association (RDA) Centre when he was just six years old and was soon competing in competitions and tournaments across the region.

Five years on, Rowan, who has hydrocephalus, has progressed so well with his riding that, with a prestigious Long Service Trophy to add to his collection of prizes, he has 'retired' (at 11 years old!) from his RDA group and is now riding a friend's horse Moggie every Saturday.

Rowan's father Richard told *Link* a little about Rowan: "Rowan is a bright, happy, healthy boy and thanks to his successful shunt operation, has been able to get on with some active pursuits.

"He really seems to have a way with animals, especially horses, and riding has given him a great deal of confidence as well as helping with his balance and co-ordination.

Earlier this year Rowan competed in a regional qualifying round for the RDA South Western Region at Taunton, scooping a second place rosette in the dressage section. His most recent equestrian achievement was a great weekend of performances at a two day RDA national championship held at Hartbury College in Gloucestershire, the venue of the next World Paralympic Dressage Championships. Richard explains: "A lot of kids might have been daunted by such an impressive venue, but Rowan shone and did a brilliant round in the 'Ride in the Country' class where he had to negotiate a series of obstacles like opening gates and ducking under arches. He came 6th and also took part in the dressage as well as the horse care and knowledge quiz. It was a proud day for the whole family."

I love getting ready for competitions and training to improve my riding and horses are a big part of my life

So what does Rowan think of it all? He told *Link*: "When I used to ride my favourite RDA horse Blackie I felt really good and now I have built up a good relationship with Moggie too – I like walking and trotting – it gives me so much freedom and I've also made some good friends along the way."

"Every Saturday, I go along to the stables to meet Moggie's owner Rebecca and I enjoy grooming Moggie, and helping around the yard before my ride. I do flat work in the sand school and sometimes go out on hacks and I've even had a go at driving Moggie in the trap around the lanes near the stables – it was quite a challenge but it was good fun and I'd like to do it again.

"I'm hoping to join another RDA group soon so that I can compete in more events – I love getting ready for competitions and training to improve my riding and horses are a big part of my life."

Warwick, at the age of eight, after being diagnosed as an "idiot". But following his death one year on, a post mortem revealed that the cause of death was "chronic hydrocephalus".

Leamington-based Carol says her recent exhibition, "Opening the Casebooks" was aimed at releasing the Victorian psychiatric patients from the confines of their medical records and for the first time, to give them a voice.

Carol said: "Although Asylum Admission records show that this William Shakespeare was an "idiot", I'm determined to put the record straight. Had this child been alive today, his hydrocephalus would have been diagnosed and treated.

"William's case notes make for sad reading as life in the Asylum clearly contributed to his deterioration. Behavioural problems from watching others in the asylum were inevitable. The drug used to sedate "Little Shakespeare", paraldehyde was strong smelling and would have emanated from his pores, breath, sweat and urine, making his young life unbearable."

William Shakespeare died on 7 March 1877. He is one of the 1104 asylum patients whose remains lie in the Burial Ground 1 at Hatton, Warwick.

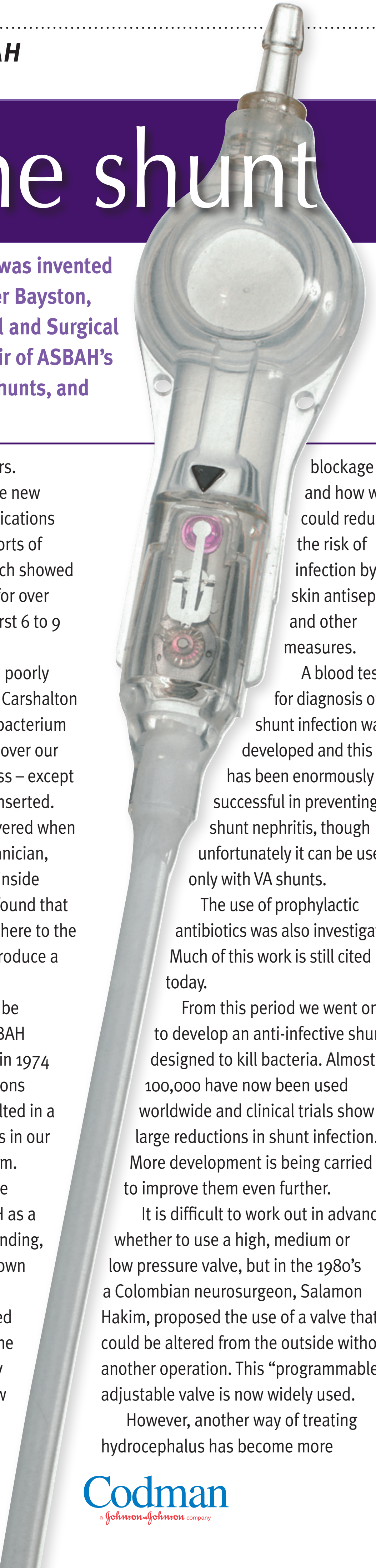
Carol Ballard

Codman - Working in partnership with ASBAH

50 years of the shunt

Roger Bayston

Shunts have come a long way since the first was invented by John Holter half a century ago. Here Roger Bayston, Associate Professor at the School of Medical and Surgical Sciences, University of Nottingham, and Chair of ASBAH's Medical Committee, looks at the history of shunts, and what the future holds.



Codman Hakim™ Programmable Valve

The future for patients with hydrocephalus 50 years ago, before the invention of shunts, was grim.

But their prognosis improved in 1956, when John Holter, an American engineer, had a child, Charles Casey, who was born with spina bifida and hydrocephalus.

John Holter was told by surgeons that nothing could be done for his son, but he asked what was needed and eventually invented the Holter valve.

This allowed shunting at a controlled rate and the material, silicone, could be sterilised.

Others at the time were trying to produce a workable valve but the Holter valve revolutionised the treatment of hydrocephalus and therefore of spina bifida too, as surgeons now began to see that the prognosis was vastly improved now that the hydrocephalus could be treated.

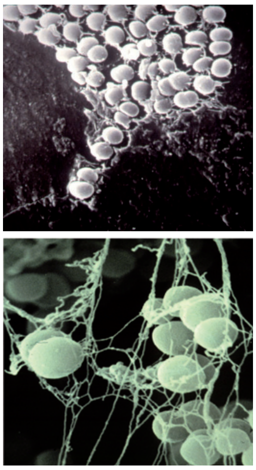
John remained a generous donor to research and a longstanding member of the Society for Research Into Hydrocephalus and Spina Bifida (SRHSB), until his death a few years ago.

As another example of medical advances made by "non-professionals", the author Roald Dahl, along with neurosurgeon Kenneth Till and engineer George Wade, designed the Wade-Dahl-Till valve.

Wade gave his name to the Wade Charitable Trust which was set up to support my research and Kenneth Till served as a Trustee for many years.

Unfortunately, shortly after the new shunt came into wide use, complications began to appear and in 1959 reports of infection were published. Research showed that shunt infections accounted for over half of the complications in the first 6 to 9 months after shunting.

For some time infections were poorly understood until Richard Holt at Carshalton Hospital identified the cause - a bacterium that is present quite naturally all over our bodies and is completely harmless – except when a shunt or other device is inserted.



Biofilm formation -the Enemy inside shunts

The reason for this was discovered when I and a histology technician, Steve Penny, looked inside infected shunts and found that the bacteria could adhere to the shunt material and produce a type of "glue".

I was fortunate to be awarded the first ASBAH Research Fellowship in 1974 to study these infections further, and this resulted in a great deal of progress in our understanding of them.

This underlines the importance of ASBAH as a source of research funding, as research councils have not shown any interest in this area.

From this Fellowship developed a clear understanding of where the bacteria came from and how they reached the shunt, as well as how the symptoms of shunt infection differed from those of shunt blockage etc, and how we could reduce the risk of infection by skin antisepsis and other measures.

A blood test for diagnosis of shunt infection was developed and this has been enormously successful in preventing shunt nephritis, though unfortunately it can be used only with VA shunts.

The use of prophylactic antibiotics was also investigated. Much of this work is still cited today.

From this period we went on to develop an anti-infective shunt designed to kill bacteria. Almost 100,000 have now been used worldwide and clinical trials show large reductions in shunt infection. More development is being carried out to improve them even further.

It is difficult to work out in advance whether to use a high, medium or low pressure valve, but in the 1980's a Colombian neurosurgeon, Salamon Hakim, proposed the use of a valve that could be altered from the outside without another operation. This "programmable" or adjustable valve is now widely used.

However, another way of treating hydrocephalus has become more widely used. This is endoscopic third ventriculostomy (ETV), in which an endoscope is used to make a small hole in the bottom of the third ventricle inside the brain, letting the cerebrospinal fluid (CSF) flow through and escape.

Though this is effective in some patients, it applies only to selected types of hydrocephalus and shunting remains the main treatment.

When shunts were first widely used they drained CSF into the heart (VA shunts) but after a few years drainage into the abdomen was favoured (VP shunts).

ASBAH's Rosemary Batchelor and I recently carried out a survey of people in England and Wales with VA shunts and we have found that they are relatively trouble-free, with two out of three people still having their VA shunt after over 40 years.

We are now analysing data from a similar group with VP shunts, and we are preparing to repeat the survey in Germany for comparison.

This gives neurosurgeons another alternative if the abdomen can no longer be used.

VP shunts are thought to be more at risk from over-drainage, and Hakim claimed 25 years ago that VA shunting was more physiological in this respect.

Before this he also described a new form of hydrocephalus, "Normal Pressure Hydrocephalus" or NPH.

This concept was difficult to understand and only recently has become recognised as a major cause of gait disturbance, incontinence and dementia in the elderly.

Though the CSF pressure is more or less normal, the condition can usually be treated by shunt insertion.

The reasons for this are only now being understood and we are in the process of learning a great deal about all forms of hydrocephalus that could affect the way it is treated in the future.

Only now are we learning what the CSF is for and how it affects brain function and development.

There is perhaps the possibility of the use of drugs to limit the damage caused by hydrocephalus to the brain, and this gives hope for future treatment.

Shunt infections down by 90% thanks to Bactiseal

Recent worldwide research into the effectiveness of Bactiseal shunts reveals that infection rates have dropped by at least 90 per cent.

Hydrocephalus shunt infections have always been the main cause of shunt failure despite the use of antibiotics, with the risk of infection greatest during the first few months.

Bactiseal, the brainchild of Roger Bayston, Associate Professor School of Medical and Surgical Sciences, University of Nottingham, and Chair of ASBAH's Medical Committee, is incorporated into shunt catheters manufactured by Codman which have been marketed worldwide since 2000.

An estimated 100,000 of these shunts have been used by surgeons around the globe in the past six years, with only 28 shunt failures reported.

But Roger, who is also ASBAH's Honorary Consultant in hydrocephalus, and Chair of ASBAH's Medical Advisory Committee told *Link*: "One can't accept that only 28 failures caused by infections have occurred in 100,000 shunts. Massive under-reporting can't be ruled out.

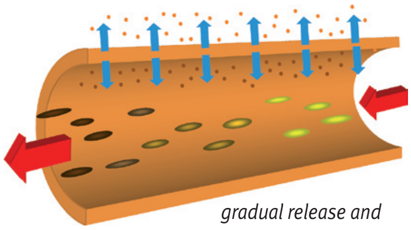
"However, evidence from clinical trials shows a 90 per cent reduction in infection rate since Bactiseal shunts were introduced.

"While we're very pleased with this figure, more development is needed. Standards can be improved."

As part of ongoing research, Codman are required to collect data on shunt failure.

For every reported failure, data is collated and sent, with any parts of the removed shunt, to Roger Bayston's laboratories for analysis.

The removed shunt material is rigorously examined microbiologically to try and determine why infection occurred.



gradual release and diffusion of antibiotics

What is Bactiseal?

Bactiseal shunts are silicone shunt catheters which have been specially impregnated with two antibacterial drugs, clindamycin and rifampicin to kill bacteria which are the main cause of shunt failure.

The protective activity of Bactiseal lasts for around two months, which easily covers the period when infection is most likely.

Linda's line

Someone I met recently gave me a bit of a laugh so I thought I'd share the joke. The person concerned was of the (erroneous) opinion that there were too many disabled parking spaces in Sutton town centre and was trying to enlist my sympathy!

Don't get me wrong, if you're selling sunflowers for the local hospice, or it's guinea pig welfare week, you have my total support, but why would I think there are too many spaces for blue badge holders? And, more importantly, why would I care even if there were? Would it really matter if the rest of the population was just a teensy weensy bit inconvenienced by being able-bodied? I think not.

For many people, this bit of blue plastic is absolutely vital and parking far away from whatever facilities you are going to is an ordeal, only surpassed by the performance involved in getting the dratted photos to go with it. Last time we went through this essential part of the badge-renewal process, we used the photo booth in our local shopping centre, and whoever purchased this gadget clearly didn't believe anyone under 5 foot could possibly want a passport photo, as the eye line indicated on the screen was way above my head. After an initial test, Andrew wound the seat up to its maximum height but when I tried to climb onto the stool, the eye line seemed as elusive as ever! By this time, the machine had woken up and was firing questions like what language did I want the instructions in and what sort of photos did I want (any chance of some decent ones this time?)

Meanwhile Andrew was now trying to wind the seat up passed its maximum height using brute force and the machine was requesting money with increasing urgency. With the two of us in a rather cramped space, I was getting quite hot and bothered so Andrew helped me climb onto the now wobbly seat and I balanced precariously while he fed some coins into the slot.

It would be unfair to blame the machine entirely for the output, but the result was surprisingly awful. What was even more surprising was that Andrew did not appear in any of the pictures, given that he had been acting as curtain holder, handbag minder, seat support and machine operator all whilst trying to prevent my bottom from slipping off the stool.

I'm sure I am doing this the hard way, so if anyone can suggest a way of improving this tortuous process, please let me know – otherwise I will have to commission an artist's impression for next time around!

LiNK

the lifestyle magazine for people with hydrocephalus and spina bifida

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Antibiotics before dental treatment?

A common enquiry to ASBAH and an on-going anxiety for people with shunts, their families and often their dentists, is whether they should have antibiotics before having dental treatment.

Many dentists routinely prescribe antibiotics – often a "one off" dose – before any treatment. Their reasoning seems to be that invasive dental treatment will release bacteria into the bloodstream that will get into the shunt and cause infection.

It is true that after extractions, drilling and even scaling there will be a high level of bacteria in the circulatory system for a short period.

However, a paper in the British Dental Journal in 2000 showed that chewing, flossing and tooth brushing produced bacteria levels almost as high and that these levels are likely to be higher in people who don't look after their teeth and whose oral health is poor.

CSF shunts are closed systems and, to cause, infection, the bacteria would have to enter and colonise the inside (lumen) of the shunt tubing.

In 1998, a review of literature published over the previous 30 years found no reported cases of CSF shunt infections being caused by any dental procedure.

Indeed, there are good reasons why antibiotics should not be given randomly to people with shunts.

Some people may have a serious (anaphylactic) reaction to the antibiotic; some may develop resistance to the commonly used antibiotics. This can mean that when given to combat infection, these antibiotics will be ineffective and one of the more powerful antibiotics will need to be given.

Those dentists who prescribe antibiotics for fear of being sued if their patient gets a dental infection, should take these points into consideration. It is thought by some dentists that antibiotic cover is the safe option.

The risk of CSF shunt infection following dental procedures appears to be almost negligible.

On this basis, antibiotics should only be given where there is a dental need, for example, dental abscess and not to "protect" the shunt.

Depression and Disability

Depression can affect anyone at any time although young people with disabilities may be more at risk than those without disability.

Dr. Sarah L. Minden, a psychiatrist who treats people with MS is a leading expert on disability and depression.

She said: "Some people who are profoundly disabled are not depressed while others are very depressed but not physically disabled at all." Research has shown no correlation between depression and an individual's degree of disability.

"What makes a person depressed seems to relate to a host of factors," she explained. "These include genetics, individual coping styles, past and present experiences, and what sorts of social supports a person has.

"But while we don't yet know how depression originates, we do know how to treat it."

It is important that signs of depression – not just feeling "fed up" – are identified and acted upon. The people most likely to notice that someone is depressed are parents, teachers, friends and you.

So what should you look for?

You may:

- **feel generally down and fed-up in every way**
- **feel bad about yourself and have no confidence**
- **feel cut-off, empty and miserable**
- **blame yourself and feel bad about things that are not really your fault**
- **find it hard to think or decide things**
- **get annoyed and lose your temper more than usual**
- **eat more and put on weight, or not eat properly and lose weight**
- **not want to go out with your friends or do other things that you like**
- **not feel like having sex**
- **use more tobacco, alcohol or other drugs than usual**
- **hurt yourself or think about hurting yourself or try and kill yourself**
- **be really tired and not have enough energy to do anything**
- **stop talking to people and not ask anyone for help or support**
- **think that nothing good is going to happen in the future.**

There are many causes for depression: they vary from person to person and sometimes there may be no identifiable cause.

Often depression is started off by things that happen in your life. Things like being bullied, attacked, or raped or if some one who is close to you dies.

But it is not just the bad experience that causes depression but how you deal with it.

(continued overleaf)

(Depression and disability - continued)

Treatment

Your GP is the person who will initially help you. He will probably prescribe anti-depressant drugs which are the most common medical treatment for depression. Your GP may also offer a course of counselling in addition to medication.

Some people may need psychotherapy, which is a long term commitment, or cognitive behaviour therapy which will concentrate on how you can change how you feel and behave.

If your depression is really severe, your doctor will refer you to a specialist (a psychiatrist) who may admit you to hospital.

How you can help yourself

Being depressed makes you think bad, negative thoughts a lot and then these negative thoughts can make you more depressed.

An important thing to remember is that problems in life cannot be sorted out straight away.

Sorting out problems takes time, energy and work. When you are depressed, you may not have much energy or feel like working to make things better.

You need to get out of the habit of thinking bad or unhelpful thoughts. Try and notice when you are thinking bad thoughts and do something else instead.

Try and find things to do which interest you. Activities such as exercise can be very helpful. Increasing your heart rate can make chemicals in the brain called endorphins, which can help you to feel better about yourself.

- *Try and treat yourself kindly.*
- *You need to look after yourself, eat well, exercise and try not to smoke, drink too much alcohol or take drugs.*
- *Take care of your appearance because looking nice can help you feel better about yourself.*
- *It can also help to treat yourself sometimes by buying yourself something or going out for a nice meal.*
- *Phone your friends and go out with them.*

How you can help others with depression

People who are depressed often shut themselves away from friends and family, instead of asking for help or support. But this is a time when they need help and support the most.

Perhaps the most important thing which family and friends can do is encourage the depressed person to find the right help.

Helping a friend or family member who is depressed can be a chance to build a closer relationship with them and it can also be hard work.

What people who are depressed need most of all is someone who cares for them.

Keith's story

Keith Collins, 47, from Birmingham has spina bifida and has experienced depression throughout his life since spending nine months in hospital as a young child.

More recently however he has battled depression caused by a sudden loss of mobility and other health problems, which led to Keith taking early retirement from his position as a social worker for Birmingham City Council.

Here he talks about his experiences.

My first memories are when I was around two years old during a nine-month stay in a hospital close to Bromsgrove General. All I can really remember was 'being allowed out' every second weekend and my parents drove for miles so that I could watch a train. That was the highlight of my life during those early years.

The experience of being away from my parents from such an early age had a negative effect, which I believe has caused me to suffer from depression intermittently throughout my life.

Having studied psychology as a social worker, I am aware of how poor attachment with one' parents can impact on later life. In the early sixties parents were discouraged to visit their children in hospital but researched has since proved that such separations are very harmful to a child's development.

Keith Collins

After major surgery to my spine my parents were told I would never walk. But they were both convinced that, with the correct shoes and appliances, I could learn to walk. I attended a 'special school' in Birmingham from the age of four and a half to seven where the philosophy was ' if he would rather play in the sand-pit rather than learn to read or write, we'll let him because we do not have any expectations for these children.'

This next phase of my life was with

- *You can show that you care by listening carefully to them, by giving them a hug, or simply by spending time together.*
- *You can help by encouraging them to talk about how they are feeling and help them to work out what they can do, or what they need to change, in order to deal with their depression.*
- *If the person you are supporting is extremely depressed it may be hard for you to know exactly how much you should do for them.*
- *If they are not looking after themselves properly it can be difficult to decide if you should take over and do the shopping, cooking and cleaning for them, or if it would be better to try and get them to do it themselves.*

When supporting a friend or someone in your family, you must try not to blame them for being depressed or tell them to ‘pull themselves together.’ They are probably already blaming themselves.

It is much better to tell them good things about themselves as this can help them to feel a bit better. You can remind them that they can do things to help their situation, but this needs to be done in a gentle caring way.

For more help and information about depression contact:

MIND
www.mind.org.uk
Mind info Line - 0845 766 0163

The Depression Alliance
www.depressionalliance.org
0845 123 23 20

Defeat Depression
www.depression.org.uk

The Royal College of Psychiatrists
www.rcpsych.ac.uk

Antidepressants

Antidepressants work on chemicals in the brain to lift your mood. They do not get rid of depression, but can make you feel better so you can do more things for yourself to make you feel better.

Antidepressants do not work for everyone and some people will experience side-effects.

It usually takes between two to four weeks before the antidepressants start working.

Some antidepressants can be dangerous if you take them with other drugs and if you stop taking them you can feel poorly and feel strange or very upset. Make sure that you tell your doctor about any side-effects that you have when you are taking anti-depressants or if you have any worries about them.

out doubt one of the happiest. Mom and dad fought the education authorities to allow me to attend a ‘normal school’. I had a great time there because I could play football every playtime, and I managed to catch up on my schooling.

But when I was looking forward to attending the ‘big’ school the carpet was pulled from under me again. The Headmaster refused to accept me because he did not want the responsibility of someone on crutches negotiating a flight of stairs. So I had to leave all my friends and finished up at a school with twice as many stairs!

The past three years have been the darkest and most difficult of my life.

After leaving school with three ‘O’ levels I took a job at Lucas Aerospace. Most of the work I found very tedious and boring and I left in 1991, to move into social work, one of the best decisions I’ve ever made... although family and friends were against it at the time.

I loved the work and thrived on the responsibility of working with other people in the community who were experiencing problems in their lives. Within three years, I was seconded to undertake a two-year Diploma course in social work which really stretched me to my limit academically but in July 1996 I passed the course.

However the following year I went through various undignified tests in order to establish whether my bladder and kidneys were working normally. I had never been warned that having spina bifida also meant that people would often experience other problems, which came as a shock.

My mom and dad have always done everything in their power to support me and give me the best opportunities in life. But like many people who are disabled from birth, I was often sheltered from the real world by my parents.

I believe this approach hinders the child in later life, as they have not developed the skills to ‘manage’ problems when they arise.

I stayed in social work until 2002, when I decided to take early retirement due to ill health. It was one of the hardest decisions I have ever had to make.

The past three years have been the darkest and most difficult of my life. Within weeks of taking early retirement from social work, I was no longer able to walk. I know I have been very fortunate. Compared to many people with the severest form of spina bifida, I have been mobile and enjoyed a very full life considering I was never supposed to walk.

But I was totally unprepared when it did happen. I went from being able to play football with my dog and walk a reasonable distance to not being able to get out of my house on really bad days.

I wasn’t aware of ASBAH’s existence until about ten years ago, when a colleague, who also has spina bifida, put me in touch with the organisation. However let down I feel by the authorities, ASBAH can always be relied upon to provide a quality service by staff who support people with empathy and understanding as well as providing expert advice.”

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.

It is with great excitement that I respond to the article Speaking Out to Change the Church in *Link* 217.

I am a walking spina bifida disabled person and for the past 20 years I have belonged to St Andrew's, a fairly lively Methodist/United Reformed Church.

I realised after reading the article that it isn't only church buildings which need to be disabled friendly, it is the people. The attitude, vision and mission statement of the Church should be as inclusive as is humanly possible, not only towards disabled people, but also other minority groups.

But this isn't to say that the Church does not try its best to accommodate all sorts of people. Our church building is new which makes it easier to improve disabled access. The 12th/13th century parish church in the centre of town has had some alterations done and is able, but with more difficulty, to accommodate wheelchairs.

Best wishes to Rev John Naude. I was very grateful to read his article.

Andrew Gilson

I recently found out that my baby, which is due in November, has spina bifida. At first, when we had no support or information, I thought it would be impossible to keep the baby.

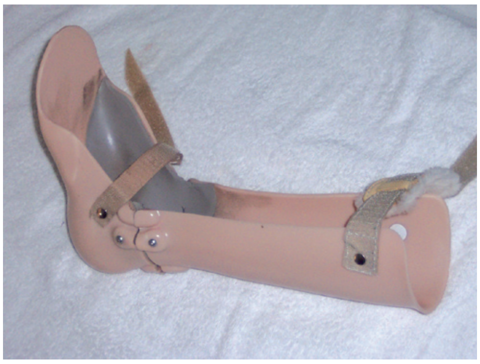
But then I contacted ASBAH. Thanks to the information I received from staff, especially my adviser, we are now feeling positive and looking forward to meeting the baby.

I'd just like to say a big thank you to everyone. It also helped reading about the Copeland family's experiences of having a baby with spina bifida.

I'd love to make contact with anyone in a similar position to me. (I also have two sons aged two and four).

Reann Jenkins
Maesteg, South Wales

- **If you would like to contact Reann, write to *Link* and we'll pass your details on to her.**



Mike's walking tall

After 60 years of sporting health service issue boots, ASBAH Cymru Chair, Mike Mason can now pound the high street in search of funkier footwear.

Mike was dragged into the 21st century after a recent visit to his Orthotist to be measured for new boots.

Staff at Glan Clwyd Hospital in St Asaph, North Wales were amazed by his old-style metal calipers and health service issue footwear and introduced him to lightweight polypropelyne splints.

Mike said "These new splints are so much lighter than my calipers and, given the design and size of the splint, I can now purchase my own shoes...for the first time in nearly 60 years.

"I've gone from a size 5 to a size 8 overnight! I was very nervous at first, particularly about driving, but I needn't have worried. My balance, walking and self image have been improved and my Hush Puppies look really cool."

Mike advises anyone in a similar position to talk to their Orthotist or Health Professional without delay.

Mike Mason

No competition as Russell scoops national poetry prize

When Russell Shepherd entered a poetry competition at school, little did he know that within a few months he would be a national poetry champion, but this is exactly what happened.

Twelve-year-old Russell, who has hydrocephalus, scooped first prize in the National Association for Special Educational Needs (NASEN) poetry competition with his entry "I Don't Know How to Spell" – winning himself £50, plus £250 for his school to spend on software.

The award winning poet from Ainley Top in Huddersfield enjoyed another recent win when he was awarded a gold medal after completing a 50m walk at the Leeds Disabled Sports.

We've reproduced Russell's poem below for you to enjoy – which we're sure you will enjoy as much as we did! Congratulations Russell!

I Don't Know How to Spell

I just don't know how to spell
I just can't play football
BUT I DO KNOW HOW TO SIGN

I need my mum to help me dress
If we're running out of time
BUT I'M GOOD AT DANCING

I need help to carry my lunch
So that I don't spill it
BUT I DON'T NEED HELP TO EAT IT

Russell Shepherd

Holiday let

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

ISLE OF WIGHT ASBAH - HOLIDAY BUNGALOW

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

PAIGNTON, DEVON

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

PRESTATYN, NORTH WALES

Choice of two adapted caravans for disabled holiday makers. Each sleeps 6 people (2 wheelchair accessible bedrooms), wheel-in shower with seat, open plan lounge, dining, kitchen area. Caravans have ramp access and are overlooking a children's play area in a site adjacent to the beach at Prestatyn – a small market town on the North Wales coast within easy travelling distance of Rhyl, Llandudno, and Snowdonia National Park. Costs are between £95-£275 per week; **for further information contact Leeds & Bradford ASBAH, c/o Jo Baxter, 8 Staveley Court, Shipley, BD18 4HF. Tel. 01274 591850, e-mail** *jo.baxter2@btinternet.com*

TRENERRY LODGE, CORNWALL

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

ROPERS WALK BARNS, MOUNT HAWKE, CORNWALL

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

BERWICK COTTAGE, EAST HARLING, NORFOLK

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

WANTED

Accommodation

One or two bed GFF with garden suitable for wheelchair user preferably Croydon/Hastings area but will consider anywhere suitable. If required, I have in return large one bed GFF, with wheel-in shower, private garden/shed/car park 10 minutes from Worthing town and sea front.
Further details contact Lisa on 07940 720920 or by email lisa.buck4@virgin.net

Accommodation

ILKLEY, WEST YORKSHIRE

Flat 1 Wharfedale. Three bedrooms, living room, kitchen, bathroom and toilet. Fully wheelchair accessible and on the ground floor. The person to hold the tenancy must have a disability and need housing related support. Care and support packages can be arranged with Bradford Social Services.
Contact: Mark Best, Tel/Fax: 01943 603013, or write to Five Oaks Housing Scheme, Ben Rhydding Drive, Ilkley LS29 8BD.

Diary dates

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

Wheelie Club

Wheelchair skills training for young people aged between 3 - 16 years old.
Saturday 9 December: McKinney House, Musgrave Park Hospital, Belfast.
Two groups. Group one starts at 10.30 am - 12.00 noon and group two starts at 12.30 pm - 2.00 pm. Details from Northern Ireland regional office.

Hydrocephalus Study Day

Tuesday 6 February 2007
11.00 – 3.00pm
Banstead Civic Centre,
The Horseshoe, Banstead, Surrey.
Details from South East regional office.

Hydrocephalus Study Day

Monday 12 March 2007
2.00pm to 4.30pm
Talardy Hotel, St Asaph, Denbighshire
Contact ASBAH in Wales. Venue fully accessible.
Further info: Tony Murphy PALS Officer at the Walton Centre 0151 529 6100 or email tony.murphy@thewaltoncentre.nhs.uk

Eastern Region

Local associations, Forum Saturday 10 March. Details from Eastern regional office.

Family weekend

Friday 23 March to Sunday 25 March: Isle of Wight. Cost per family is £75 plus cost of ferry. Further information from your adviser and/or an application form, or contact Shelley at National Office - *shelleyg@asbah.org* or telephone 01733 555988.

Please e-mail the editor (link@asbah.org) dates of your events for the next issue of Link by Friday 2 February 2007, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.

Classified rates

£3.75 for 30 words max.
£5.50 for 30-45 words
£6.75 for 45-60 words

Cheques and postal orders should be made payable to 'ASBAH'. Classified adverts for the next issue of *Link* should be submitted by Friday 2nd February 2007

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Tel: 01733 555988. Email: *link@asbah.org*

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Belfast BT8 8BH
Tel: 028 90798878
Fax: 028 90797071
Email: ***niro@asbah.org***

Simon Wrigley

Determined to make a difference

PROFILE:

Name:	Simon Wrigley
Age:	28
Occupation:	Preparation adviser with Local Solutions in Liverpool
Family:	Married to Vicky. The couple live on the Wirral with their Dog Ursula, a French Mastiff.

From an early age Simon Wrigley was determined to make a difference and this motivation continues to influence his career.

Simon, who has spina bifida, works at Local Solutions in Liverpool, a charity which supports people with health conditions into work, through training courses, work placements and job coaching.

He was one of the speakers at the recent Your Voice weekend residential, giving a general overview about employment matters and where people can go for additional help and support.

Simon, whose father has been treasurer at the Wirral local association for many years, originally planned to become a teacher, after studying French at Liverpool University.

He explained: "I was fortunate and got a place at a grammar school where we were encouraged to be ambitious. I really enjoyed my time there and got a lot from the school.

"I decided early on that I would like to inspire people with that sort of confidence and make a real contribution to society.

"But during my teacher training I found that unfortunately not all schools were like the one I'd attended and I was really brought up short."

Instead he joined the New Deal training scheme as supervisor, where he relished the chance to work with people on a one-to-one basis. But when the scheme closed in 2002 he was forced to job hunt again.

Around 60 per cent of my clients do find a job at the end of the 6-weeks, which is pretty good success rate. Even if a client doesn't find employment immediately, our work with them has still been hugely beneficial and is a tremendous boost to their confidence.

Simon said: "I was out of work for a couple of months but I was eventually offered three jobs. The position with Local Solutions wasn't the best paid, but the work appealed, and money isn't so important to me. What matters most is that I enjoy my job and get a lot out of it."

His role with Local Solutions involves dealing with between 15 – 30 clients who have health problems ranging from physical and mental conditions, or sensory impairments such as deafness.

He helps clients enrol on job placements or training courses, supporting them for an initial six weeks in a range of ways including building their confidence and helping them get into the new routine of getting out of the house on time.

"For many people I deal with just getting out of the front door can be a huge challenge," Simon explained.

His work is split between the office, catching up on paperwork, and out on the road, meeting existing clients for a weekly review, or new ones, to see how he can help them back into employment. He covers the Wirral and Cheshire areas.

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which is pretty good success rate. Even if a client doesn't find employment immediately, our work with them has still been hugely beneficial and is a tremendous boost to their confidence."

Following a job offer Local Solutions continues to support clients for a further three months. "Some schemes just sever ties with their clients once they are in employment," Simon added, "but that is like dropping someone off the end of a cliff. To settle into their job they need help planning ahead and advice when things aren't going so well.

"I do get a fantastic sense of achievement when I help someone to fulfil their potential. It's a great job and I really enjoy what I do. I wouldn't be here if I didn't."

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